Evidence-Based Practices in Behavioral Health
Series Editor: Nirbhay N. Singh

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Handbook of Evidence-Based Practices in Intellectual and Developmental Disabilities

Springer

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Medical College of Georgia
Augusta University
Augusta, GA, USA

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For Judy, Ashvind and Subhashni
With much love and affection

Preface

There has been an impressive growth in the field of intellectual and developmental disabilities—in diagnosis, assessment, interventions, and quality of life issues—and there is an urgent need to draw together evidence-based findings from across this field. Philosophy and advocacy continue to be very strong forces that drive the care of people with intellectual and developmental disabilities. For example, person-centered individual support plans preceded any evidence for their efficacy or effectiveness and, even now, the evidence is somewhat slim. Indeed, empirical evidence often tries to catch up with philosophy-driven practice. In addition, fads such as facilitated communication and secretin continue to be used by some professionals. Much has been written about fads and, due to the skepticism generated, proponents of new approaches and treatments often have to weather the scientific angst during the proof-of-concept phases of their clinical treatment and research. This delays effective interventions being used in a timely manner with those who so desperately need it.

This has led to an acute need for a comprehensive handbook that maps the evidence base for all aspects of care for people with intellectual and developmental disabilities. The current status of approaches to their care is quite diverse and impressive, both in the depth and the breadth of assessment and interventions. As a veteran in this field, when I decided to bring together what we currently know about the care of these individuals, I was motivated to integrate the philosophy and science in this field. I wanted to provide a comprehensive guide that is based on as much of the evidence base as possible, but I also did not want to forget the individual who would be receiving the care. Relying on the evidence base to inform care is one thing, but delivering the care in a mindful, supportive way that enhances the individual's quality of life in the short and long term is quite another. It requires a dance, where evidence-base partners with quality of care and the caregivers make an emotional connection with people whom they care for on a daily basis. This applies regardless of whether the caregiver is a parent, family member, paid staff, teacher, friend, or volunteer.

The *Handbook of Evidence-Based Practices in Intellectual and Developmental Disabilities* is an attempt to bring together both the philosophy and science of intellectual and developmental disabilities. I am aware that given the vast swath of the field many issues remain to be resolved and that an entire field of endeavor cannot be captured in a single handbook. What I envisioned was that a careful reader would have a relatively enhanced, if not a more complete, view of the many facets of this field and that a clinician would gain considerable insight into improving the quality of life of individuals with intellectual and developmental disabilities. It is my hope that this clinical handbook will serve as a comprehensive reference, assisting clinicians, caregivers, and researchers to understand, evaluate, and ultimately enrich the lives of people with intellectual and developmental disabilities.

A clinical handbook of this scope requires the diligent efforts of a great many people. I would like to thank the contributors who wrote uniformly excellent chapters and for their patience with the editorial process. If there is any merit to this book, it is theirs. I also thank those others who have helped me with this book, especially those colleagues, friends, and family members I have neglected in the process. I am most grateful to Judy Singh at home and Judy Jones at Springer for making this book possible. Finally, I thank my clients, colleagues, and teachers who taught me virtually everything I know, but, of course, not everything they know!

Augusta, GA, USA Nirbhay N. Singh

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About the Editor

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Implementing Evidence-Based Practices Wisely

Nirbhay N. Singh

Introduction

People with intellectual and developmental disabilities (IDDs) face many challenges, above and beyond the limitations imposed on them by their compromised abilities. The sequelae of their disabilities often manifest as medical, physical, learning, and behavioral challenges. Of these, learning and behavioral challenges occasion greater dilemmas for caregivers in terms of service delivery than their medical and physical disabilities. The overriding issue is how to best provide services without compromising self-determination and choices that contribute to the well-being of the individuals. Unfortunately, the history of service provision for people with IDD is replete with examples of approaches that, in hindsight, we have come to view as less than positive.

Services provided to people with IDD can be broadly categorized as those focused on their general well-being, as documented in their individual support plans (ISPs), and those aimed at managing or treating their challenging behaviors (e.g., aggression, property destruction, pica, rumination). Current treatments for challenging behaviors include behavioral, cognitive–behavioral, and psychopharmacological approaches (Singh, Lancioni, Winton, & Singh, 2011). Behavioral approaches have used three general kinds of intervention: (a) antecedent strategies for environmental, biological, or other setting events maintaining the challenging behaviors; (b) self-management strategies or instructional strategies for making the challenging behaviors inefficient by teaching the individual functionally equivalent alternative behaviors; and (c) contingency management strategies that rely on programmatically altering the consequences of the challenging behaviors. Cognitive behavioral strategies focus on the individual's irrational thinking that may lead to problems in cognition, emotion regulation, and behavior. Psychopharmacological approaches may target specific psychiatric disorders that give rise to challenging behaviors or the behaviors themselves if there is a proven rationale and evidence for their efficacy in managing those specific behaviors (Singh et al., 2011).

ISPs for people with IDD are based on a person-centered philosophy of care that requires the development and implementation of plans that purportedly enhance their quality of life. Theoretically, these plans have centered on the general idea of caring, but their implementation often devolves into something far less for those receiving the care. For many people with IDD, rather than developing a life worth living, their

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ISPs eventually degenerate into plans that institutionalize care, often for the convenience of the caregivers and service provider, and with an emphasis on safety and a restricted lifestyle. For example, for people with multiple medical and cognitive challenges, safety is all about avoiding potential risks, such as bedsores, falls, and other medical complications, rather than on providing quality of care that centers on making their life more meaningful—a life that maximizes their inherent potential. It is as if one's disability defines whether a life of worth is possible and where assessment of this possibility resides with the caregiver and not the care receiver. But people with IDD expect more from life than safety and protection, regardless of the level of their abilities. Indeed, many individuals with IDD resist this kind of benign care by engaging in challenging behaviors and not cooperating in rigidly scheduled activities. However, when they engage in challenging behaviors, further restrictive treatments are prescribed. Caregivers appear to have forgotten that their role must move beyond ensuring health and safety to supporting the person's well-being and aspirations.

The manner in which caregivers provide services often falls into well-worn grooves of automaticity, built through mindless mechanical repetition over time. They find moving onto a new system of support very difficult, which often leads to their covert and overt resistance. Some caregivers seem bereft of curiosity about what people with IDD care about in life and how to support these individuals to experience the joys that matter to them. They confuse care with treatment—the programs or plans developed by the treatment team that prescribe exactly what the individual needs to do throughout the day, 7 days a week, and how to deal with deviations from those prescriptions. Changing this system of institutionalized treatment planning and rigid rules for implementation requires overcoming the caregivers' inertia and fear of change. Making the lives of people with IDD meaningful and not merely safe requires creativity and imagination. It requires commitment to a singular aim—to make their lives worth living and to support them to be fully engaged with their lives, within the parameters nature has imposed on them (Thomas, 1996). While people with IDD may not be able to change or control what nature gave them, this should not preclude them from controlling what they do with what they have.

The task of caregivers is to support and enhance quality of life, that is, to ameliorate as much as possible the medical, mental, and physical effects of the disabilities and to maximize the opportunities for active engagement. While we may not be able to completely or even partially overcome the ravages of the disabilities of people with IDD, caregivers can make their disabilities more manageable and avert many of their effects. The way we provide care and support allows greater preservation, or a more gradual loss, of the abilities that matter most to the person. When the cumulative toll of the medical, mental, and physical disabilities eventually reaches the point where the person is too debilitated to participate fully, that is when caregivers need to provide the most support to enable the person to use their residual skills as much as possible to maximize independence.

Often caregivers take over tasks that people with IDD can manage only laboriously—such as bathing, toileting, dressing, and other activities of daily living—because they are working on a schedule that focuses on task completion and not the person. Given the daily schedule, timely task completion matters more than the individuals. We understand that these activities need to take place at some time, but the schedules are designed essentially for the convenience of staff, rather than the well-being of the individuals. They are not designed to enable the individuals to make choices, to have some degree of autonomy, or to give meaning to their lives according to their own priorities. Caregivers tend to forget that their role is to make life worth living for the person, a goal that is not any different from those without disabilities. This role is to support people with varying degrees of ability to nourish and enjoy their lives, to continue to actively engage in a meaningful life, regardless of their condition. Indeed, assistive technologies are increasingly being developed that support people with disabilities, regardless of how severe their physical, mental, and medical conditions might become (Lancioni, Sigafoos, O'Reilly, & Singh, 2013; Lancioni & Singh, 2014).

Supporting an individual with IDD means that caregivers need to reverse the power differential from them to the people they provide services to. Thus, for example, when entering a community group home, caregivers should begin with the premise that they are entering the individuals' home and behave accordingly. The residence should genuinely feel like a home to the individuals and not merely a facsimile of a home. The residents need to have control over their schedules, house rules, dining habits, and preferred activities, including determining the dignity of risk they want to take when engaging in preferred activities. They must not be made to feel institutionalized in their own homes under the guise of safety or benevolent care. While being cognizant of the risks, caregivers also must understand the importance that a preferred activity may be for people with IDD in terms of their well-being. The caregivers' role is not to withhold the activity but to provide support and added protections so that the individual can engage in it.

To produce this more positive mindset in the caregivers requires a paradigm shift in the delivery of services from treatment to supportive care. This shift needs caregivers to have heightened self-awareness, which will enable them to be acutely sensitive to the moment-by-moment changes in the individuals' behaviors as well as to their own reactions to these changes. This mind shift will enable caregivers to support people with IDD to have flexible daily rhythms and patterns in their life that are dictated by their own preferences and choices, and the authority to change their choices, as their preferences change. To enable this mind shift to occur, we need to look at the evidence base for the services that we can and should provide.

Evidence Base

The genesis of evidence-based practices can be traced to a series of papers published in 1981 by staff in the Department of Clinical Epidemiology and Biostatistics at McMaster University, designed to teach physicians how to critically review medical research literature (Guyatt & Rennie, 2002). The aim was to enable physicians to use research evidence appropriately in routine patient care. The approach was understood to mean "the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence-based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research. By individual clinical experience we mean the proficiency and judgment that individual clinicians acquire through clinical experience and clinical practice" (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996, p. 71). As Sackett et al. (1996) noted, an evidence-based approach leads to "more effective and efficient diagnosis and in the more thoughtful identification and compassionate use of individual patient's predicaments, rights, and preferences in making clinical decisions about their care" (p. 71). This approach brings the best of science and practice together in terms of person-centered care. It provides general and specific methodologies for searching the research evidence and critically evaluating published and unpublished research evidence for treating specific diseases, disorders, and disabilities (Singh & Oswald, 2004a, 2004b, 2004c).

There is growing recognition that the field of intellectual and developmental disabilities needs to move from *best practice* or *research-based practice* (Cook & Cook, 2013) to evidence-based practices. This recognition arises from findings that many caregivers engage in practices for which there is little evidence for their efficacy or effectiveness (Goin-Kochel, Myers, & Mackintosh, 2007) or, worse still, use interventions that have been amply demonstrated to be ineffective (Goin-Kochel, Mackintosh, & Myers, 2009). In this context, efficacy refers to outcomes of an intervention or program that has been evaluated under tightly controlled but optimal conditions—the evaluation trials used rigorous research designs, interventions were implemented as specified in the research protocol, virtually all confounding factors were controlled, and the interventions were delivered by highly qualified and supervised research personnel. The Society for Prevention Research developed an overlapping set of standards for identifying efficacious interventions, effective interventions, and those interventions ready for dissemination. They classified interventions as efficacious if they have been "tested in at least two rigorous trials that (1) involved defined samples from defined populations, (2) used psychometrically sound measures and data collection procedures; (3) analyzed their data with rigorous statistical approaches; (4) showed consistent positive effects (without serious iatrogenic effects); and (5) reported at least one significant long-term follow-up" (Flay et al., 2005, p. 151).

Effectiveness refers to outcomes of an intervention or program that has been evaluated under real-world conditions—the evaluation trials being conducted under naturalistic conditions, by regular staff, with relaxed fidelity of implementation. The Society for Prevention Research held that effective interventions must meet all the standards of efficacious interventions but "also will have (1) manuals, appropriate training, and technical support available to allow third parties to adopt and implement the intervention; (2) been evaluated under real-world conditions in studies that included sound measurement of the level of implementation and engagement of the target audience (in both the intervention and control conditions); (3) indicated the practical importance of intervention outcome effects; and (4) clearly demonstrated to whom intervention findings can be generalized" (Flay et al., 2005, p. 151). While both efficacy and effectiveness studies may be considered when determining evidence-based practices, it is rare to find the same level of outcomes when the data from efficacy and effectiveness trials are compared.

There are also other considerations when developing and implementing evidence-based practices in the field of intellectual and developmental disabilities. First, how is *evidence base* determined in evidence-based practice? Traditionally, an intervention or program can be attested as evidence based if a statistically significant effect and a moderate to large effect size have been reported in two or more randomized control trials by independent researchers. Determining what is evidence-based practice with studies using single-subject research designs is somewhat more difficult because there are no gold-standard criteria. The generally accepted criteria, proposed by Horner et al. (2005), classify a practice as evidence based when "(a) a minimum of five single-subject studies that meet minimally acceptable methodological criteria and document experimental control have been published in peer-reviewed journals, (b) the studies arc conducted by at least three different researchers across at least three different geographical locations, and (c) the five or more studies include a total of at least 20 participants." While these criteria are not empirically based, they do provide the beginnings of a conversation regarding what may be considered evidence-based practice derived from single-subject research.

Second, there is the issue of what exactly the *practice* in evidence-based practice entails. Horner and Kratochwill (2012) advanced the notion that it is "any operationally defined set of procedures that are used by a specified target audience, under defined conditions/contexts, to achieve valued outcomes for one or more defined populations" (p. 267). They enumerated the following five features of this practice: "(a) Operational definition of component procedure(s); (b) Designation of any competency criteria that must be met by individuals implementing the procedure(s); (c) Designation of the context(s) in which the procedure(s) are appropriate; (d) Designation of the population(s) of individuals who are intended to benefit from the procedure(s); (e) Designation of the valued outcomes that the procedure(s) are expected to affect" (p. 267). Horner and Kratochwill emphasized that evidence-based practice can be implemented and replicated only if the practice is operationally defined.

Third, one of the greatest challenges in this field is that there are few randomized controlled trials from which we can extract evidence-based practices. For example, services provided to people with IDD are based on their individual support plans that are ostensibly based on person-centered planning by the individual's treatment team. In practice, the majority of these plans include only those services that the team members deem appropriate for the individual. Whether a true person-centered plan, developed on the basis of the contribution made by the person and his or her significant others, is any better or worse than those developed by the individual's treatment team cannot be determined because there are no randomized control trials comparing these two approaches to care.

Fourth, a more basic challenge lies in the very notion of a randomized control trial as the primary basis for determining what is evidence-based research. For example, people with IDD form such a heterogeneous population that it is almost impossible to establish equivalent experimental and control groups for efficacy or effectiveness trials. The numerous variables that people with IDD differ significantly on present a daunting task in enrolling the large numbers of participants who meet the inclusion and exclusion criteria as indicated by power analyses. While we have a plethora of single-subject experimental studies, particularly on behavioral interventions for challenging behaviors, the field is still struggling to reach consensus on suitable statistical and meta-analytic approaches to determine which procedures can be classified as evidence-based practices (Kratochwill & Levin, 2014). The heterogeneity problem has not been solved with either approach—randomized control trials or single-subject experiments—because it is very difficult to determine, with some degree of certainty, what procedures are effective for whom and in what contexts. In addition, because people with IDD need services and care from multiple specialties—psychology, psychiatry, nursing, social services, habilitation therapies, medicine, and orthopedics—research findings from all these specialties need to be accounted for in determining evidence-based services.

Evidence-Based Services

Regardless of the challenges in determining evidence-based practices, there is an enormous amount of good research that can be used to inform the quality of services caregivers can deliver in the field of intellectual and developmental disabilities. The *Handbook of Evidence-Based Practices for Individuals with Intellectual and Developmental Disabilities* gathers most of this research in one place so that clinicians can have access to what we know and how we can translate this into practice (Singh, 2016). But, there are caveats that are important to bear in mind when advocating or using evidence-based research in practice. First, regardless of how good the evidence is, no evidence-based practice will meet the diverse needs of *all* individuals with IDD. Evidence-based practice does not mean that we have sound research showing that the practice will be effective with all members of a given population. Indeed, the outcome of research is inherently probabilistic rather than absolute, and aggregating such research to derive evidence-based practice does not change this basic fact. In practical terms, it means that caregivers should always be willing to accept that a given evidence-based practice might not be effective for some of their clients. For these nonresponders, caregivers must search for alternative methods that can produce the required effects.

Second, we know far more about evidence-based practice than about implementation of these practices. Indeed, there is minimal research documenting how these practices are implemented and what outcomes they produce. In the field of intellectual and developmental disabilities, implementation is a multifaceted and challenging endeavor because of the many stakeholders that have a say in what and how interventions are implemented. Often, there are institutional barriers to implementing new interventions and programs because change means altering time-honored institutionalized practices—practices that have been developed over time that often are for the convenience of the staff and administration. When there is no buy-in from the administration, there is little likelihood that clinicians and caregivers will implement new interventions and programs with sufficient fidelity to produce meaningful outcomes. To ensure adherence, the core components of evidence-based practices need to be implemented at the institutional level; change agents should not rely on the expertise and goodwill of selected individual clinicians and caregivers to effect the changes.

It is useful to remember that few evidence-based practices actually get implemented in real-world settings (Katz, 2010). On the one hand, current estimates suggest that less than half of evidence-based practices in health care are ever implemented and that it takes about 20 years for research in health or mental health to be translated into actual service delivery (Brekke, Ell, & Palinkas, 2007; Glasgow & Emmons, 2007). On the other hand, research suggests that between 30 and 45 % of people receiving mental health care do not receive care that is based on scientific evidence and between 20 and 25 % receive care that either they do not need or is potentially harmful to them (Grol, 2008; Grol & Grimshaw, 2003). So, how do we increase implementation of evidence-based practices in the field of intellectual and developmental disabilities? The answer may lie in evidence-based interventions that can realistically be made to work. Interventions that are typically implemented are those that can "(a) reach large numbers of people, especially those who can most benefit, (b) be broadly adopted by different settings (worksite, school, health, or community), (c) be consistently implemented by different staff members with moderate levels of training and expertise, and (d) produce replicable and long-lasting effects (and minimal negative impacts) at a reasonable cost" (Glasgow, Lichtenstein, & Marcus, 2003, p. 1264). Those that are too intensive or effortful, and not manualized, are much less likely to be implemented (Glasgow & Emmons, 2007).

In sum, evidence-based practice is a guide that must be used wisely with practice-based evidence; it is not a panacea for all the ills that befall people. It must be used judiciously, with wisdom, loving kindness, and compassion for the care receiver. The caregiver must be present for the care receiver on a moment-by-moment basis so that subtle or obvious changes can be made to the evidence-based practice, depending on what the care receiver is giving back to the caregiver (Jackman, 2014; Singh & Jackman, 2016). We must use evidence-based practices to enhance not only the *experiential* interests of individuals with IDD—engaging in activities that one finds pleasurable and exciting—but also their *critical* interests—engaging in activities that give meaning to their lives (Dworkin, 1994). This can only be achieved by pairing evidence-based practices with wisdom and delivering such practices mindfully.

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Part I

Foundations

Definition and Nature of Intellectual Disability

2

James C. Harris and Stephen Greenspan

Introduction

The nature and definition of intellectual deficits have been debated since the beginnings of the classification of mental disorders. The terminology has changed at least ten times in the past century. Moreover, because people with intellectual deficits are often undervalued in society, scientific terms describing them have been used disparagingly. Consequently, classification systems must contend with stigma and seek to introduce non-pejorative terminology. Currently, the emphasis in classification is placed either on the underlying neurodevelopmental disorder (Author APA, 2013) and resulting deficits in adaptive reasoning and functioning in academic, social, or practical settings or on disability, functional deficits, and the identification of needed supports (Schalock et al., 2010; Shalock, 2011).

Esquirol (1845) referred to intellectual deficits overall as conditions of incomplete mental development based on known (or unknown) biological or environmental causes. From this perspective, Intellectual Disability (ID) or Intellectual Developmental Disorder (IDD) can be considered first and foremost as a failure of cognitive progression that occurs during the developmental period. Failure in cognitive progression during development impacts adaptive reasoning and may result in deficits in functioning and disability. The link between developmental deficits in general mental functioning and resulting difficulties in adaptive reasoning and functioning is emphasized in DSM-5, but these elements were not specifically linked in DSM-IV-TR or in the AAIDD definition and often are considered as independent criteria, often referred to as prong one and two of the definition.

Unlike the USA, the World Health Organization (WHO) has two classifications, the International Classification of Diseases (ICD) and the International Classification of Functioning (ICF). Like the ICD, the DSM-5 definition focuses on health conditions and makes clear that it is a classification of disorders by using the designation intellectual disability (intellectual developmental disorder) while the AAIDD description focuses on human functioning. The AAIDD states in its manual, seeking to clarify their approach, that its focus is on the disability construct like that of the ICF. The AAIDD focuses on the interaction of the person with their environment, and rather than emphasizing an underlying person-centered neurobiological deficit, its focus is on the social

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interface between a person and the environment. The AAIDD emphasizes that, without adequate environmental supports, the extent of functional disability can worsen. The differences in classification systems have led to confusion in the field because ID (IDD) is treated as a developmental "disorder," in DSM-5 an etiologically based condition specified by neurobiological criteria (Author APA, DSM-5), and in the USA also as a "disability" (Schalock et al., 2010) by AAIDD, typically specified by IQ criteria that are statistically determined and linked to support services.

Another difference is in how severity is dealt with in the DSM and AAIDD approaches. For example, when classified as neurodevelopmental disorders (a new grouping in DSM-5 introduced to parallel neurocognitive disorders (e.g., Alzheimer's disease) with onset later in life), neurodevelopmental syndromes raise issues in classification regarding the role of intelligence scores and adaptive behavior in establishing severity. DSM-5 addresses this issue by continuing to require standardized intelligence testing but eliminating IQ cutoff points in defining severity. Severity is determined based on adaptive functioning in everyday life. Instead of a severity classification, the AAIDD focuses instead on listing the extent of environmental supports needed for different degrees of severity.

Because there is tremendous variability in the degree of severity (globally and in the intensity of impairments and needed supports) characterizing individuals within the broad category on ID (IDD), who have various neurobiological etiologies, it is difficult to generalize about people with ID (IDD); they do not strongly resemble each other because there is considerable variability in their neurocognitive profiles. The majority of those identified are mildly intellectually impaired. In the past, mildly intellectually impaired was presumed to represent the lower end of the normal distribution of intelligence or to be linked to sociocultural/familial variables. Previously, it had been proposed that there were two groups: a pathological group and sociocultural/familial group (Lewis, 1933; Penrose, 1938; Zigler, 1967). Sociocultural factors include low parental IQ, adverse social risk factors, lack of environmental stimulation, and social deprivation. Those with "pathological" forms fell in the severe range (IQ less than 50) and the mild forms with higher IQ scores. Severity is important in determining services. However, the two-group approach is overly restrictive because intellectual functioning is believed to be polygenetic for most who score in the mild range and do not have identified syndromes (Butcher et al., 2005; Kaufman, Ayub, & Vincent, 2010). In addition families with sociocultural adversity may have family members who are mildly and/or severely affected (Broman, Nichols, Shaughnessy, & Kennedy, 1987).

Many people with ID (IDD), even those with known brain-based syndromes, may fall in the upper end of the ID (IDD) spectrum (IQ in the 60s or low 70s). People with known neurogenetic causes such as fragile X syndrome can vary in ability from severe to mild. Moreover, despite being disabled, not everyone with an identified neurogenetic or neurodevelopmental disorder actually qualifies for the status of ID (IDD). This is because higher-functioning individuals with a known neurogenetic/neurodevelopmental syndrome may fail to meet statistically devised criteria (IQ ceilings) specified for the diagnosis of ID (IDD); however, they do meet adaptive functioning criteria generally because of atypical brain development. Overall, insufficient attention has been paid to developmental neurobiology during the life cycle in the mildly impaired group. Longstanding stereotypes held by laypeople and even many mental health professionals are grounded in beliefs about more severe manifestations of ID (IDD) without consideration of the full range of deficits. Because the implications of the differences between disorder and disability are not sufficiently emphasized in the USA, the implications of these approaches will be developed further in this chapter and serve as the unifying framework for much of its content.

This chapter will review historical landmarks, diagnosis and classification, and issues that arise about the current classifications. It will discuss the nature of ID (IDD) and will trace the history of recognition and services for people with intellectual deficits moving from early descriptions to early interventions and to the current focus on empowerment and self-determination.

Historical Landmarks

The earliest reference to intellectual disability (intellectual developmental disorder) may be from ancient Egyptian medicine in the Papyrus Ebers (1552 BCE) (Bryan, 1974). Yet despite recognition since antiquity, there is little evidence available to suggest early medical interest. Still references in the various religious traditions suggest and indicate that people who were affected were to be treated with kindness. Despite such positive admonishment, infanticide was practiced in Greek and Roman cultures, and trephining was utilized in Europe and Central and South America as an intervention, probably based on beliefs that evil spirits might be released. People diagnosed with ID (IDD) may have been slaves in some cultures or chosen for court jesters in others. Thus, historically, attitudes ranged from humane concern to ostracism and abuse. In some countries, those affected were viewed as harmless innocents and allowed to wander at will. In England, Henry II promulgated legislation to make them wards of the king to provide for their protection (Harris, 2006).

At the end of the eighteenth century, with rising respect for the individual at the time of the French and American Revolutions, the rights of not only mentally ill, blind, and deaf people but also those with an ID (IDD) were beginning to be acknowledged (Kanner, 1964). Jean Marc Gaspard Itard, ignoring the opinion of the experts of his time, invested 5 years (1801–1806) seeking to teach and habilitate Victor, the wild boy of Aveyron (Lane, 1976), with support from the French Academy of Sciences that followed his interventions. Despite Victor making limited progress, the methods Itard established were acknowledged as highly meritorious by the French Academy of Sciences. Gradually the effort to educate people with an ID (IDD) spread, first to Switzerland and later in other parts of Europe and the USA. Interest in ID (IDD) was stimulated by Rousseau's positive philosophy regarding prospects for human development. Pestalozzi and the encyclopedists promulgated this philosophy. Moreover, Itard's success encouraged Edouard Seguin to develop treatment programs for persons with ID (IDD).

Amentia or idiocy had been thought to be a homogeneous category. Both "idiocy," a designation for ID (IDD), and "insanity," a designation for mentally ill, were regarded as homogeneous entities. In 1845, in his treatise on mental maladies, Esquirol divided ID (IDD) into two levels, idiot and imbecile. He proposed that in the idiot, intellectual and moral faculties did not develop, writing "Incapable of attention, they cannot control their senses. They hear but do not understand; they see but do not regard. Having no ideas, and thinking not, they have nothing to desire…" (Esquirol, 1845, p. 467). The imbecile was near normal in their intellectual faculties yet would never attain normal knowledge for age, normal educational level, or normal social relations (Scheerenberger, 1983). Seguin in 1846 accepted these two categories and added to them feeblemindedness and superficial retardation (Scheerenberger, 1983).

Soon afterward in 1850, early medical attention to cretinism resulted in a periodical publication, *Observations on Cretinism*. Griesinger (1876) noted that even though everyone diagnosed with cretinism was developmentally retarded, not every developmentally retarded person was a cretin (Scheerenberger, 1983). Thus he insisted that ID (IDD) is a heterogeneous category (meta-category) and not a single entity. Previously no distinctions had been made between etiologies of ID (IDD). The next distinctions were made by John L.H. Down in his classical paper, "Observations on an Ethnic Classification of Idiots" (Down, 1866), that addresses heterogeneity and Desire-Magloire Bourneville in his description of tuberous sclerosis in 1880 (Scheerenberger, 1983). An era began to find more clearly defined disorders, commonly named after their discoverers.

With the recognition that ID (IDD) was not a homogeneous category, the way was paved to distinguish specific conditions that differed in both pathology and etiology that were characterized by intellectual deficits. Degenerative diseases were recognized such as Tay–Sachs disease. These findings established the view that ID/DD is caused by brain pathology and is not curable and raised questions about the possibility of any medical habilitation. With no medical treatment, educators provided amelioration.

Attention soon turned to intelligence testing and to the heredity of disorders of intellectual development. The most important people involved in early IQ testing are Francis Galton (Galton, 1869, 1883) and Alfred Binet and Theodore Simon (1911). Galton was a cousin of Charles Darwin whose theory of natural selection suggests that there is inherited variation among members of a species transmitted from one generation to the next. Galton sought to establish the hereditary basis of differences in ability and was first to see the importance of the twin method in investigations of intelligence.

In 1905, two French physicians, Alfred Binet and Theodore Simon (Binet & Simon, 1911), introduced psychometric tests. With the advent of compulsory primary education, Binet was charged by the French Ministry of Public Instruction to find a reliable method to find children who were unable to profit from instruction in normal schools (Mackintosh, 2011). Because the tests were considered objective and scientific, they were widely accepted. Binet and Simon wrote: "It seems to us that there is a fundamental faculty in intelligence, any alternation or lack of which is of the utmost importance for practical life. This is judgment, otherwise known as common sense, practical good sense, initiative, and the ability to adapt oneself to circumstance. To judge well, to comprehend well, these are the essential ingredients of intelligence" (Binet & Simon, 1911 quoted by Mackintosh, 2011). Their focus is on the ability to cope in everyday life. Binet sought norms for age and made comparisons among children of the same age to establish a mental age. The next steps in intelligence testing were taken in the USA. Henry Goddard, director of the Vineland Training School, in New Jersey, translated Binet's tests. He found that these tests were a reliable means to assess intelligence by evaluating 400 residents of the Vineland Training School and afterward administering these tests to 2000 typically developing children (Goddard, 1911). By 1916, Goddard had distributed 22,000 copies of the Binet and Simon paper (Mackintosh, 2011). Goddard added a third designation, moron, to the long-standing usage of idiot and imbecile.

It was Lewis Terman at Stanford University who made the greatest early advances in test development (Terman, 1916). His Stanford–Binet test was a revision of Binet's 1908 and 1911 tests with 40 new items along with his changes in other items. This resulted in six test items for each age. Terman tested around 1000 children ages 4–14 years to establish his norms. All participants were of similar social status. Terman adopted a previously published intelligence quotient, or IQ, based on mental age divided by chronological times 100. Thus the average child would have an IQ of 100 and a 6-year-old child with a mental age of 7 would have an IQ of 133. Subsequently, group tests were devised to test large numbers of people and used in the First World War in the USA by a team led by Robert Yerkes (Yaokum & Yerkes, 1920). Because these tests were so widely administered, the American public became more aware of intelligence testing.

Goddard, Terman, and Yerkes adopted the view that intelligence was highly heritable as Galton earlier had claimed. His interest in hereditary led Galton to propose the term eugenics to refer to the science of improving adaptability by selective breeding. Eugenics was noted to take into account influences that may "give the more suitable races or strains of blood a better chance of prevailing…" (Mackintosh, 2011 p. 19). People with ID (IDD) were thought to be incurable and by some to be morally and socially deviant and a menace to society. This led Goddard to seek to document the relationship between ID (IDD) and antisocial behavior in a family study of the *Kallikaks* that consisted of two family lineages with the same father; one lineage was socially prominent and the other filled with members with antisocial behavior and intellectual deficits. Goddard's *The Kallikaks* sought to determine whether ID (IDD) and antisocial behavior were genetically rather than socially transmitted by neglect, poverty, and mistreatment by following these two lineages. Goddard's (1912) description of the Kallikaks described persons in the ID (IDD) lineage as a menace with increased criminality and drug abuse. Moreover, this lineage was determined to be the genetic source of more retarded persons in each new generation. The eugenics movement used this Kallikaks study as evidence of danger to society characterizing their "moral imbecility," indiscriminate sexual behavior, and excessive procreation. Eugenic considerations resulted in the placement of persons ID (IDD) in institutions and in sterilization programs. Such views increased the institutionalized population in the USA and led to the sad, long-lasting sterilization programs in the USA and in Europe, most tragically culminating in involuntary euthanasia programs in Nazi Germany.

Despite the misuse of science in negative eugenic experiments, productive research into the causes of ID (IDD) continued. The earliest preventive intervention for a neurodevelopmental syndrome resulted from Ivar Asbjörn Følling's (1888–1973) discovery in 1934 that phenylketonuria (PKU) is a metabolic disorder that could be reversed and treated by a restriction diet (Harris, 2006). The identification of biochemically based ID (IDD) syndromes made clear that such research was a legitimate endeavor in the biological sciences (Hagerman & Hendren, 2014).

The early discoveries led to national programs that bring medicine, education, psychology, sociology, genetics, and the various specialties together into special federally funded university-affiliated centers to find treatments. Currently, academic medicine is actively involved with other specialties, community organizations, and parent groups to investigate the etiology of neurodevelopmental syndromes, find therapeutic interventions, and establish habilitation and prevention programs. Advances in the developmental neurosciences, developmental psychology, developmental psychopathology, phenomenology and classification, family, behavior, and drug treatments have led to a renewed and ongoing commitment to persons with intellectual developmental disorders.

Terminology for Intellectual Disability (Intellectual Developmental Disorder)

Terminologies and Criteria Used in the Twentieth Century

The use of early diagnostic terms such as idiocy, imbecility, moronity, and mental subnormality persisted in diagnostic manuals in the first half of the twentieth century (1921, 1933, 1941, 1952, 1957, 1959). Major change came in 1961 when the American Association on Mental Retardation (AAMR) introduced the term "mental retardation" to replace earlier terms that had become pejorative. The 1961 definition was the first definition that provided objective criteria and test scores for measurement, and it introduced dual criteria for intelligence and adaptive behavior. It was the first classification to be nearly universally adopted (Greenspan & Switzky, 2006a). The 1961 definition was "Mental retardation refers to subaverage general intellectual functioning which originates in the developmental period and is associated with impairment in adaptive behavior." Subaverage was defined as more than one standard deviation from the population mean and operationally defined as a score of 84 or less on a standardized psychometric test. The developmental period was defined up to the age of 16. Severity levels of intelligence were numbered 1–5 (borderline, mild, moderate, severe, profound) corresponding to standard deviations from the population mean. Adaptive functioning was subcategorized as levels 1–4 (mild, moderate, severe, profound).

The manual was revised again in 1973. Because one standard deviation from the population mean was found to be overly inclusive and resulted in the over-assignment of minority students to special education and because the adaptive behavior criteria were widely ignored, the wording was changed from subaverage to "significantly subaverage" and the IQ cutoff point changed to two standard deviations from the population mean. Impairment in adaptive functioning was defined as "concurrent with deficits in adaptive behavior." The developmental age range was increased to 18 years.

The next revision in 1983 was significant in adding the IQ's standard measurement error (typically five points) to the definition. Severity ratings based on standard deviations from the population mean were maintained but the actual numbers were now spelled out (e.g., mild 50–55 to approximately 70, moderate 35–40 to 50–55, etc.). The importance of clinical judgment was emphasized in the 1983 definition. Emphasis was added in regard to the importance of the impact of social milieus in facilitating or impeding intelligence. An important goal was to keep the classification system congruent with the American Psychiatric Association's diagnostic manual (DSM-III 1980) and the ICD of the World Health Organization.

The 1992 AAMR definition represented a paradigm shift that sought to take into account differences in service models and to provide greater emphasis on self-advocacy and on the disability construct. It makes the philosophy of the AAMR clearer regarding the model of mental retardation preferred by the organization that mental retardation should be viewed as a state rather than a trait. The 1992 AAMR manual states that "mental retardation refers to a particular state of functioning that begins in childhood in which limitations in intelligence coexist with related limitations in adaptive skills" (Luckasson et al., 1992, p. 9). It notes that mental retardation is neither a mental disorder nor a medical disorder. The focus on the disability construct is clarified by stating that mental retardation is not an absolute trait expressed solely by an individual but an expressed interaction between the affected person and the environment (Luckasson et al., 1992, p. 9). The intelligence criterion is a score of 70–75 or below on a standardized intelligence test. Major 1992 changes were to extend adaptive behavior to ten specific adaptive skill (not behavior) areas and to require significant disabilities in two or more adaptive skill areas in the definition. Subclasses of mild to profound were replaced with four-level subclassification systems of intensities and patterns of supports (intermittent, limited, extensive, and pervasive). Finally, a multidimensional approach to classification was introduced with 4 dimensions (intellectual functioning and adaptive skills; psychological/emotional considerations; biomedical, social, behavioral, and education factors; and environmental considerations). The age of onset remained below the age of 18 years. Spitz (2006) in a critique of the 1992 definition points out that the AAMR does not discuss familial (hereditary) mental retardation and does not acknowledge polygenetic contributions to the mild level.

The 1992 AAMR diagnostic manual created some dissatisfaction within the psychological community, for two reasons: (a) the attempt to eliminate subcategories and replace them with support need profiles and (b) a shift from a 70 to a 75 IQ ceiling. This dissatisfaction was expressed most concretely in an attempt by Division 33 of the American Psychological Association to put forth its own diagnostic document, which was published in 1996 (Jacobson & Mulick, 1996). This manual consisted of two parts: (a) a brief definitional section and (b) a longer section with chapters by distinguished authors (who had no input into the definition) on various topics related to mental retardation. The manual section essentially was a return to the definition in use by AAMR before its 1992 manual. The document led the AAMR to revise its manuals to bring back the possibility of severity subcategories (as options) in subsequent manuals and to move away from an IQ ceiling of 75 and adopt IQ "70–75" range based on test standard error.

During the twentieth century, the American Psychiatric Association (APA) essentially followed the lead of the AAMR in DSM-III (1980) maintaining compatibility between the classifications. In DSM-IV, the definition remained compatible between the classifications, but DSM-IV maintained the earlier levels of severity with the same IQ cutoffs as before and continued with the DSM multiaxial classification rather than adopting the AAMR multidimensional approach. Moreover, in a classification of disorders, unlike the AAMR, the American Psychiatric Association views ID (IDD) as a trait that may be heritable. It is a trait that may result from a variety of neurogenetic developmental disorders and polygenetic inheritance.

Terminologies and Criteria Introduced in the Twenty-First Century

In the twenty-first century, the AAMR updated its 1992 definition and description in 2002 by specifically stating that mental retardation is a disability to emphasize its severity and to align its position with that of the WHO's International Classification of Functioning (ICF). It emphasized that there are significant limitations in both intellectual functioning and adaptive behavior. Previous definitions noted concurrent limitations in adaptive behavior but now each was placed on equal footing. It introduced a tripartite model of adaptive behavior by emphasizing adaptive skills in conceptual, social, and practical domains. It added a fifth dimension of human participation, interactions, and social roles.

In 2007, the American Association on Mental Retardation (AAMR) changed its name to the American Association on Intellectual and Developmental Disabilities (AAIDD) and in 2010 published its most recent update to its manual. It clearly places intellectual disability, the new naming it proposes, as being solidly placed in the broader construct of disability noting that intellectual disability is no longer viewed as an invariant trait of a person. The focus instead is on a social–ecological construct of the person interacting with his or her environment. It highlights the principles of self-worth, well-being, and self-determination emphasized within the disability movement. It continues the focus of its earlier classifications of supports needed to help each person reach their potential. The accompanying manual text includes a chapter on etiology that draws attention to the multifactorial nature of etiology. It recognizes that the traditional two-group approach (biological and cultural familial) is focused on multiple risk factors that may be present for both of these categories. Those with severe known neurogenetic disorders and others with nonsyndromic milder presentations (and potentially polygenetic inheritance) may both be impacted by environmental risk factors that affect functioning. Still, fundamentally, the AAIDD's classification focus is mainly on functioning, adaptive behavior, and support needs that are consistent with the conceptual model proposed by the ICF and not that of the WHO's International Classification of Diseases (ICD).

The adoption of the disability construct (consistent with the ICF) by the AAIDD and its decision to introduce intellectual disability as the new term for mental retardation gained momentum in the context of the revision of the two major classifications of mental disorders: the ICD-10 and the American Psychiatric Association (APA)'s Diagnostic and Statistical Manual of Mental Disorders (DSM).

If disorders of intellectual development were defined as disabilities and not as health conditions, they would not be included in the ICD. They would only be classified using codes from the ICF. However, it is the ICD rather than the ICF that is primarily used by the 194 WHO member countries to provide health care to their citizens. ICD categories, including those related to intellectual development, are used to designate which people are eligible for specific health care, educational, and social services. Thus removal from the list of ICD health conditions could have impact on national and global health statistics and on the service availability (Bertelli, Harris, & Salvador-Carulla, 2016).

The World Psychiatric Association's section on Psychiatry of Intellectual Disability solution was to indeed consider disorders of intellectual developmental to be health conditions in the International Classification of Diseases (ICD) viewing them as "a syndromic grouping or meta-syndrome analogous to the construct of dementia, which is characterized by a deficit in cognitive functioning prior to the acquisition of skills through learning." They note that the intensity of the intellectual deficit interferes in a significant way with an individual's normal functioning and results in limitations in activities and restriction in participation (disabilities) as described in the International Classification of Functioning (Salvador-Carulla et al., 2011).

These deliberations assumed importance in the USA with the revision of the American Psychiatric Association's diagnostic manual, DSM-5. It is the *official* classification for mental disorders in the USA and by international agreement shares diagnostic codes with the ICD. For DSM-5, there was liaison with the WHO ICD-11 committee to assure harmonization of the two classifications. The ICD-11 committee at the time that DSM-5 was being finalized used the term intellectual developmental disorder (the newest draft uses disorders of intellectual development). To harmonize the naming and to make clear that the DSM-5 definition was on disorder, the final naming in DSM-5 is intellectual disability (intellectual developmental disorder) or ID (IDD). The term intellectual developmental disorder in parenthesis is listed to make clear that the DSM-5 focus is on disorder and not the disability construct preferred by AAIDD and the ICF. Moreover, the term intellectual disability is used in the scientific literature in the USA for both the disorder construct and the disability construct.

The DSM-5 definition is a major revision from DSM-IV-TR. The DSM-IV criteria were similar to the 1992 AAMR definition in requiring significantly subaverage intellectual functioning and concurrent deficits in present adaptive functioning in 2 of 11 designated areas, among them communication, self-care, social/interpersonal skills, functional academic skills, and self-direction. However, it went further in designating an IQ of approximately 70 or below on an individually administered IQ test in the body of the definition. In DSM-IV-TR, mental retardation was listed in the multiaxial system on Axis II separating it from other developmental disorders with the expectation that this placement would lead to its regular assessment.

DSM-5 introduces a new category, *neurodevelopmental disorders*, not used in DSM-IV-TR to make it clear that intellectual and other developmental disorders are neurodevelopmental problems in brain functioning. *Neurodevelopmental disorders* parallel neurocognitive disorders of late-life onset (e.g., Alzheimer's disease) as disorders of brain functioning in DSM-5. DSM-5 eliminates the term mental retardation that was used in DSM-IV-TR and eliminates the multiaxial classification that had placed mental retardation on Axis II. The new term that replaces mental retardation in DSM-5 is intellectual disability (intellectual developmental disorder) and provides new disorder diagnostic criteria thus aligning it with all the other mental disorders in the classification. As noted earlier, "disorder" is placed in parenthesis to make clear that the focus in DSM-5 is on a disorder of neurodevelopment of the brain. It is classified as a brain-based disorder. Additional specifier codes are used to indicate specific causative syndromes such as fragile X syndrome.

The term "intellectual disability" is retained in DSM-5 because this term is commonly used to obtain services and this term is used in federal legislation (PL 111-256) for service determination. Both DSM-5 and AAIDD provide similar definitions for intellectual disability in the body of the definition. However, as noted earlier, the AAIDD makes clear in their manual (2011) that, like the WHO's International Classification of Functioning (ICF), it is based on the disability construct rather than the disorder construct.

The DSM-5, for the first time, includes a definition of intelligence in Criterion A (Harris, 2013; 2014a). This inclusion is a major clarification meant to make clear how intellectual deficits are defined and their relationship to adaptive functioning. These criteria are based on a consensus definition of intelligence accepted by the APA and AAIDD (Gottfredson, 1997). Defining intellectual deficits is important to assure their assessment in both clinical (psychiatric interview) and psychometric (IQ and neuropsychological testing) evaluations. This is a departure from the DSM-IV-TR classification that does not delineate intellectual deficits in its definition. Unlike the earlier DSM classifications, DSM-5 does not refer specifically to an IQ number in the definition nor does it refer to IQ in Table 1 (severity levels on pp. 34–36 in DSM-5). Instead it lists intellectual deficits in reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience.

These deficits must be confirmed by *both* clinical assessment and individualized standardized intelligence testing to make a diagnosis.

Importantly, DSM-5 (unlike DSM-IV-TR) clarifies that the first two criteria, A and B, are interrelated. DSM-5 specifies that adaptive functioning (Criteria B) is an outcome of intellectual deficits (Criteria A). DSM-IV-TR has been interpreted by the courts as having 2 prongs—prong 1 in DSM-IV-TR is based on statistically derived IQ test numbers and levels and prong 2 defines deficits in adaptive functioning that impact adaptation in the community. Because Criteria A and B are interrelated in DSM-5, they should be considered together rather than as prong 1 and 2 and understood as linked. By defining intellectual deficits as deficits in reasoning, problem solving, and planning, DSM-5 links the first and second criteria. Thus, rather than distinct elements, they are interrelated ones and both must be considered together to make a diagnosis.

Specifically, in this neurodevelopmental disorder, intellectual deficits result in *problems in adaptive reasoning* leading to deficits in adaptive functioning in academic, social, and practical. Thus, in DSM-5, the severity of the disorder (mild, moderate, severe, profound) is NOT based on IQ score. It is based on the severity of the adaptive functioning in conceptual, social, and practical domains as noted in Table 1 in DSM-5.

The medical community recognizes that the IQ test is imprecise even though it is of considerable significance. When IQ scores (taking into account the standard error of measurement) are used to assess a defendant's eligibility for the death penalty, it is important that the courts view test scores with the same skepticism with those who do design and use the tests because an IQ test score represents a range rather than a fixed number. Moreover, in regard to the IQ test, DSM-5 states that the use of a battery of neuropsychological tests that measure discrete intellectual functions such as verbal comprehension, executive functions, and memory provides a better description of a person's overall cognitive abilities than an IQ test alone. As noted in the explanatory text to DSM-5 on page 37: "in some instances if adaptive deficits are severe then one can meet criteria based on those adaptive deficits even if the IQ is in the 70s." Thus DSM-5 shifts the emphasis in diagnosis when determining the severity to focus on adaptive functioning and reasoning and makes clear that Criterion A and B are interrelated. As stated in the DSM-5 text, "IQ tests scores are approximations of conceptual functioning but may be insufficient to assess reasoning in real-life situations and mastery of practical tasks" (DSM-5, p. 37). Thus the critical issue is adaptive reasoning in the three domains described in DSM-5 (conceptual, social, and practical).

The third criterion is onset of deficits in the developmental period. In the explanatory text, the developmental period is discussed in the section on *developmental course*. Here information is provided that recognition of deficits in adaptive functioning is recognized in early life and persists throughout life. ID (IDD) is not simply a development delay but a long-term chronic disorder of functioning. Thus any assessment of adaptive functioning must take into account early developmental history and make reference to school records, testing, and reports.

Finally, individuals with ID (IDD) diagnoses are at increased risk of co-occurring mental disorders that further impacts their adaptive functioning. Such diagnoses occur in up to a third of individuals in published studies and include the full range of psychiatric disorders such as attention deficit disorder, schizophrenia, major depression, and bipolar disorder. The co-occurrence of mental disorders further impact adaptive functioning (Harris, 2014b).

History and Limitations of the IQ Statistic

Adoption of the Deviation IQ Method

The first widely used intelligence test, devised in France by Binet and Simon in the first decade of the twentieth century and imported to the USA by Goddard and Terman, chose to use a measure of mental age (MA). This was determined by establishing mean scores for all subjects in a standardization sample. The tested individual was compared to a norm table and his or her MA is established identifying the comparable age mean. Thus, if a 15-year-old subject scored at the mean level of a 10-year-old, he or she would have a chronological age (CA) of 15 and a MA of ten.

The invention of the intelligence quotient (IQ) in the 1930s by the German psychologist William Stern had major implications for the diagnosis of ID (IDD). Initially, IQ was calculated by use of the "ratio method" that entailed dividing CA into MA and multiplying the result by 100. Using the previous example, if a youth of 15 had a MA of ten, he would have an IQ of 67 ($10/15 = 0.67 \times 100 = 67$). If the same youth at age 15 had a MA of 15, this IQ would be 100 ($15/15 = 1.0 \times 100 = 100$). Thus, the convention was established that an average IQ equals 100.

An obvious problem with the ratio method is that, at some point in adolescence, growth in MA ceases to increase very much, while CA increases at a steady pace. In diagnosing ID (IDD), the use of MA resulted in many false positives. For example, a 20-year-old with a MA of 14 would have an IQ of 70 and falsely be identified as defective. Fourteen is the age at which MA growth begins to reach an asymptote, so the person in question would actually have a relatively normal intelligence.

The solution to this problem was a change introduced in the 1960s to move from the ratio method to the "deviation IQ" method. In this method, the norming sample (typically only a few thousand subjects) would be divided up into small age blocks, and statistics would be calculated separately for each age block. The basic statistic is a "z-score" that indicates the distance an individual falls from the mean for that sample in a number of standard deviation units. The zero point in the z-distribution is arbitrarily set at 100, which means that 50 % of the distribution falls above or below 100. Individual scores are then calculated based on number of z-scores from the age-block mean (thus, a score of minus 1.5 means that the individual's IQ score falls one-and-a-half standard deviation units below the mean). Just as the z-score of zero is arbitrarily set at 100, a z-score of 1 is arbitrarily set at 15. Thus a z-score of minus one would equate to an IQ score of 85, while a z-score of minus two would equate to an IQ score of 70. As the distribution of z-scores follows the very well-defined "normal" (bell-shaped) curve, with a severe drop-off to the right or left after minus one or plus one z, an IQ score of 75 places one at the fifth percentile, an IQ score of 70 at the second percentile, and an IQ score of 55 at a tiny fraction of the first percentile.

Thus, the IQ standard deviation (SD) units were used not only to define the upper level of the ID (IDD) population but also to devise subclassification categories (mild, moderate, etc.). Interestingly, in the 1961 AAMR manual, there was so little emphasis on IQ standard deviation-based subcategories that they are to be found only in a single footnote in a table. That changed dramatically in later years, where subcategories were entrenched. Because subcategories were so well established, the removal of IQ-based subcategories based on discontinuous standard deviation units by the AAMR in its 1992 manual and replacing them with a continuous index intensity of support needs caused the American Psychological Association (Jacobson & Mulick, 1996) to publish its own manual as mentioned earlier. This decision was successful and the AAMR reversed its decision agreeing that IQ SD-defined subcategories were important. In the long run, the effort to restore IQ-based subcategories failed when DSM-5 decided that subcategories should be based on the degree of adaptive deficits and not on the degree of IQ deficit.

An advantage of the deviation method is that one can reliably locate where an individual falls in relation to the norming sample of people of approximately the same age. Still, there are a profusion of problems that inhere in the heavy reliance on IQ scores, particularly the full-scale (overall summary) statistic that is its most widely used index. Three of these problems are (a) problems with norms, (b) problems with content coverage, and (c) problems with use (particularly reification).

Problems with Norms

Because performance on an IQ test derives its meaning from where it places someone in the distribution of scores in a standardization sample, a score is valid only if the test developers used adequate methods to constitute the normative sample and statistically analyze the results properly. That is not always the case. For example, the developers of the WAIS-III, in compensating for the WAIS-R's "tree stump" (floor effect) problem caused by too few low-functioning standardization subjects (if a tree stump took the WAIS-R, it would have received a full-scale IQ in the 40s), overcompensated by recruiting too many low-functioning subjects for their new test edition. As a result, the WAIS-III overstated IQ by over two points (Flynn, 2007). That a new IQ test (such as the RIAS) correlates well with older tests (people who do well or poorly on one also do well or poorly on the other) does not mean that they produce the same results (the RIAS results, especially nonverbal ones, are significantly higher). While consistent differences can sometimes be addressed through a correction of the resulting score, one cannot fix, or even interpret, a score obtained from a test that is incorrectly constructed, as was the case with the Mexican Spanish-language version of the WAIS-III (Suen & Greenspan, 2009).

A common source of IQ score invalidity is termed the *Flynn effect* (Flynn, 1987, 2007) and refers to the fact that, on newer IQ tests (e.g., the WAIS-IV), subjects produce lower scores than on its earlier edition (e.g., the WAIS-III). The reason is not because a subject has gotten less intelligent in the intervening years but because the population from which standardization sample is drawn has scored higher on some subscales (especially the nonverbal ones). This is established when tests are being constructed, as a subsample of the standardization sample is given both the old and new test in counterbalanced order. Subjects uniformly do worse on the new test, by an average of three full-scale points per decade of norm obsolescence. In high-stakes assessments (such as capital punishment proceedings), it has become standard practice to do "Flynn corrections" in which all full-scale scores are adjusted downward by multiplying the number of years of norm obsolescence by 0.3 and subtracting the result from the obtained score. This ensures that all persons are being evaluated by the same standard. This is especially important in a death penalty case to assure that a life-affecting decision is not based on the accident of the age of a test edition that was used.

Problems with Content

Existing "gold-standard" intelligence tests are modeled after the Binet–Simon test that was substantially revised by Louis Terman. These tests were constructed by sampling items from different grades in the school curriculum and rank subjects in relation to age-matched peers. While intelligence tests have evolved considerably over the years, their items are still mainly representative of the logico-mathematical tasks that are taken highly predictive of school performance. More broad-based models of intelligence have been devised, which tap into other aspects of intelligence, such as what Guilford (1967) termed "behavioral" (social) and "mechanical" (practical) forms of intelligence. People with ID (IDD) all have problems in what Sternberg (1984) termed "academic intelligence" but if properly diagnosed also have problems in what he termed "everyday [social and practical] intelligence." But social and practical intelligence are not tapped directly by the IQ statistic, and thus an IQ score cannot adequately answer the question "how lacking in everyday intelligence is this person?" In theory, measures of adaptive behavior are attempts to assess practical and social functioning, but because they lack a cognitive focus, they have been criticized as inadequately tapping into the IDD taxon (which can be described as "low intelligence, broadly defined").

Problems with Use

Evolutionary biologist Gould (1981), in *The Mismeasure of Man*, a book about the mistaken uses of IQ testing, noted that these uses reflect two deep fallacies: the fallacy of ranking and the fallacy of reification. Ranking is based on the mistaken belief that all people (including individuals with Down syndrome) can be adequately described by where they fall on a continuum on a single summary domain such as “g” (full-scale IQ). Reification refers to the tendency to turn an abstraction into a concrete entity, as reflected in the mistaken belief that one’s IQ score is an immutable and unchangeable property of a person, in essence a snapshot of the person’s brain. A reflection on the reification of IQ is the view, expressed by some experts in criminal proceedings, that if there is any variation among results of multiple IQ tests (which there invariably are, as human performance is inherently variable), then the highest score must be the only valid one, while the lower ones may reflect conscious malingering (attempt to look less competent than one is). In fact, there are many other explanations for IQ score variability, including mistakes of administration, improper scoring, and even (one would like to think rarely) examiner corruption (Greenspan & Olley, 2015).

Executive Functioning and Other Indices

Both DSM-5 and AAIDD define intelligence with a list of cognitive processes, originally adopted from a mainstream consensus statement devised by a committee of prominent psychologists (Gottfredson, 1997) mentioned earlier. The constituent elements are not sufficiently tapped by the two leading gold-standard intelligence tests or captured by a full-scale IQ score. This is clearly a problem for the diagnosing of ID (IDD), given the exclusive weight given by many diagnosticians to the results of an IQ test.

In the past few decades, executive functioning has become a subject of research and clinical assessment, both in research and in the armamentarium of tests administered by clinical neuropsychologists (Diamond, 2013). In recognition of the contribution that executive functioning measures play in capturing important aspects of intelligence, the ID (IDD) section of DSM-5 states that testing for executive functioning and IQ may provide a more comprehensive assessment. The important point here is that the first diagnostic prong (Criterion A in DSM-5) is not isomorphic with an IQ score (or even multiple IQ scores).

Efforts to Reduce Reliance on IQ Ceilings

The definitional history of IDD over the past half-century has been characterized by various efforts to minimize the distorting effects caused, when in 1973 the IQ cutting score was set at 70. At minus two standard deviation (z-score) units, that established ID (IDD) in regard to intelligence at the bottom 2 % of the population. As the general consensus was that the 3 %, based on statistical assumption about IQ being a normally distributed trait, was a more appropriate dividing line, a variety of steps have been taken to address the resulting problem of too many “false negatives” (people deemed to require the ID (IDD label) but are denied it because of an IQ over 70). Moreover, because severe neurogenetic syndromes of ID (IDD) cluster in the severe range and there is increasing focus on polygenetic inheritance in the mild range. There is mounting evidence for the neurodevelopmental model and how it relates to IQ ceilings.

History of Adaptive Behavior and Adaptive Functioning

The concept of adaptive behavior originated in ethology (where it refers to competence of organisms in the wild as opposed to controlled laboratory, e.g., rat studies in a maze). This approach was borrowed by the American Association on Mental Deficiency (precursor of today’s AAIDD) in its 1961 diagnostic manual. Its inclusion was to emphasize that, when diagnosing intellectual disability ID (IDD), one should consider how an individual functions and solves problems in the real world, rather than in the controlled setting of an intelligence test. A problem with the construct is that it initially lacked a theoretical framework, and that problem has never been fully resolved.

The Heber (1961) manual in which adaptive behavior became part of the definition was preceded by a preliminary version published as a journal supplement (Heber, 1959). The earlier version referred to impairments in the three areas of “maturation,” “learning,” and “social adjustment.” Maturation was described as self-help skills usually acquired in early childhood, learning was described as academic skills usually acquired in middle childhood, and social adjustment was described as interpersonal skills usually acquired early but reaching fullest development in adolescence and adulthood, as manifested in successful work, relationships, and socially appropriate law-abiding behavior. Instead of a single integrated construct to be applied at all life stages, one was to apply only one of the above three constructs, depending on whether the individual in question was a young child, an older child, or an adolescent/young adult. In spite of this work, few clinicians ever used these preliminary constructs.

This pattern continued to be largely the case for a decade or more with the 1961 replacement construct of adaptive behavior that incorporated the three abovementioned domains into a single construct intended to be applied at all subject ages. The failure of clinicians to routinely include the adaptive behavior criteria undoubtedly contributed to the decision by AAMR to drop the “borderline” (IQ 71–85) subcategory 12 years later (Grossman, 1973). Tassé et al. (2012) pointed out that although the field of ID (IDD) has veered into different directions with respect to defining adaptive behavior, 50 years after Heber (1959), the field has essentially returned to defining adaptive behavior with the same original framework: conceptual skills (learning), social skills (social adjustment), and practical skills (maturation).

The force driving the development of what was then termed the “dual criteria” definition of IDD (i.e., IQ and adaptive behavior) was concerned about the problem of “false positives” in the over-assignment to self-contained special education classes of low-socioeconomic-status children of ethnic minority groups. This group was described as the “6-h retarded children”; that is, they were identified as having an intellectual disability while in school but not outside of school. This phenomenon reflected two things: (a) the sole reliance on full-scale IQ scores as the basis for assigning the IDD label and (b) the (typically reported) lower IQ scores of low-socioeconomic-status minority children. Thus, the introduction of the adaptive behavior prong can be seen as reflecting a desire to ground ID diagnosis on real-world functioning and to be less culturally biased than measures of intelligence particularly.

Developing adequate ways of measuring adaptive behavior/adaptive functioning has proven to be challenging. Initially AAMD developed its own rating measure—the AAMD Adaptive Behavior Scale (ABS, not to be confused with the later ABAS)—but this was handicapped by the absence of population norms and its development at an institution (Kansas’ Parsons State School) with a consequent emphasis on very basic skills such as self-toileting. This was remedied by the development of other rating measures—such as the ABAS, Vineland, and SIB—but there still has been a failure to fully address aspects of community functioning, such as negotiating the social world. Recently, AAIDD has again put out its own instrument (expected out at the end of 2015), the Diagnostic Adaptive Behavior Scale (DABS), which is justified as the first instrument to be devised primarily for diagnostic rather than for programming purposes. This instrument appears to be better at tapping social deficits (its several gullibility items are reported to strongly discriminate ID from non-ID samples) but is limited by age norms that do not go above 22. Use of rating instruments is justified by the absence of valid “direct” test measures, but they pose problems of possible third-party rater bias. Use of descriptive/qualitative information is encouraged for getting at aspects (such as gullibility) not covered adequately in existing measures and for more fully understanding a person’s functioning (Greenspan, Loughlin, & Black, 2001), but (perhaps reflecting the quantitative bias in the IDD field) such a qualitative supplement to rating data is typically not used.

IDD Equivalence

The term “IDD equivalence” refers to accommodations that are made by legal and other governmental entities when they provide services, supports, or protective arrangements to people who—because of brain impairment—function as if they have IDD but fail to qualify for the IDD label because their IQ scores are a few points too high. Individuals with various brain-based syndromes are candidates for such an accommodation, as IQ scores often are around or above the 70–75 IQ ceiling, while adaptive functioning is typically much lower. IDD-equivalence accommodations are, thus, an attempt to free the human services field from the excessive constraints caused by rigid reliance on full-scale IQ ceilings to determine service eligibility.

IDD-equivalence solutions can take various forms. These include using the broader category of "developmental disabilities" (DD), establishing both categorical and non-categorical procedures for declaring people eligible for developmental services in spite of IQ over arbitrary IQ ceilings and raising the IQ ceiling itself. A full description of the history of DD and other ways of broadening IDD can be found in Greenspan, Brown, and Edwards (2015).

Service Eligibility Solutions to the IQ Ceiling Problem

Other solutions, some in response to lawsuits or lobbying efforts, have been devised to get around the straightjacketing effects of IQ ceilings in defining ID (IDD) and allowing access to developmental services. One solution has been the use of individual add-ons. Thus, in Connecticut, a 2006 state law defines ID (IDD) thusly, "Any person… who is, appears to be, or believes him/herself to be a person with mental retardation, as defined in Connecticut General Statutes 1–1 g [note: DSM definition] *or Prader-Willi Syndrome*…[italics added]." In other states, there are different add-ons. For example, in Minnesota, special mention is given to Patau syndrome (a trisomy on chromosome 13) and Edward syndrome (a trisomy on chromosome 18). Why these specific add-ons? The obvious answer is that there have been effective lobbying efforts by parents and advocates for individuals with these specific syndromes. It also does not hurt that these are rare disorders that can be very reliably medically diagnosed, and the consequences to public funding agencies are more limited than if, for example, IDD equivalence were automatically granted to people with autism, a much more frequent disorder with relatively broad functional diagnostic criteria.

Another approach to IDD equivalence is used in California for what is termed the "fifth category." This refers to developmental services provided to IDD for service purposes defined as ID (traditional criteria) and three other disorders (as long as adaptive functioning criteria are met): cerebral palsy, epilepsy, and autism. The fifth category refers to others who function adaptively as if they have ID (IDD) or who have service needs similar to those who have IDD (Greenspan et al., 2015).

From Institutional Care to Self-Determination

In the not-too-distant past, virtually all individuals with IDD, including children and adults with mild or even borderline levels of impairment, were often placed in large congregate public institutions. Today, many such institutions have been closed or are slated to close, relatively few of them are still operating, and the remaining few contain no children and only adults with the most severe forms of impairment. Many institutions were constructed during the height of the eugenics movement; a major reason for their existence was to prevent people with even the mildest forms of ID (IDD) from reproducing (people with severe or profound ID (IDD) are very unlikely to procreate). This is reflected both in strict gender segregation and discharge upon reaching a certain age. Sterilization, often without consent or even foreknowledge, was practiced during the eugenic era (Scheerenberger, 1983).

A variety of living arrangements have been developed to accommodate children and adults who cannot reside with their families or on their own, either because of inability to meet daily needs or because of self-abusive or aggressive behaviors. These range from specialized foster care to group homes to supported one- or two-person apartments with degree of support ranging from occasional dropping-in around specific issues to full-time monitoring to deal with all issues. As a rule, the degree of support provided depends on the person's individualized needs and the risks (of death or great harm) associated with granting substantial freedom. The level of one's IQ and even of adaptive functioning is only mildly predictive of supports provided, as: (a) there is a bureaucratic tendency to put eligible persons into available residential slots regardless of specific need and (b) existing measures of competence, and even of support needs, do not automatically translate into or adequately tap needed supports, especially in the realm of interpersonal behavior (where one foolish action, in response to a confrontational situation, can produce life-threatening consequences for even a generally competent individual).

A current frontier in the evolution of individualized programming is the wrapping of individualized supports around people living in their own homes ("supported living"), work settings ("supported employment"), and even childrearing ("supported parenting") (Bradley & Knoll, 1995). An even more radical development in the movement to greater empowerment and autonomy is self-determination, which involves giving control of residential grants to the person with IDD, who can hire and even fire staff persons as they meet his or her needs (Wehmeyer & Schwartz, 1998). This development is a reflection of as well as a spur to definitional developments, as the field has come a very long way from the "defectology" view that was so pervasive a few decades ago.

The trend in developmental services, both for children and adults, has been toward greater respect, increased autonomy, lessened emphasis on global defects, and more emphasis on differentiated competence profiles. This trend is an external reflection of a shift in underlying values, driven generally by a philosophical system termed the "normalization principle" (Wolfensberger, 1972). That system is grounded in a view of people with IDD as having the potential to attain a good quality of life and the possibility of bringing pleasure and hope rather than a sense of tragedy and resignation to service providers and family members. Not surprisingly, this shift in underlying values is reflected in changes both in the terminology used to refer to people with ID (IDD) and in the evolving definitions of ID (IDD).

When the two authors of this chapter became introduced to the IDD field, the field was referred to as "mental deficiency"; the switch to "mental retardation" was seen as a more respectful development; the subclassification system consisted of terms such as "idiot," "imbecile," and "feebleminded"; research subjects were referred to as "retardates"; and the tendency was to use sentences with "is" (as in "John is retarded") and terms where the disability word comes first (as in "mentally retarded people"). A major development in the 1980s, in part initiated by people with disabilities (who referred to themselves as "self-advocates") themselves, was the shift to what is termed "people-first language" (Shoultz & Williams, 1982). This language is characterized by substituting the verb "has" for "is" (as in "John has mental retardation") as well as putting the disability word at the end preceded by "with" (as in "people with mental retardation"). Part of this shift also involves avoiding pity words, such as the once common "John suffers from" (or "is afflicted with") mental retardation. This terminology makes for lengthier and more cumbersome sentences, and that is a reason (among others) why professionals resisted its adoption initially. But today, any professional who does not adopt the people-first language is likely to be criticized, particularly when submitting papers to research journals.

A major development in North America was the change in 2006 of the name of the field's major professional and research organization from the "American Association on Mental Retardation" (AAMR) to the "American Association on Intellectual and Developmental Disabilities" (AAIDD). This was preceded two decades earlier, by a 1987 shift from the "American Association on Mental Deficiency" (AAMD) to AAMR. Adoption of the term "intellectual disability" (which has already come into widespread international usage) was initially resisted by professionals and agencies, as reflected in the fact that a first attempt at changing to AAIDD was rejected in a vote by a majority of the membership. Much of this resistance was driven by concern expressed by agency directors who feared that the name change would presage a broadening of the class of people they would be expected to serve. Approval of the change was won by a promise that it would have zero impact on prevalence and incidence rates. This probably regrettable promise indicates that the "science" of disability classification is affected to some extent by political and economic considerations. In 2010, the US Congress passed, and the President signed, "Rosa's Law" (Public Law 111–256), a bill named after a 9-year-old Maryland girl with Down syndrome. The law specified that henceforth any use of the words "mental retardation" or "mentally retarded" would be replaced by "intellectual disability" or "intellectually disabled" in any federal legislation, regulations, or proceedings.

Problem of Diagnostic Overshadowing

The term "diagnostic overshadowing" refers to the tendency to deny or overlook the possibility that someone could have and ID (IDD) diagnosis because of the existence of some salient or diverting characteristic of the person. Two forms of diagnostic overshadowing are particularly common: (a) psychiatric overshadowing and (b) cultural/racial overshadowing.

Psychiatric overshadowing refers to the tendency to overlook the existence of ID (IDD) in persons with a significant co-occurring mental disorder (Kanne, 2013). People with IDD have a higher likelihood—because of brain impairment or environmental deprivation—of also having co-occurring mental disorder. The existence of significant psychopathology should not be used to deny the possibility that the person may have an ID (IDD) diagnosis or that the ID (IDD) may predate the mental disorder. When faced with a person who has significant mental disorder, a diagnostician may falsely assume that the person's cognitive difficulties are a reflection of behavioral or emotional issues, when instead the underlying cognitive disorder is a risk factor for a mental disorder.

Cultural/racial overshadowing refers to the tendency to assume that the learning difficulties of all poor or minority individuals are a reflection of their socioeconomic or racial background. Such overshadowing is commonplace, even when the individual has a significant neurodevelopmental disorder and even if he or she resides in a family where they are the only one who is significantly impaired.

A reverse form of diagnostic overshadowing can also occur, in that an individual with an ID (IDD) diagnosis may also have emotional problems or a psychiatric disorder that is not fully recognized. This is not uncommon with individuals diagnosed with Down syndrome, where the stereotype of being universally happy and well adjusted may obscure the fact that, for some individuals, the reality is very different (Menolascino & Stark, 2012).

The Psychological Nature of Intellectual Disability (Intellectual Developmental Disorder)

The Construct of Intelligence

The construct of intelligence, as reflected both in definitions and measures, is central to the definition of ID (IDD). Yet, the construct is controversial and considerable disagreement exists regarding its meaning. In an edited book, titled *What Is Intelligence?* (Sternberg & Detterman, 1986), over a dozen leading intelligence researchers were asked to provide a definition, and virtually every one came up with something different. Both DSM-5 and the AAIDD manuals refer to an operational definition comprising a number of general mental functions ("reasoning, problem solving, planning, abstract thinking, academic learning, and learning from experience") based on a mainstream definition of intelligence that is a consensus of 52 psychologists (Gottfredson 1997). To this list, DSM-5 added judgment as a feature. But a diverse list is not the same thing as a focused definition. As earlier noted, some characteristics of the list of mental functions are more in line with factors characterized by executive functioning than by full-scale IQ. This is one reason why DSM-5 proposed that both executive functioning measures and standardized IQ testing are often more useful than full-scale IQ alone. It is especially important to include executive functioning testing in the assessment of mild ID (IDD).

One distinction between various definitions of intelligence discussed in the ID (IDD) literature has to do with intelligence as a "learning" versus a "thinking" process and ID (IDD), by extension, as a "learning disorder" versus a "thinking disorder." Learning has to do with the acquisition of cognitive schemas while thinking has to do with the flexible and effective application of those schemas to solve novel problems. Many people think of ID (IDD) as a learning disorder (in fact, in the UK, the term mental retardation or mental handicap was replaced by the term "learning disability"), and it is certainly the case that people with an ID (IDD) diagnosis, as a rule, are slower to acquire concepts and to master academic or vocational skills. But for people in the so-called mild range (where over 80 % of people with IDD can be found), we now understand that, with persistence and skilled teaching, many roles and activities, formerly considered impossible for them, can be learned. However, limitations in thinking are much more difficult to overcome, because novel and complex situations, especially those involving risk, will arise for which existing schemas cannot be used successfully.

Application of Psychometric Testing to ID (IDD)

In our classification systems of ID (IDD), we maintain the standardized measurement of general intelligence as a diagnostic criterion despite their being many different patterns of intellectual impairment in neurodevelopmental syndromes and people diagnosed with them with conditions that impact subtest score measurement. The disability approach is at the center of the AAIDD's advocacy for normalization in using a normative approach to adaptive behavior and focusing on the use of supports separately from the IQ. The APA's DSM approach to diagnosis seeks to understand the etiology of neurodevelopmental disorders and seeks to apply neuroscience to our understanding of intelligence and the brain.

Our understanding of the core features of human intelligence is ongoing. There is a longstanding debate regarding whether there is a distinct general intelligence or if it derives from overlapping component processes. An alternative approach to the *g* model is the three-stratum model, proposed by Raymond Cattell and John Horn and modified by John Carroll (Carroll, 1993; Deary, 2012). This model proposed that individual tests draw from several broad factors. This account of the psychometric structure of intelligence has resulted in a consensus that there is meaningful variance with three strata: general intelligence ("g"); a second grouping of broad domains that include fluid intelligence, crystallized intelligence, general memory, visual perception, auditory perception, retrieval, or cognitive speed; and the third stratum is based on specific abilities, such as induction, lexical knowledge, associative memory, spatial relations, general sound discrimination, or ideational fluency. The main contribution of the three-stratum model is the second stratum. Here there are two cognitive factors fluid intelligence and crystallized intelligence (Gf and Gc), short-term memory factors, and factors related to sensory modalities, visual and auditory. Hunt (2011, p. 106) noted that "the body of evidence favors the three-stratum theory over a simple intelligence model" but added that a revision of the *g* theory, the *gVPR* model, statistically also deals with the evidence very well. The heart of the *gVPR* model focuses on verbal (V) and perceptual (P) skill factors and a perceptual ability of mental rotation (R).

Consistent with the importance of these two models, when evaluating current psychometric theories, Hunt (2011 p. 109) concluded that "a theory of intelligence has to include something like general intelligence 'g'. But g alone is not enough." Because of the complexity of brain functioning in neurodevelopmental disorders, the full-scale IQ score alone is not sufficient, and additional neuropsychological testing is needed to describe an individual neurocognitive profile. The three-stratum model and the *gVPR* model provide the needed models to justify conducting both standardized intelligence testing and focused neuropsychological testing for the comprehensive evaluation and testing for people with an ID (IDD) diagnoses.

Social Incompetence

If you ask family members or experienced caregivers to list the top three concerns for an individual who has an ID (IDD) diagnosis, the list would almost surely include the difficulties that he or she has in navigating the social world (Turnbull & Turnbull, 1985). This lack of social competence puts the person with ID (IDD) at risk for a range of problematic outcomes, including: social isolation or friendlessness, bullying or social ostracism, and financial or sexual exploitation. Similar concerns are also expressed by knowledgeable service providers who echo research findings suggesting that failure in integrated work or residential settings is most likely to stem from inability to read social cues or to understand unstated behavior rules and expectations (Borthwick-Duffy, Greenspan, & Ho, 2006). In spite of the experience of family members and knowledgeable service providers about the critical role that social incompetence plays in the failure experiences of individuals with IDD, the social domain is very sparingly addressed by ID (IDD) researchers and clinicians, who tend to see the disorder mainly in cognitive terms. In fact, social incompetence can be, and largely is, a cognitive problem, if one approaches it in terms of social reasoning and judgment. However, the general approach to social competence in the main adaptive functioning instruments is inadequate. There is an overemphasis on maladaptive behavior items into the “social” subscales of adaptive behavior instruments.

Although people with IDD diagnoses are universally socially incompetent, it is important to understand exactly what that means. IDD syndromes, such as Williams syndrome, are associated with extreme friendliness. But friendliness does not equate with social competence, as reflected, for example, in high rates of sexual victimization of women with Williams syndrome (Frigerio et al., 2006). The social incompetence of people with IDD reflects a lack of social judgment, particularly in the recognition and understanding of social risk.

Recognition that social competence has a cognitive component was not appreciated when the first adaptive functioning measures were under development. Although it was correctly understood that social competence is an aspect of adaptive functioning, social competence was conceptualized mainly in terms of temperament (emotional reactivity) and character (aggression or its absence) and social judgment was not directly addressed. While maladaptive behavior is no longer explicitly part of the diagnosis of ID (IDD) (e.g., the Vineland Adaptive Behavior Scale has a maladaptive behavior section that is more of a supplemental scale), there are few items that tap social judgment (e.g., the Vineland has one gullibility item, while the ABAS has none), and social competence is generally given little emphasis (e.g., the social component of the ABAS has two skills: “social,” which mostly taps character and temperament, and “leisure,” which has many items (such as “plays nicely by himself”) that are not social).

An aspect of deficient social functioning that is increasingly recognized by ID (IDD) researchers and clinicians is social vulnerability, especially gullibility: a high likelihood of being duped by manipulators using coercive methods grounded in deception. In fact, the first textbooks about individuals with ID (IDD) in the nineteenth century emphasized their unusual “credulity,” but that insight was lost until recently. In thinking about gullibility, it is important to keep in mind two facts: (a) gullibility does not occur in every interaction (not all interactions are coercive) but it only takes one such instance (as when giving a false confession to a crime) to destroy a life, and (b) gullibility can be considered to be a social subtype of a broader construct of “risk unawareness,” something that is frequently found in the social histories of all people with IDD even if instances of gullibility may be harder to find.

Risk Unawareness as a Core Feature

As currently constituted, both AAIDD's "green book" (Schalock et al., 2010) and DSM-5 (APA, 2013) require deficiency in only one out of three adaptive domains (in DSM-IV-TR, it was 2 out of 11 adaptive skills). Thus, there is no single adaptive domain for which deficiency is critical to the diagnosis of ID (IDD). The rationale (that is questionable) given by AAIDD for only requiring one area of deficiency is that the domains are correlated, so global deficit is assumed even if not established. While we agree that global deficiency should not be a requirement, a better reason is that requiring deficiencies in all three domains might have made qualifying for IDD extremely difficult. Furthermore, while there is consensus that ID (IDD) is characterized by low intelligence (broadly defined) and some areas of deficient adaptive functioning, there is no unanimity yet regarding a specific adaptive domain or skill that should be universally impaired.

Given that broadly constituted low intelligence is the hallmark of IDD, the best candidate for any universal adaptive deficit should contain a strong cognitive component. Thus, while being independent in maintaining good personal hygiene is more likely than not to be a problem for people with ID (IDD), it cannot be a universal adaptive indicator because some people with ID (IDD) do maintain good hygiene. Many people with other disorders have poor hygiene, and there are strong noncognitive (e.g., motivational) factors that explain failure to maintain adequate hygiene. Failing to understand the probability of social rejection and potentially physical illness as consequences of poor personal hygiene, on the other hand, comes closer to capturing the essence of the IDD behavioral phenotype. Thus adaptive functioning must be framed in terms of cognition and judgment rather than behavior per se consistent with DSM-5 with emphasis on the central importance of "adaptive reasoning."

It has been suggested that one aspect of adaptive reasoning that is especially indicative of IDD is a failure to recognize and give sufficient weight to risk, both social (e.g., dealing with a person with hidden malevolent intent) or practical (e.g., operating a common machine which has the potential to grievously harm person or property) (Greenspan, 2009). In light of the community revolution in disability services and the related shift away from paternalism and toward emphasizing potential and positive attributes, discussion of risk or deficit is increasingly unacceptable. But, people with ID (IDD) are more in danger of failing in various roles without supports, and the purpose of providing supports is to reduce risks to manageable and safe levels (Greenspan, Switzky, & Woods, 2011; Greenspan & Woods, 2014).

IDD Provides a Window into Human Competence

Although relatively few mental health professionals specialize in or are adequately knowledgeable about ID (IDD), the field has been the source of important conceptual and methodological advances and insights, beginning with the study and understanding of brain functioning and human intelligence. Parents have many hopes for their children, but the most basic hope is that they grow up to become competent individuals, capable of adequately negotiating age-appropriate roles within the societies in which they live. A necessary, but not sufficient, basis for achieving adequate competence at any age is having a normally developed and fully functional cognition.

The field of ID (IDD) is basically the study and provision of services to children and adults with neurodevelopmental disorders whose brains (for any number of reasons) have failed to develop or function normally. Impaired brain functioning poses obstacles to one's ability to competently navigate the academic, vocational, and community living challenges that confront him or her as he or she goes through life. The connection between brain impairment and cognitive or social functioning is complex and has been the source of considerable research as discussed in the next section.

The Neurobiological Nature of Intelligence

Genetics

General intelligence is a human trait that is believed to account for much of the variation in cognitive abilities. Data from twin and family studies are consistent with a high heritability of intelligence. In a genome-wide association study involving nonclinical populations, a substantial proportion of individual differences in human intelligence was due to genetic variation and was consistent with many genes of small effects underlying additive genetic influences on intelligence (Davies et al., 2011). In nonclinical populations, intelligence is genetically stable throughout the life course. This longitudinal stability of IQ in neurotypical people is well documented, as is its increasing heritability with age. Although increased heritability of general cognitive abilities during the transition from childhood to adolescence is robust in typical development, cognitive abilities may plateau in adolescence in some syndromes such as the fragile X syndrome (Dykens et al., 1989).

Current neuroscience research on intelligence is focused on genetics—quantitative and molecular—and brain imaging. Quantitative genetic studies find additive genetic contributions to various facets of cognitive ability, in particular to general intelligence. Genetic studies show change through the lifespan. Studies of genetic correlations with behavior (behavioral phenotypes) and neurocognitive profiles of neurogenetic syndromes are rapidly progressing.

Genetic and neuroimaging studies are essential next steps to understand brain functioning in persons with an ID (IDD) diagnosis. In this regard, a reevaluation of the Thomson–Spearman debate is pertinent (Hunt, 2011). Thompson challenged Spearman's *g* by proposing that there are a large number of biological units (bonds) present in brains. When an individual attempts to solve mental test items, each of the items sampled a number of these bonds. The extent to which tests overlapped in the bonds they sampled accounted for their correlation. In modern parlance, his "bonds" might be considered to be distributed neuronal networks. There is recent support for this model and current research has documented that both Thompson and Spearman's models of intelligence can both account for the psychometric patterning of tests' intercorrelations (Barbey, personal communication, August 9, 2015). A central question regarding these models is how neuroscience evidence from brain imaging on human intelligence may inform psychological theory. Does general intelligence reflect a unitary construct (Spearman) or a broader set of competencies (Thomson)? The three-stratum model of intelligence is a model that can be investigated in genetic and in neuroimaging studies. For example, Christoforou et al. (2014) reported that GWAS-based pathway analysis can differentiate between fluid and crystallized intelligence.

Neuroimaging

Structural and functional brain-imaging studies have found differences in brain pathways that contribute to intelligence differences (Deary, Penke, & Johnson, 2010). The best evidence is for parietofrontal pathways (Colom, Karama, Jung, & Haier, 2010; Jung & Haier, 2007). Brain efficiency correlates positively with intelligence. Brain-imaging research may examine intelligence as a unitary construct (Spearman) or as a broader set of broader set of competencies (Thomson). The analysis is complicated because a given brain region may support multiple cognitive functions. Conversely, a given cognitive function can be implemented with multiple brain regions. This complicates the use of neuroscience evaluation of local versus distributed representations to inform the nature of cognitive representations of intelligence.

Nevertheless, recent studies of an integrative architecture for general intelligence and executive function have been initiated with lesion mapping (Barbey et al., 2012). The authors confirmed that psychometric *g* and executive function for the most part do depend on shared neural substrates and on the communication between frontal and parietal cortex. However, the analysis revealed other areas that were related to psychometric *g* and may not be involved with executive function. General intelligence and executive functioning scores shared 76 % of the variance but 24 % of the variance was unique. Areas related to executive function but that may not be involved with psychometric *g* were identified within the left anterior frontal pole that is consistent with anterior prefrontal cortex regions involved in the executive control of behavior. Overall, psychometric *g* is associated with a distributed network of brain regions, sharing common anatomical substrates with verbal comprehension, working memory, perceptual organization, and processing speed, while executive function deficits were associated with a distributed network of left lateralized brain areas, including regions that are necessary for executive control processes.

Moreover second-stratum fluid intelligence and working memory have been studied by neuroimaging (Barbey, Colom, Paul, & Grafman, 2014b). This approach allows the examination of the functional networks that support adaptive behavior and novel problem solving. The authors conclude that the frontolateral parietal network that is central to human intelligence may be lateralized with mechanisms for general intelligence being linked to the left hemisphere and fluid intelligence to the right hemisphere. Barbey, Colom, and Grafman (2014) have studied a distributed neural system for emotional intelligence by lesion mapping. Latent scores for measures of general intelligence and personality predicted latent scores for emotional intelligence. These processes depend on a shared network of frontal, temporal, and parietal brain regions. The results support an integrative framework for understanding the architecture of executive, social, and emotional processes. This group used similar methods to study social problem solving (Barbey et al., 2014a) and report that working memory, processing speed, and emotional intelligence predict individual differences in everyday problem solving. Tasks included friends, home management, and information management. Social problem solving, psychometric intelligence, and emotional intelligence were found to engage a shared network of frontal, temporal, and parietal regions, including white matter association tracts. The results supported an integrative framework for understanding social intelligence. Finally, adaptive reasoning requires cognitive flexibility. Barbey and colleagues (Barbey et al., 2013) investigated the neural underpinning of cognitive flexibility. They examined mental flexibility. Lesion mapping results further indicated that these convergent processes depend on a shared network of frontal, temporal, and parietal regions, including white matter association. Unique variance was explained by selective damage within the right superior temporal gyrus, a region known to support insight and the recognition of novel semantic relations. These findings contribute to the neural foundations of adaptive behavior. This series of neural lesion studies highlight the importance of the adaptive reasoning construct and the prospects for extending this approach to people with ID (IDD) diagnoses.

Neurodevelopmental Perspective

A developmental perspective focuses on how an individual engages other people and masters environmental challenges. For people with a disorder of intellectual development, there may be progressive thresholds for capacity in cognitive problem solving. A developmental approach may be used to unravel developmental dynamics by focusing on the development of mental processing. Demetriou, Christou, Spanoudis, and Platsidou (2002) combined information processing models, differential psychology, and neo-Piagetian developmental theory. They proposed a framework for study by focusing on the emergence and maturation of working memory, executive functioning, and cognitive efficacy in problem solving.

Co-occurring Neurodevelopmental Disorders

Autism Spectrum Disorder

Autism spectrum disorder (ASD) has long been viewed as highly associated with ID (IDD) and to show a characteristic IQ subtest profile. It is difficult to diagnose IDD in infants and young children because of the lack of development of language of representational (symbolic) capacities. However, diagnosis is appropriate when social communication and interaction are impaired relative to the developmental level of the individual's nonverbal skills (fine motor, nonverbal problem solving). Because of the association with ID (IDD) in DSM-5, the specifier "with or without accompanying intellectual impairment" is required for ASD. Thus, it is not essential to diagnose both ID (IDD) and ASD. Severity rating is complicated because severe social communication deficits in ASD may result in placement in a severity level that is not commensurate with cognitive functioning. Moreover, because of discrepancies in verbal and performance scores, the full-scale IQ is not reflective of overall functioning in people with ASD.

The previous consensus suggested that up to 75 % of those with a diagnosis of ASD had a co-occurring IDD diagnosis with severe impairments in adaptive behavior. Typically, the performance IQ (PIQ) was higher than verbal IQ (VIQ). This PIQ/VIQ discrepancy (nonverbal advantage) has been linked to increased head circumference and enlarged brain volume. On the Wechsler test, a characteristic subtest profile was noted with higher scores on block design and lower ones on comprehension.

With increased recognition of the breadth of autism spectrum, the prevalence of ID (IDD) is less than before. In one comprehensive epidemiological study of 75 children with ASD based on IQ test score, 55 % had IQ<70 and were diagnosed mild (Charman et al., 2011). Fewer than 1 in 5 were diagnosed as moderate to severe IDD. Twenty-eight percent tested in the average range (115>IQ>85). Three percent were of above-average intelligence (IQ>115). The group mean for PIQ was higher than the VIQ. The frequency of PIQ>VIQ was more common than VIQ>PIQ, but higher PIQ was not associated with greater social impairment. On WISC subtests, neither block design nor object assembly was a significant strength. The relationship with ASD and intellectual deficits is the subject of genetic analysis. In one study, common polygenic risk for autism spectrum disorder (ASD) was found to be associated with cognitive ability in the general population (Clarke et al., 2015).

In summary, cognitive function must be assessed in all children and adolescents diagnosed with ASD and is an important prognostic feature. Thus, DSM-5 requires coding using the specificer with or without intellectual deficits. Overall, adaptive functioning is lower than expected for IQ in persons with an ASD diagnosis; this is most apparent in the higher-functioning people. A higher IQ score in ASD does not necessarily predict functioning in the everyday world because of the underlying social deficit.

Fetal Alcohol Spectrum Disorder (FASD)

Fetal alcohol syndrome is the most prevalent preventable cause of ID (IDD). In Western countries, it is the leading preventable cause. Fetal alcohol spectrum disorder (FASD) may affect up to 5 % of all pregnancies. Since the early 1970s, alcohol has been recognized as a severe teratogen. When consumed during pregnancy, it may result in serious structural and functional damage to the developing child's brain, particularly to midline structures. Following the recognition of fetal alcohol syndrome (FAS), it became apparent that there is a spectrum of impairment that is referred to as fetal alcohol spectrum disorder. This spectrum includes partial fetal alcohol syndrome (PFAS) and alcohol-related neurodevelopmental disorder (ARND). Individuals with full-fledged FAS are dysmorphic with distinctive facial features such as small horizontal eye opening, flattening of the philtrum between the nose and upper lip, and a thin upper lip. Those diagnosed with PFAS have subtler and fewer facial anomalies; those with ARND do not have visible facial anomalies.

All persons with diagnosable FASD have executive functioning deficits and adaptive functioning deficits. This is the result of the extension of midline morphological abnormalities to involve the midbrain especially the shape and volume of the corpus callosum. There is smaller volume in the basal ganglia and hippocampi (Donald et al., 2015). Executive function weaknesses are most consistent for measures of planning, fluency, and set shifting (Kingdon, Cardoso, & McGrath, 2015). Neuropsychological testing for these executive functional deficits may improve differential diagnosis and facilitate treatment of FASD.

Behaviorally there is increased risk of inattention, hyperactivity, and impulsivity. Moreover, there is increased prevalence of oppositional defiant/conduct disorder (ODD/CD). Of particular concern is the lack of social judgment and failure to learn from experience that result in behavioral and legal problems (Kodituwakku, 2009). Children with FASDs show reduced intellectual functioning. Their average IQ scores fall within borderline to below-average ranges. Thus, although they generally do not quality for an ID (IDD) diagnosis and fail to meet the first criterion, their deficits in social judgment and failure to anticipate the consequences of their behavior frequently meet the adaptive behavior criteria of ID (IDD).

The cognitive and behavioral deficits in FASD led to consideration being given to include it in DSM-5 as a mental disorder. The decision was not to include it in the body of the classification but include it instead in the appendix of DSM-5 among "Conditions for Further Study." The DSM-5 term is *Neurobehavioral Disorder Associated With Prenatal Alcohol Exposure*. The proposed definition the requires impaired neurocognitive functioning manifested by one of the following 4: an IQ of 70 or below; deficits in executive functioning; memory impairment; or visual–spatial reasoning deficits along with deficits in adaptive functioning. The proposed DSM-5 definition does not specifically deal with the IQ-equivalent issue nor sufficiently describe the deficits in social functioning. Further study is clearly needed before considering including it in the DSM-5.

Still in Minnesota, FASD is an IQ-equivalent condition. Minnesota statute 252.27 (2012) notes several "related conditions," defined as: "a condition that is found to be closely related to a developmental disability, including but not limited to, cerebral palsy, epilepsy, autism, fetal alcohol spectrum disorder, and Prader-Willi syndrome." Minnesota is one of a very small list of jurisdictions where FASD is specifically included in an expanded disorder list. However, Minnesota's eligibility document then goes on to state that, even if one has a qualifying medical underlying disorder, the condition must still cause "substantial functional limitations," as established by deficits in three out of the seven adaptive life activities.

ID (IDD) and the Law

Developmental Disabilities and Disability Law

Before the enactment of the Education for All Handicapped Children Act in 1975, US public schools accommodated approximately only 1 out of 5 children with disabilities. This situation dramatically changed with passage of the Education for All Handicapped Children Act (EHA) and its evolution in over the years between the years 1970 and 1990.

The term developmental disabilities (DD) was introduced as an umbrella term for "mental retardation, epilepsy, cerebral palsy, and other neurological conditions originating before the age of 18" (Gettings, 2011). The term is now widely used in many state and provincial eligibility statutes. In 1975, early legislation was expanded as Public Law 94-142. DD was defined categorically to include mental retardation plus conditions closely related to mental retardation including cerebral palsy, epilepsy, autism, and dyslexia with onset before the age of 18. The term "other neurological conditions" was dropped. In the long term, dropping "other neurological conditions" may have contributed to IQ equivalence being limited to people in only these named diagnostic categories. The intent of the IQ-equivalence functional formulation appears to have been an attempt to capture the adaptive limitation profiles of individuals who functioned as if they had ID (IDD) in spite of having IQs that fell above the 70–75 IQ ceiling. However, at least two of the skills (language and mobility) were not specific to ID (IDD) (likewise, one also could argue that self-direction was not specific to ID equivalence). The source of this list is not clear. A limitation in this list is that none of the items address deficits in social functioning, which many people (and virtually all family members) consider to be at the top of any list of reasons why people with ID need protections and supports.

In 1990, Congress reauthorized the original education legislation but changed the name to the Individuals with Disabilities Education Act (IDEA). The current IDEA Public Law is No. 94-142. It is composed of four parts and includes six main elements. The six elements include individualized education program (IEP), free and appropriate public education (FAPE), least restrictive environment (LRE), appropriate evaluation, parent and teacher participation, and procedural safeguards.

Forensic Issues and ID (IDD)

In 2002, the Supreme Court ruled in *Atkins v. Virginia* (536 U.S. 304) that executing people with an ID (IDD) diagnosis violates the Eighth Amendment's ban on cruel and unusual punishment leaving it up to the individual states to define the criteria for ID (IDD). The court cited that an increasing number of states banned execution of people with ID (IDD). State law helped convinced a majority of the court that a national prohibition was justified under the principle of "evolving standards of decency."

Following *Atkins v Virginia*, a possible diagnosis of IDD is often raised in a capital criminal proceeding regard to eligibility for the death penalty as a mitigating condition (Greenspan & Switzky, 2006b). In such proceedings, the court—typically a judge, but occasionally a jury—decides taking into account expert testimony. There is a tendency for judge and/or jury to rely on their stereotypes of ID (IDD) drawn from the media or from experience with an affected family member or an acquaintance. Implicitly, the stereotype is that of severe impairment than that found in the great majority of people (or criminal defendants) with ID (IDD) who engage in such crimes. Psychiatrists, but much more commonly psychologists, testify about ID (IDD) in such criminal proceedings. They too may lack expertise in ID (IDD), particularly in community (noninstitutional) settings.

The main effect of stereotyping in forensically diagnosing ID (IDD) is termed as "cherry-picking," that is, isolated alleged accomplishments by the defendant (e.g., driving a car, holding a job, robbing a store, having a romantic relationship) are pointed out as proof that the person could not have ID (IDD) if they could carry out these tasks despite evidence that such "accomplishments" frequently turned out to involve significant failure (e.g., a roofer who kept falling off the roof; a robber who kept getting apprehended). However, official diagnostic manuals state that (a) the diagnosis does not require global impairment and (b) evidence of significant adaptive deficits need only be found in one domain. An example of stereotyping ID (IDD) occurred in an official court doctrine in Texas, ex parte Briseno, when the highest state court promulgated the so-called Briseno doctrine. The Briseno doctrine actually gave as an example of ID (IDD) a fictional character, Lennie, in the Steinbeck novel *Of Mice and Men*, of the kind of severely and obviously impaired person for whom judicial relief should be limited.

A number of other problems may arise in judicial determinations of ID (IDD), but the biggest problem is undoubtedly the tendency to rely rigidly and sometimes exclusively on the full-scale IQ test score numbers. Court proceedings illustrate some of the pitfalls of a strictly "disability" (just the numbers) approach to the definition and diagnosis of ID (IDD).

The explanatory text of DSM-5 in the section on associated features supporting the diagnosis describes features that may be of importance in Atkins Hearings (DSM-5, p. 38). These include associated difficulties in "social judgment; assessment of risk; self-management of behavior, emotions and interpersonal relationships; or motivation in school or work environments. Lack of communication skills may predispose to disruptive and aggressive behavior." Moreover it states that "gullibility and lack of awareness of risk may result in exploitation by others and possible victimization, fraud, unintentional criminal involvement, false confessions…" (APA Author, 2013).

Atkins v. Virginia and Hall v. Florida

Although the Supreme Court cites the DSM and AAIDD manuals as authoritative and refers to the three-prong model contained in those models, in Atkins v. Florida, it declined to provide operational guidance for the diagnosis of ID (IDD) and left it up to various state legislatures or high courts to do so. This has resulted in tremendous variability in state law that eventually forced the Supreme Court to clarify one issue that of a bright line IQ cutoff in some states. In its 2014 *Hall v. Florida* decision, the use of a rigid "bright line" (IQ of 70) ceiling score, without consideration of the standard error of measurement, was adjudicated. In this case, the US Supreme Court narrowed the discretion under which US states can designate an individual convicted of murder as too intellectually incapacitated to be executed by stating in its majority opinion that ID (IDD) is "a condition not a number" and rejected Florida's use of a bright line IQ of 70 (Hall v. Florida. Majority opinion. 572 U.S. 2014, p. 21). Even though the death penalty may be seen as relatively peripheral to the broader field of ID (IDD), its use in legal proceedings has brought to the forefront heightened concern about limitations in existing definitions and diagnostic methods. The definition of ID (IDD) involves great stakes for an individual that have come about from these highly adversarial and contentious court cases.

Conclusion

This chapter reviewed the evolution of two approaches to classification that seek to improve the lives of people with deficits in intellectual functioning. Both emphasize a developmental perspective. The first of these focuses on the provision of services and may be traced back to the Itard's efforts to habilitate Victor of Aveyron by testing a then current proposal that the mind at birth is a blank slate and all knowledge is gained through the senses. His partial success initiated a special education movement that began in Europe and spread to America that emphasized early intervention and has been increasingly refined over the years. Its focus is on normalization and most recently self-determination. The American Association on Intellectual and Developmental Disabilities adopted this approach in its classification system. It emphasizes the standardized measurement of intelligence but focuses on the provision of supports to help each person reach their potential. This approach is based on the disability model that emphasizes the importance of facilitating the optimal functioning of each person to the extent possible. It is an approach that advocates for the human rights of people with disability in education, community settings, and the law.

The other approach focuses on the etiology of the intellectual deficits and on their underlying neurobiology and biomedical treatment. It recognizes that the mind is not a blank slate at birth and that each individual has a distinct inherited neurobiology that interacts with environmental forces in development. Intellectual deficits are largely the result of atypical brain development whose causes must be ascertained. These deficits are assessed psychometrically by standardized measures of both general intelligence and specific neuropsychological measures, especially executive functioning. Both types of testing are needed because, although we maintain the standardized measurement of general intelligence as a diagnostic criterion in DSM-5, there are many different patterns of intellectual impairment in neurodevelopmental syndromes that impact subtest score measurement and adaptive reasoning. The DSM-5 approach to diagnosis seeks to classify neurodevelopmental disorders and encourage finding their etiologies. Research in the basic neurosciences, genetics, and neuroimaging is providing new insights into our understanding of the underlying neurobiologies.

This chapter emphasized that the full-scale IQ is an inadequate basis for establishing an ID (IDD) diagnosis, especially when taking into account the new first criteria in DSM-5 based on the mainstream definition of intelligence. Both individualized standardized and culturally appropriate IQ testing and focused neuropsychological testing, especially for executive functioning, are needed. Moreover, it is not uncommon for people with brain dysfunction and/or neurodevelopmental disorders like FASD to have IQ scores over 75 but have severe deficits in adaptive functioning and reasoning in social judgment, social understanding, and other areas of adaptive functioning so that the person's actual functioning in the real world is comparable to that of individuals with a lower IQ score. This has led to the establishment of ID (IDD) equivalence pathways to developmental services for children and adults who are viewed as deserving services but do not receive them because their IQ score exceeds the standard cutoffs.

In closing, achievement of functional competence in age-relevant roles is a developmental goal for all human beings, including those who, because of brain-based limitations, need special supports in pursuing that achievement. The field of ID (IDD) thus contributes importantly to understanding various forms of human competence, the role of the brain in facilitating or impeding competence, and the kinds of interventions that may contribute positively to that process.

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Evidence-Based Practices

3

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Introduction

Selecting and implementing interventions and treatments may be the most critical activity of practitioners committed to improving the outcomes and lives of individuals with intellectual and developmental disabilities (IDD). To do this well, practitioners will benefit from knowing the most effective interventions or "evidence-based" programs and practices for individuals at-risk or with intellectual disabilities. Further, such knowledge needs to be combined with effective implementation methods that are consistent with the intent of these specific intervention practices. Although intervention research began in early 1900s, interest in identifying and translating research-based findings into effective instructional and intervention practices has been incentivized with the evidence-based practice (EBPs) movement in the USA, Canada, the UK, Australia, and other countries (see APA, 2006; Fixsen, Naoom, Blase, Friedman, & Wallace, 2005; Gibbs, 2002; Kratochwill & Stoiber, 2000, 2002; Odom, 2009; Odom et al., 2005; Stoiber & Kratochwill, 2000; Stoiber & Waas, 2002). As an example of the surge of interest in EBPs, there were virtually no citations in Medline or PsychINFO on EBP between 1900 and 1995, with marked rise in citations occurring since 1995 (Burns & Hoagwood, 2005; Hoagwood & Johnson, 2003). With regard to the application of EBPs in school settings, no guidelines on intervention selection were available prior to the 1990s (Association for Behavioral and Cognitive Therapies).

Researchers and policy makers have recently become advocates for EBPs in an effort to improve outcomes for individuals with and at risk for disabilities. There also exists a growing voice among practitioners and clinicians for guidance in the application of EBPs in their work with individuals with disabilities. Only through a combined effort focused both on knowledge of evidence-based practices (EBPs) and dissemination that is useful and feasible for practitioners will optimal intended improvement or change occur (Fixsen, Blase, Metz, & Van Dyke, 2013). Thus, researchers, policy makers, and practitioners have joined together in support of uncovering scientific knowledge and implementation procedures to inform instructional and intervention practices. As a result of these efforts there has been a proliferation of resources, such as books and registries, dedicated to reviewing and listing programs and strategies that are considered to be evidence-based.

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Although interest in EBPs is generally widespread in medicine, social sciences, and education, only recently have EBPs been identified by highly regarded EBP sources for individuals with disabilities (Cook & Odom, 2013). For example, the federally funded *What Works Clearinghouse* (WWC) registry, which is viewed by many researchers and practitioners in education as the most comprehensive and accessed source on EBPs, only recently added reviews of EBPs for individuals with disabilities (WWC, 2011). Further, the WWC has currently limited its review to only select disability groups (i.e., early childhood special education, students with learning disabilities, and students with emotional and behavioral disorders). Notably absent from WWC are EBPs for those students with cognitive and/or intellectual disabilities. Similarly, there is a distinct lack of evidence-based treatment manuals or programs designed for addressing the needs and disorders associated with ID (see, for example, LeCroy, 2008).

Thus, there exists a significant disparity in the advances made to define, identify, translate, and disseminate EBPs for individuals with ID when compared to other populations such as students in general education and those with certain disabilities. Such a chasm in the understanding of EBPs for addressing ID is noteworthy. To reach the ideal of optimal educational and/or treatment approaches for individuals with ID, it is important to establish evidence-based programs and research-informed practices to produce better outcomes for individuals with ID. Efforts are also critically needed to diffuse, translate, and disseminate evidence-based programs and strategies into the routine educational and service practice with individuals with ID. In this chapter we examine several research and implementation activities focused on furthering the development and understanding of evidence-based practices and programs for ID populations.

This chapter begins with an overview of the origins and definitions of evidence-based practices, with particular attention to the rationale for incorporating EBPs into service delivery systems for individuals with IDD. Next, an EBP framework or process for reviewing and selecting EBPs is provided. The third section highlights the empirical support for initiating implementation of EBPs for individuals with IDD, with a specific focus on the applications of potential EBPs to address academic performance. These sections also incorporate considerations that may be made by administrators, interventionists, and other stakeholders in the selection and implementation of evidence-based practices in schools and within community settings. Following these sections we discuss the application of EBPs within early childhood special education settings and EBPs for inclusion practices. After, we review considerations in conducting assessment and progress-monitoring activities within an EBP framework, and we discuss implications for research and practice specific to improving implementation efforts.

Origins and Definitions of Evidence-Based Intervention and Practices

The notion of EBPs began receiving traction in the field of medicine in the early 1990s (Sackett, Rosenberg, Muir Gray, & Haynes, 1996). The task force on interventions by the American Psychological Association (Task Force on Promotion and Dissemination of Psychological Procedures, 1995) helped stimulate significant interest across clinically oriented psychology fields (e.g., clinical, counseling, school) in identifying EBPs. Thus, in the past two decades, the use of EBPs has emerged as the accepted standard for increasing academic and mental health outcomes as well as the functional capacities of individuals, including those with disabilities (see Forman et al., 2013; Kratochwill & Shernoff, 2004; Kratochwill & Stoiber, 2002; McCall, 2009; Stoiber & Kratochwill, 2000). Evidence-based prevention and intervention refer to research-based or empirically supported programs, practices, or strategies intended to increase skills, competencies, or outcomes of children, youth, and/or families in targeted areas (Shlonsky & Gibbs, 2004; Stoiber & DeSmet, 2010). Cook and Odom (2013) described EBPs as "practices and programs shown by high-quality research to have meaningful effects …" (p. 136). For a program or practice to be considered evidence based, it should be supported by scientific theory and be tested empirically. Studies examining the intervention need to provide clear evidence of producing positive and relevant outcomes for the individual(s) or groups (e.g., children demonstrating reading difficulties; adolescents with severe behavioral challenges, adults with co-occurring depression and anxiety) for whom it was designed and implemented. Thus, in contrast to prior efforts aimed at identifying effective practices, such as "best practices" or "research-based practices," for a program or practice to be regarded as an EBP it must meet prescribed, rigorous standards (Cook & Cook, 2011; Kratochwill & Stoiber, 2002; Stoiber & Waas, 2002).

Despite the call for practitioners to integrate evidence-based interventions (EBIs) or programs into their practice more than a decade ago (Kratochwill & Stoiber, 2002; Odom, 2005; Shlonsky & Gibbs, 2004; Stoiber, 2002), there continues to remain a gap between the evidence-base knowledge and evidence-base practices occurring in the school and community (Cook, Cook, & Landrum, 2013; Forman, Olin, Hoagwood, Crowe, & Saka, 2009; Noonan, Sleet, & Stevens, 2011; Stoiber, 2011). This gap in efforts to diffuse, disseminate, and implement EBPs successfully in practice settings is typically referred to as a "science-to-practice" or "science-to-service" gap. Although considerable attention has focused on the science-to-practice gap in most education and applied social science fields (see, for example, Cook et al., 2013; Fixsen et al., 2013; Forman, Lubin, & Tripptree, 2014), such a gap is especially remarkable for individuals with IDD.

More specifically, the gap surrounding EBPs typically regards the chasm between EBP identification and implementation, but in the field of intellectual disabilities it is situated at the foundational level of EBP knowledge construction (i.e., identifying what works for individuals with ID). Most scholars engaged in work on EBPs have noted that successful implementation of EBPs must begin by defining and identifying those practices that produce meaningful and reliable benefits to children and families (Odom, 2005; Stoiber, 2002; Weisz & Kazdin, 2010), with "knowledge construction" occurring through well-designed research investigations. As we move along the continuum on "how to make EBPs happen," activities focus on efforts to diffuse, translate, mandate, and transport EBPs into practice settings. These efforts are referred to as dissemination or implementation science (Cook et al., 2013; Forman et al., 2013), which are aimed at the systematic uptake of EBPs into routine field-based practices and include the "spreading and sustaining" of innovation in service organizations (Eccles & Mittman, 2006; Forman et al., 2013; Greenhalgh, Robert, Macfarlane, Bate, & Kyriakidou, 2004). Implementation science is perhaps the most frequently used term in contemporary education and psychology fields, however, the term is not meant to convey that definitive implementation practices have been established on "how to" translate research findings into practice. Rather implementation science "denotes a field of scientific inquiry in which issues related to implementation are investigated" (Cook & Odom, 2013, p. 139).

Most leaders in the field of EBPs have argued that solely identifying practices based on research findings is not sufficient to "make change happen" in terms of getting practitioners to adopt and use EBPs (Cook et al., 2013; Fixsen et al., 2013; Kratochwill, 2007; Stoiber & DeSmet, 2010). In addition, several researchers have pointed out the importance of considering the unique context dimensions of their application, including issues related to when and how they should be adapted to specific groups such as ethnic minorities and individuals with disabilities (i.e., when and how they should be altered to accommodate cultural background and/or ability level). Stoiber and DeSmet (2010) have noted the advantage of research designs whereby a scientific basis informs practice, and field-based practice outcomes inform implementation science so as to "get it right" and assuring the EBPs are feasible and meaningful for practitioners. As such, practitioners function as researchers by applying data-based approaches for systematic planning, monitoring, and evaluating outcomes of their own service delivery (Stoiber & DeSmet, 2010; Stoiber & Kratochwill, 2002). The point is that as a profession we must hold responsibility for not only revealing the mechanism of change, but for how these mechanisms are integrated into practice (Kratochwill & Stoiber, 2000), so as to understand what works, with whom, and under which conditions (Cook & Odom, 2013; Kratochwill & Stoiber, 2002; McCall, 2009). Stated simply, finding a practice that works is not enough. Nonetheless, implementation relies first on establishing a knowledge-base of effective intervention; absent such a base dissemination and feasible application of EBPs cannot occur. For implementation of EBPs to take place at a socially significant level in helping those with IDD, it is important to consider implementation approaches that facilitate knowledge construction and at the same time move promising and supported intervention into routine practices with this group of individuals.

The breakdown both at the level of knowledge construction and at getting EBPs to individuals who clearly need and should benefit from them (i.e., individuals with IDD) is striking considering research- and evidence-based practices are mandated by current federal policies, such as the *No Child Left Behind* (NCLB) Act of, 2002 (Public Law 107-110) and *Individuals with Disabilities Education Improvement Act* (IDEIA, 2004). These policies underlie the intent of improved outcomes for individuals with disabilities, including those with IDD. NCLB directed schools to use strong and effective practices and programs based on scientific evidence; the term scientifically based research conveyed this concept stipulating that practitioners should determine and put into practice the most effective interventions in the federal NCLB. That scientifically based research interventions should be adopted in schools is indisputable as this phrase or some form of it was stated 111 times in NCLB (Tilly, 2008). IDEIA drew on the NCLB statute and incorporated scientifically based research into its 2004 amendments. IDEIA emphasized the need to implement improved assessment and intervention approaches to address racial disparities in special education decisions. Thus, implementation of scientifically based or evidence-based practices was viewed as a viable mechanism to address the disproportionate number of minority children receiving special education, which had been a problem for decades (Donovan & Cross, 2002; Skiba et al., 2008). The overrepresentation of minorities is also evident for students classified as having IDD, yet recent data indicate there has been a significant reduction in the number of African Americans youth classified as having an IDD (Zhang, Katsiyannis, Ju, & Roberts, 2014).

Both NCLB and IDEIA policies promoted early and sustained use of scientific-informed or evidence-based practices and programs as not only necessary, but as ethical. Together NCLB and IDEIA aimed to rectify several long-standing issues, with several holding particular relevance for individuals with IDD. These include: (a) significant percentage of students enter school lacking readiness skills that lead to school failure and possibly misdiagnosis if not addressed early, (b) problems with relying on IQ measures in identifying students as having disabilities, (c) ethnic minority children being overrepresented in special education, and (d) special education found to be more costly although can be less effective. Thus, a number of sources of evidence on student performance (or lack of performance) triggered support for change in how we identify student needs and disabilities, and perhaps more importantly, how we provide instruction and intervention so as to improve the outcomes of particular groups of students (Johnston, 2011). It should be noted, however, that although these policies clearly mandated scientific- or evidence-based practices, they did not specify how programs or practices should be identified, or how they should be delivered (Macklem, 2014).

Reflecting the important role being assumed by EBPs in improving intervention effectiveness and outcomes, several groups have developed guidelines and criteria for reviewing the effectiveness of prevention and intervention efforts and for establishing them as evidence based. These groups include the *Promising Practices Network on Children, Families, and Communities* (www.promisingpractices.net), the *Collaborative for Academic, Social, and Emotional Learning* (www.casel.org), the *National Registry of Evidence-Based Programs and Practices* (www.nrepp.samhsa.gov), and the previously noted WWC (www.whatworks.ed.gov). Also available are several well-regarded compendiums on evidence-based programs, such as the *Handbook of Evidence-based Treatment Manuals for Children* (LeCroy, 2008), *Treating and Preventing Adolescent Mental Health Disorders* (Evans et al., 2005), and *Evidence-Based Practices for Educating Students with Emotional and Behavioral Disorders* (Yell, Meadows, Drasgow, & Shriner, 2013). In addition, progress has occurred in developing EBPs for some populations of individuals served in special education (e.g., National Professional Development Center on Autism Spectrum Disorders, n.d.; National Secondary Transition Technical Assistance Center, 2011). Interestingly, none of the available registries or research-based compendiums on EBPs, such as those listed previously, includes EBPs for individuals with IDD.

The concept of EBP creates an impetus for change in service delivery for individuals with intellectual and developmental disabilities. The practice of using evidence-informed interventions impacts on how interventions are selected and on the ways that they are made useful to practitioners (and in turn, the individuals they serve). Unfortunately, the term evidence-based practice has become somewhat amorphous in that it may be applied loosely when there is a lack of agreement regarding what EBP constitutes. In this regard, it is important to acknowledge considerable controversy has surrounded evidence-based interventions and practices, with concerns being raised about what has been purported as sufficient evidence by some organizations or professional groups as being too strict and unreasonable (Waddell & Godderis, 2005), as well as not being relevant for practitioners or grounded in their day-to-day, often complex routines (Klingner, Boardman, & McMaster, 2013; Kratochwill & Stoiber, 2002; Stoiber & DeSmet, 2010).

In view of the lack of documented research-based interventions for individuals with IDD it is incumbent on the discipline to examine both the utility of EBPs and how they can be feasibly implemented to enhance services for individuals with IDD. Planned, systematic efforts are clearly needed if EBPs are to have a more widespread impact on individuals with IDD. There exists, then, an urgent need both to examine procedures for practitioners to identify EBPs and along with feasible and relevant implementation models. So that EBPs for individuals with disabilities are matched and connected to the systems that serve them (e.g., schools, community centers), we propose an EBP framework that fosters a practitioner as researcher or evidence-base decision making (Kratochwill & Hoagwood, 2006; Penuel, Fishman, Cheng, & Sabelli, 2011; Puddy & Wilkins, 2011; Stoiber & DeSmet, 2010). To begin to establish such a framework for EBP knowledge construction along with the capacity to implement them, it is useful to consider conceptual templates that can be used or adapted to help advance EBPs with individuals and groups with IDD.

Criteria for Developing and Selecting Evidence-Based Practices

As argued by several EBP scholars, the noted science-to-service gap is unlikely to be solved by researchers in isolation of the realities of field-based practitioners (Klingner et al., 2013). In this regard, it is important to balance the *rigor* of well-designed research standards with the *relevance* and problems of practice reflected in real-life intervention contexts (Cook & Odom, 2013; Smith, Schmidt, Edelen-Smith, & Cook, 2013; Stoiber, 2002; Stoiber & DeSmet, 2010). As research is diffused, translated, or transported in implementing interventions with individuals with disabilities, the notion of finding a “good fit” between the study characteristics and the circumstances of the implementation site emerges as a critical consideration. By examining carefully the characteristics of the study, practitioners should be better able to determine whether an intervention will likely produce intended outcomes for their targeted population. In this regard, the APA *Policy Statement of Evidence-Based Practice in Psychology* which was approved as policy by the APA Council of Representatives during its August 2005 meeting (APA, 2006) should hold relevance for practitioners who provide services for individuals with intellectual disabilities:

> Psychological services are most effective when responsive to the patient's specific problems, strengths, personality, sociocultural context, and preferences. Many patient characteristics, such as functional status, readiness to change, and level of social support, are known to be related to therapeutic outcomes …. Some effective treatments involve interventions directed toward others in the patient's environment, such as parents, teachers, and caregivers. A central goal of EBPP is to maximize patient choice among effective alternative interventions. (p. 284)

It is useful, then, to examine intervention features of studies that are typically required or suggested for the designation of evidence-based within the context of how the intervention is likely to be applied with individuals with IDD. Such a consideration seems especially important because ID is a low-incidence disorder, and the individual with IDD may experience other comorbid disorders (e.g., seizure disorders, emotional disturbance, sensory impairment). In light of the diverse characteristics surrounding individuals with IDD, the notion that "one size fits all" in intervention effectiveness appears questionable. Several indicators of evidence can be drawn upon when evaluating and selecting interventions, thus it is important to determine those features of research that matter most.

Several conceptualizations for determining what works to improve the outcomes for individuals or groups of individuals have emphasized the importance of research study features that incorporate a rigorous design and high internal validity. For example, research designs that incorporate an active treatment control group and randomized controlled trials (RCT) are regarded more highly than quasi-experimental, single-case studies, or qualitative research in substantiating treatment efficacy (Cook, Tankersley, & Landrum, 2009). In particular, RCT's are viewed as the gold standard in reliably demonstrating proven outcomes. The WWC for example classifies studies into three categories: (a) meet evidence standards, (b) meet evidence standards with reservations, or (c) does not meet evidence standard. Only studies incorporating RCT design can meet evidence standards without reservation. Quasi-experimental studies that match other methodological criteria set by the WWC can only meet evidence standards with reservations.

Table 3.1 summarizes four types of criteria (i.e., research design, quality of research, methodological quality, magnitude of effect) noted by Cook et al. (2009) as useful in determining EBPs. These researchers examined the EBP guidelines or criteria set by several different organizations or groups (e.g., divisions of APA such as clinical and school psychology and fields within education) in their review of what criteria might work best in determining evidence-based practices in special education. For each of the specified criteria, we include relevant questions based on the work by Cook et al. (2009) that the field may need to answer in determining the type and amount of evidence that would be deemed as sufficient and/or necessary to support the evidence-base of a particular intervention program or practice.

The questions raised in Table 3.1 suggest that there may be less clarity in determining the criteria that should be applied for a practice or program to have met some standard such as likely efficacious or possibly efficacious. For example, due to the variability and diverse nature of individuals with IDD, requiring that a specific number along with the type of study needed may not be the most important consideration. Thus we agree with the principles put forth by Cobb and Smith (2008), Klingman et al. (2013), Penuel et al. (2011) and others who advocate that for EBPs to be spread and sustained successfully it is critical to put into action practices and implementation procedures that go beyond demonstrating the efficacy of an intervention on large scale (e.g., found to work in several different

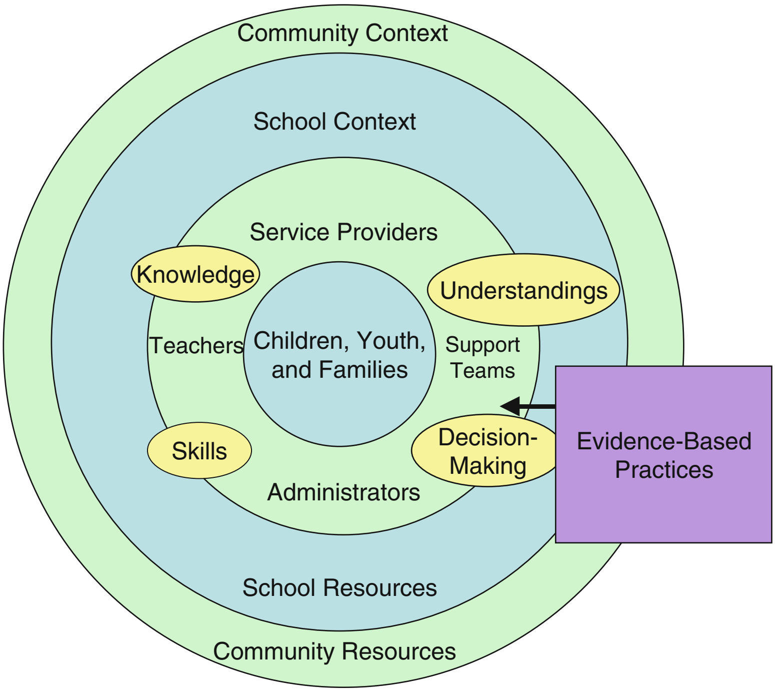
Table 3.1 Summary of typical criteria and corresponding questions for determining evidence-based practices

Criteria for EBP	Critical features	Questions in need of answering
Research design	Research design is appropriate to determining whether a practice works, generally through strong experimental control (e.g., control group, randomly assigned participants to groups, actively introducing the intervention)	Should only true experiments be considered; or can quasi-experiments, single-subject research (SSR), and qualitative research be included as an acceptable research design for determining EBP?
Quantity of research	Single studies should be cautiously interpreted regardless of the design, methods, or effects. Converging evidence from numerous studies is required	How many supporting studies are sufficient?
Methodological quality	High methodological rigor is needed to have confidence in the findings of a study (e.g., controlling for teacher effect, reporting psychometric properties of measurement tools)	What methodological features are essential for a high-quality study? Should studies with less than rigorous methodological features be considered when evaluating EBPs?
Magnitude of effect	Meaningful effects and positive outcomes, as measured by effect sizes, must be demonstrated alongside statistical significance. Changes in outcomes must be nontrivial	How should the effect of an EBP be best evaluated? How large of an effect size is needed to indicate meaningful change? How should effects be evaluated in SSR studies?

studies or with diverse cultural groups). Rather it is important to design, test, and evaluate interventions taking into account the complexities that surround individuals with IDD along with the context and conditions associated with the setting (e.g., classroom, district, community center) where the EBP is adopted.

Cook and Odom (2013) provided an example of an EBP derived from a high-quality study having a very limited impact due to problems and realities surrounding its implementation in a natural setting. Based on the RE-AIM model conceptualized by Glasgow, Vogt, and Boles (1999) to determine real-world impact, an intervention found to significantly improve the performance of a large percentage of students with disabilities may produce minimal impact at the site of implementation (e.g., school, classroom, community program). The RE-AIM model is based on not only the efficacy of the practice, but also on four other factors: Reach (R)—proportion of target population actually reached; Adoption (A)—proportion of the targeted setting in which the practice is adopted; Implementation (I)—proportion of interventionists implementing the practice as planned and with fidelity; and Maintenance (M)—proportion of settings/organizations (e.g., schools, community treatment center) and interventionists who continue to maintain the practice over time. The true or actual impact of a practice is calculated as $R \times E \times A \times I \times M = \text{impact}$. Using this model, a practice found to improve outcomes for 95 % of individuals, with 80 % of settings agreeing to implement (reach), 70 % interventionists (e.g., teachers, therapists) actually using the practice (adoption), 60 % of those adopting it as planned and with fidelity (implementation), and only 50 % maintaining the practice across the year, results in the purported 95 % expected percentage of impact having less than 16 % impact on the target group (0.95 [efficacy]×0.80 [reach]×0.70 [adoption]×0.60 [implementation]×0.50 [maintenance]=0.16). The implication of this formula is that due to a range of context factors and issues, such as the fit of the intervention to the targeted population, the practicality in implementing it routinely, the available time to deliver, and the acceptance of the practice by interventionists, even the most efficacious of practices may produce surprisingly low expected outcomes.

Fig. 3.1 Model of evidence-based practices in the context of practice factors and systems



Given the complexities surrounding contexts in which individuals with IDD are served, we suggest a model for understanding and implementing effective intervention service delivery, which is modified from prior conceptualizations of EBPs within a social-ecological model by Stoiber and DeSmet (2010), which is illustrated in Fig. 3.1.

Here we suggest that not only should EBP selection and implementation focus on research-informed knowledge, but also on the skills, understandings, and decision making of practitioners. These research factors and practitioner-characteristics should occur alongside system-level and capacity considerations, such as the resources available at implementation sites. Influences such as the teachers/instructors/therapists' skills and/or treatment philosophies and values as well as community/district/school resources all can affect how an intervention is derived, and moreover whether it is applied effectively. For example, research on implementation has identified several site variables as potent determiners of high-quality and sustained use of EBPs including: site-based administrative and technical support, support from university personnel, flexibility for interventionists to accommodate noncore intervention components, consistent communication on intervention expectations, and the clients/students' enthusiasm for and response to the intervention (Buzhardt, Greenwooe, Abbott, & Tapia, 2006; Klingner et al., 2013). Clearly, intervention success in implementation does not depend solely on the qualities of the intervention; rather, intervention success is intimately tied to site- and practitioner-level features.

Given such understandings and parameters, we suggest four categories of criteria as an organizational framework for examining intervention research qualities. These categories include (1) scientific basics—*the empirical/theoretical basis, general design qualities, and statistical treatment* of the intervention; (2) key component features—the *internal and construct validity* of the research study*;* (3) clinical utility—regards a range of *acceptability and generalizability* aspects of an intervention; and (4) feasibility and cost-effectiveness—regards the *fidelity and usefulness* of the intervention within the applied setting. The four categories suggested correspond closely to those established by the School Psychology Task

Force on Evidence-Based Interventions (Kratochwill & Stoiber, 2002), and convey the belief that good guidelines for selecting interventions should be flexible and reflect the realities of practice.

These guidelines provide an organizational framework for examining intervention research qualities and for selecting those EBPs that would best match a particular intervention goal and/or setting. A specific intervention program or practice may be rated on a scale ranging from strong to very low evidence, with more than one study typically required to make a rating of strong support. Using such a rubric, research support for an EBP could be rated as: (1) Strong support—at least two high-quality studies with consistent results or one multiple-site high-quality study; (2) Moderate support—one high-quality study or several studies with some limitations; (3) Low or No support—several studies with severe limitations or no direct research evidence.

We recommend that scientifically mindful practitioners may benefit in their decision making from considering the contribution of each category when selecting an intervention practice. Each category is described briefly below.

The first consideration used in evaluating a study relates to the *empirical/theoretical basis, general design qualities, and statistical treatment* of the intervention practice. This set of criteria focus on features such as whether there exists a strong theoretical or empirical basis for intervention, the overall quality of design methodology, and the use of an appropriate outcome evaluation (i.e., statistical procedures). These first set of criteria are meant to provide a context for understanding what was done in the study and why. The theoretical and/or empirical basis for a study may indicate that cognitive-behavioral theory provided the basis for the specific social competence skills that were emphasized in an intervention for a group of students with IDD who are rejected by their typically developing peers. Empirical support may specify that an intervention was selected because it had been shown to effectively impact on a specific problem such as engaging in sexually acting out or overly affectionate behaviors.

The appropriate use of statistical procedures is considered under this category as well as other general design features, such as the study included a sufficient sample size to measure effects, and there were significant positive effects on appropriate outcomes (e.g., improved oral reading comprehension, engagement, compliance to teacher directions). The first category also considers research methodology, including whether experimental or nonexperimental design was used, whether study has a randomized or nonrandomized design, appropriate unit of analysis is adopted, statistical error rate is controlled, and sufficient sample size is recruited.

A randomized control study may not always be feasible (or ethical) within the environment that an individual with IDD is served (e.g., school, community treatment program). Thus, qualities of quasi experiments should be examined. Even though quasi-experimental designs (QED) do not involve random assignment of participants to treatment conditions, they may include qualities aimed at reducing threats to internal validity. Thus there exists a continuum of evidence that is considered to evaluate the general design features. For example, a quasi-experimental study (QED) may involve four different types: (a) QED with no control group; (b) QED with control group but without pretest measurement; (c) QED with both control group and pretest measurement; and (d) interrupted time-series design, which incorporates several waves of observation of the comparison and intervention groups both at pre- and post-measurement. In evaluating the study design, systematic observation methods based on a reliable observation measure or method would be weighted more heavily than unsystematized observation methods; similarly, incorporating procedures of consensus or agreement in coding observations results would be more compelling than individual observation. One example of a carefully controlled study incorporating appropriate methodology is systematized case studies and clinical replication series involving an examination of intervention effects with a series of students who exhibit a similar disorder or problem behavior. As noted by Stoiber and DeSmet (2010) even randomized controlled experiments may not be considered definitive unless all design and methodology features, including the specific population of study participants, are fully represented.

Nonxperimental designs do not incorporate randomization of participants or a comparison or control group (Sternberg, Bringle, & Williams, 2010). Typically single case studies have strong internal validity but not external validity (described below), but may be the most appropriate given the research question or type of decision desired from the study. In reviewing the general study characteristics, it is useful to consider the point that different research designs answer different questions (Cook & Cook, 2008). Other general design considerations include whether the intervention occurred for a reasonable length of time and whether researchers included treatment integrity measures (intervention implemented as intended).

The second type of criteria, called *key study features*, focuses both on internal validity criteria as well as features considered important for field-based implementation or ecological validity. Internal validity regards evidence that the intervention program or practice caused what you observed (i.e., the outcome) to happen. Construct validity refers to observing what you wanted to observe. Construct validity, thus, has most relevance for observational or descriptive studies, whereas internal validity would not be relevant in such studies. It is noteworthy, however, that for studies focused on examining the effects of an intervention, internal validity may be the most critical consideration. Internal validity is relevant for assessing interventions because it is desirable to be able to conclude that the program of interest made a difference (i.e., the cause of observed results) as opposed to other possible causes. Perhaps one of the most difficult concepts to grasp regarding internal validity is that it is only relevant to the specific study in question; in this regard it is considered a zero generalizability concern.

Validity criteria examine study characteristics that include use of a control or comparison group, multiple measure points (e.g., pre–post measurement), and features of the study that may impact on the outcomes achieved. Thus these criteria are closely linked to the effects of the intervention, including: (a) outcome measurement procedures that are valid, reliable, multi-method, and multi-source; (b) use of a comparison group having a same or similar target problem (i.e., group or subject equivalence established); (c) equivalent length and level of treatment for participants; (d) key outcomes are statistically significant; (e) evidence of durability of effects; (f) identifiable components to specify certain aspects of the intervention produced expected outcomes; (g) evidence of intervention fidelity/integrity; and (h) information on replication. These eight key study components are meant to provide a template to capture the quality of intervention research as well as the likelihood that the intended outcomes will be replicated. Although all eight key evidence components may not be feasible, available, or necessary to determine the evidence-base of a practice or intervention, this category outlines important considerations in examining internal validity characteristics.

The third category regards the *clinical utility aspects* of the study and investigated practice. These include aspects that consumers may want to consider when evaluating the appropriateness of an intervention for their specific needs, and thus may have most relevance for practitioners. External validity refers to the likelihood of generalizability of effects to other participants, contexts, and/or interventionists, regardless of the efficacy established in the research setting (APA, 2006). The third category examines external validity indicators, including participant demographic characteristics and the context within which the intervention occurred. Questions posed in examining this category include: Who were the participants (e.g., grade/age, gender, ethnicity, SES, family structure, locale, disability, and functional descriptors)? How was the intervention implemented? Which patterns of change were found to be associated with the intervention? These questions help foster an understanding beyond the question of does it work to for whom is it most likely to work effectively and to be appropriate.

Because those evaluating EBPs for use with individuals with IDD are likely most interested in determining the fit between the population served and the one for which the intervention will be used, the information gleaned in this category may hold the most relevance in selecting an EBP regarding IDD. Demographic characteristics may especially be critical when evaluating interventions appropriate for ethnic minority individuals with IDD. For example, Huey and Polo (2008) suggest that at least 75 % of the study participants must be from a similar ethnic minority group to determine that the intended outcomes will likely be produced. In addition, Huey and Polo specify that it is critical to ascertain that ethnicity did not moderate outcomes, or that the program needs to remain effective for these individuals in spite of the moderator effects. Thus, the third category that includes these more specific criteria may be especially helpful to determine conditions associated with implementation success. These more specific qualifications, including demographic information, are necessary to answer questions regarding for whom the intervention worked as well as under what conditions it was found to work.

The fourth category for selecting interventions regards evidence for *feasibility and cost-effectiveness* in applied settings. Regardless of the effectiveness of an intervention, when service providers (e.g., teachers, social workers, community workers) are apprehensive or lack the necessary skills or training to implement it, the evidence to support it does not hold much utility. Feasibility specifically addresses how it should be implemented to be beneficial along with the appropriateness of the intervention for the target population or individual (e.g., How will staff view the outcomes? Will they value them as important and beneficial?). The feasibility and cost-effectiveness criteria are especially relevant for implementation sites when available budgets and resources are tight. When costs become the primary consideration, they may trump other criteria. Yet for obvious ethical reasons, nonmonetary costs should be taken into account, such as reducing the need for special education and stigma of having an intellectual disability, or on the other hand, for improving one's functional competence.

Evidence Concerning EBPs and Intellectual and Developmental Disabilities

As previously mentioned, RCT studies are the gold standard for determining EBPs. Much of the experimental research concerning interventions for individuals and students with IDD has been single case or small *n* (i.e., a small number of participants) designs, and the majority of studies occur in self-contained settings (Hudson, Browder, & Wood, 2013). These typical study characteristics may be due, at least partially, to IDD being a low incidence disability. As single case designs (SCD) are prevalent in IDD, consumers of IDD research may benefit from understanding the defining features of SCD.

The following features of SCD were identified by Kratochwill et al. (2010). These features are (a) a single participant or group of participants (e.g., a classroom or community treatment facility) is the unit of analysis; (b) within the research design the single case provides its own control for comparison; (c) this comparison is made possible, in part, by measuring the outcome variables repeatedly within and across different conditions or phases of the study; and (d) SCDs are experimental designs that have the goal of identifying causal relationships between variables. Single case designs may be evaluated using the SCD standards produced by WWC (Kratochwill et al., 2010). The WWC criteria for SCDs to meet evidence standards include: (a) the independent variable is actively manipulated by the researchers, (b) each outcome variable is measured systemically by more than one assessor, (c) the intervention effect is attempted to be measured during at least three design phases or at least three different points in time, and (d) any phase used to demonstrate an effect must contain at least three data points. These standards allow data collected from SCD to be added to the "pool of scientific evidence available for review" (Kratochwill et al., 2010, p. 2).

Statistical techniques may be used by researchers to further examine and evaluate these findings. Meta-analysis is one such method that allows for the results of many of these SCD and small *n* studies to be statistically analyzed as a group to provide a clearer and more robust view of which practices are supported by published research. Nonetheless, there remains a gap between the state of the literature and the demands of practice despite the evidence available from the body of meta-analysis research studies concerning EBPs for individuals with IDD (West, McCollow, Umbarger, Kidwell, & Cote, 2013). Many practitioners may have to rely on case studies, correlation studies, qualitative research, and self-evaluation of implemented practices when determining whether a practice may be considered effective.

An absence of evidence to support a practice does not necessarily mean that the particular practice in question will be ineffective, but there exists a higher risk that the adoption of such practices would fail to produce the desired academic, social, or behavioral outcomes. As such, practitioners and educators/clinicians should strive to adopt practices and interventions that have adequate research support over practices that are popular but lack substantial evidence (see Bouck & Flanagan, 2010 for a discussion of such an application to the limited research support for the use of a functional curriculum for secondary students with mild IDD).

Application of EBP to Address Academic Performance

Decision-making regarding appropriate EBPs for individuals with IDD is complicated by the fact that there is very limited information available from typical reliable sources, such as government websites (e.g., WWC) and other sources in which such reviews have occurred (e.g., book chapters in evidence-based compendiums). Systematic reviews can be especially helpful in guiding practitioners in their decision as to whether or not to select and implement a practice or program. Nonetheless, decisions can be made through examining the evidence base of a given intervention strategy or program by applying evaluation criteria and synthesizing the indicators for a specific study or set of investigations.

When applying the evidence-based criteria, it is important to weigh the relevance of the findings to real-life clinical/educational settings (e.g., the EBP could feasibly be implemented in that setting) in addition to the scientific rigor of the examined research studies, which are the fundamental criteria used to determine an EBP. As several scholars have argued, both sets of conditions should be considered in selecting an EBP. The later consideration should occur because practitioners are more likely to value and implement an intervention having practice-based evidence than the evidence derived from research studies with high internal validity, which is often valued more by researchers (Kratochwill & Stoiber, 2002; Smith et al., 2013; Stoiber & DeSmet, 2010).

The following two examples demonstrate how the application of the evidence-based indicators may be used to help determine if a particular practice or program can be considered evidence based. Although a complete review of the literature may be warranted during the evaluation of any particular practice, the following examples will primarily draw from only one peer-reviewed article each as the purpose is to demonstrate the *process* and not to provide a comprehensive review. For each of the two example EBPs, a brief outline of how this EBP may be implemented will be presented followed by the application of the evidence-based criteria.

Embedded Constant Time Delay

The first example of an EBP is embedded constant time delay (embedded CTD). Embedded CTD was developed as an instructional technique for teaching academic content to students with moderate to severe IDD as the strategy. The following is a brief outline of how this EBP may be implemented and the application of the evidence-based criteria.

Embedded CTD is the practice in which the educator or interventionist presents instructional content during natural opportunities throughout the typical class day (Johnson, McDonnell, Holzwarth, & Hunter, 2004). These natural opportunities include breaks and transitions between activities, with such incorporation facilitating a large number of instructional trials to occur. These instructional trials, however, are not spontaneous; rather they are planned and conducted with the same instructional rigor that would be expected if the material was instead taught in one discrete block of time. In practice, this means that students are provided opportunities to practice specific skills throughout the whole school day. Embedded CTD has been shown to be especially appropriate for teaching academic content to students with moderate to severe IDD.

To use CTD, a teacher may identify several short lists of sight words that the student(s) is currently learning. Next, the teacher specifies the type of instruction in which the learning material is presented to the student. For example, Johnson et al. (2004) wrote each word on an index card along with a distractor; the student was asked during the embedded learning trials to touch the word on the card stated by the teacher. Throughout the day, the teacher plans to present these sets of words to the student, such as after morning announcements and each bathroom break, prior to lunch, and during the transition between small group centers. Based on research findings, students who receive embedded CTD should improve their proficiency of the material faster than when presented in a traditional manner (see Hudson et al., 2013 for a list of experimental studies concerning embedded CTD). Johnson et al.'s 2004 embedded CTD study will be used to evaluate this practice using the suggested EBP criteria.

Scientific Basics: General Characteristics

Embedded instruction (of which embedded CTD is one example) has been validated by a large number of other empirical studies; embedded CTD developed from this strong empirical foundation. A multiple baseline designed was used in this small *n* study, and the benefits of embedded CTD were measured across several academic areas (sight words, science facts, etc.). Both of these characteristics of the research study strengthen the researchers' findings concerning the effectiveness of embedded CTD. Descriptive changes were reported instead of results from other statistical techniques, which is less than ideal, but an increase in academic content knowledge was present for all study participants.

Key Study Features

Three probes (e.g., brief measures) were administered by the researchers to determine baseline scores for the participants, which increases the validity of those baselines. The researchers provided training to the teachers implementing embedded CTD and routinely monitored the fidelity of that implementation; both of these procedures increase the internal validity of the study. No comparison group was included, but the multiple baseline design allowed participants to be treated as their own comparison. Statistical significance could not be concluded due to the sample size of the study, but all participants were able to master the associated academic content.

Clinical Utility Aspects

The Johnson et al. (2004) study was an in vivo study conducted within the structure of a public elementary school. As such, the individuals who provided the intervention may be said to be similar to a typical general education classroom teacher and the participants may be said to be similar to a typical elementary student with IDD. Embedded CTD is specifically designed to be conducted during the typical course of a school day; as such the dosage and intensity of this instructional technique can be reasonably accommodated by a general classroom teacher. In the Johnson et al. study, classroom teachers served as the interventionists in implementing embedded CTD, which suggests CTD can be realistically conducted with fidelity without the ongoing support of the research team. Demographic information was largely unavailable for the three participants, making it difficult to determine whether it is appropriate to apply these findings to other groups of students. Two of the participants were male and one was female. Participants had either moderate or severe disabilities: Full Scale IQ scores ranged between 53 and 57 (WISC-III) and adaptive behavior composite scores ranged between 42 and 61.

Feasibility and Cost-Effectiveness

According to Johnson et al. (2004) embedded CTD has the added benefits of being a low-cost, low-disruption EBP that teachers' rate as highly acceptable for use in their classrooms. The level of support and training teachers need to implement embedded CTD is minimal and well within the capacity of most school districts to provide. To implement embedded CTD effectively teachers will need to prioritize which instructional material to present during these embedded trials. In addition, teachers may wish to write a plan as to when these trials will occur as well as recording when they are completed by the student. This planning should increase the likelihood that the EBP is implemented with fidelity and that the embedded instructional trials are not forgotten during the busy day. Embedded CTD is a reiterative process that can be repeated indefinitely throughout the school year, and the intervention is designed to be adapted to the specific needs of the individual and the specific content of the academic class.

The Johnson et al. (2004) study had some limitations (small participant sample, exclusive focus on discrete academic skills, etc.), but overall, it demonstrated strong research characteristics along with clear applicability to the general education setting further supporting the use of embedded CTD. The presence of additional research support further warrants it as a promising EBP for use with individuals with IDD (Jameson, McDonnell, Johnson, Riesen, & Polychronis, 2007).

Reciprocal Teaching

The second example of an EBP is reciprocal teaching (RT). RT is an instructional technique in which teacher-led small groups engage in dialogue about a text (Lundberg & Reichenberg, 2013). This dialogue provides the necessary scaffolding that students need to be successful when interacting with text, and uses the following four strategies: (1) predicting what will happen next in the text, (2) generating questions about substantive information included in the text, (3) clarifying the meaning of difficult to understand text, and (4) summarizing the important information in the text. Lundberg and Reichenberg's (2013) study on RT will be used to evaluate this practice.

Scientific Basics-General Characteristics

RT is based on numerous sociocultural theories in which the social context of an educational experience impacts the amount of learning that occurs in addition to cognitive and developmental theories of learning. RT, having been developed in the 1980s, has a large body of research work supporting its use in the general education setting; however it is more recently being used with students with mild to moderate IDD. Researchers chose to apply RT to this population in part due to early pilot studies that demonstrated students with mild to moderate IDD benefited from engaging in meaningful discussions about text, rather than focusing reading instruction solely on text decoding.

The Lundberg and Reichenberg (2013) study included 40 participants who were randomly assigned in subgroups with their regular teacher to receive either RT or another intervention. Statistically significant pre- to post-intervention differences were observed for most of the reading outcomes measured, and reported effect sizes indicated that when a significant change in scores was measured the gain was greater for the RT students than the alternative treatment group. As no follow-up measures were reported by Lundberg and Reinchenberg, it is unknown whether RT produced sustained effects.

Key Study Features

Teachers were trained to conduct RT, and then observed during the intervention sessions by the researchers to increase intervention fidelity. Additionally, teacher-led talk sessions were video recorded as an additional method for assessing treatment integrity. Measures of listening, reading comprehension, and fluency include well-validated published assessment batteries as well as measures developed by the researchers to correspond to specific intervention texts. Participants in the experimental and the alternative treatment comparison groups were similar in terms of age, level of disability, and second-language acquisition. Student gains were both statistically and clinically significant.

Clinical Utility Aspects

Participants were selected from a relatively non-diverse population in Sweden, and little demographic information is provided for the sample or their teachers. The intervention was conducted, in part, by classroom teachers who were provided a minimal level of training in RT (i.e., 2.5 h which occurred during RT sessions in addition to teacher/researcher discussion of those sessions). The intervention dosage of two 30-min sessions per week could reasonably be accommodated within the typical classroom schedule. In addition, the 8-week length of the intervention study should fit well within many public school calendars.

Feasibility and Cost-Effectiveness

Information concerning the treatment acceptability or cost-effectiveness of RT was not provided by the researchers. The intervention, however, appears to require an amount of time and resources comparable to other reading interventions for students with IDD.

Lundberg and Reichenberg's (2013) findings are strengthened by prior existing empirical support for the use of RT with a general education population. Thus the conclusion of RT as a promising EBP for students with mild IDD seems reasonable. Teachers can easily adapt RT to the specific classroom by varying the size of the teacher-led group (Lundberg and Reinchenberg included groups of 2, 3, and 4 students), composing heterogeneous or homogenous groups based on student ability, or increasing the frequency of RT sessions.

Evidence-Based Assessment Practices

The topic of evidence-based assessment is covered next as a parallel and integral concept in facilitating EBPs for IDD populations. Decision-making in assessment is often linked to the quality and focus of decision-making in intervention selection and implementation. Thus, assessment that incorporates evidence-based procedures and practices is viewed as an essential component for conceptualizing and facilitating EBPs in the field of intellectual and developmental disabilities. Moreover, assessment plays a critical role in determining who should receive an intervention, how it should be implemented to maximize intended effects, and what evidence should be used to make adjustments to the intervention.

Assessment is rarely discussed as part of an EBP framework (Hunsley & Mash, 2010), despite its critical role in the provision of EBPs for individuals with IDD (Reschly, 2013). Evidence-based assessment (EBA), as defined by Hunsley and Mash (2007, 2010), involves the use of research and theory to select which constructs are measured, and to identify which methods are used for a specific assessment purpose. Within an EBA paradigm, practitioners must consider the cost of the assessment process, evaluate the results of the assessment decisions, and monitor the impact the assessment had on clinical outcomes for the person being assessed (Hunsley & Mash, 2010). Therefore, contemporary perspectives on assessment require the use of measures and practices with more traditional forms of psychometric evidence (e.g., test-retest reliability, construct validity) as well as evidence documenting positive results for individuals (Messick, 1995). Such a perspective is reflected in Kane's (1992, 2006) argument-based validity framework. Kane's assessment model incorporates traditional forms of reliability and validity while emphasizing the need for evidence supporting the interpretation and resulting decisions made with the data.

Current definitions of intellectual disabilities include significant impairments in cognitive functioning and in deficits in conceptual, social, or practical adaptive behaviors (e.g., American Psychiatric Association, 2013; Schalock et al., 2010). Deficits in these areas often occur in the developmental period and impair functioning in one or more daily activities (e.g., academic functioning; American Psychiatric Association, 2013). Evidence-based assessment of IDD necessitates the use of measures and methods that capture constructs of intelligence, adaptive behavior, or daily functioning. Interpreting these measures will therefore involve inferences pertaining to an individual's functioning in these areas or their developmental history (Kane, 2006). For example, evidence is needed to support the claim that scores from a standardized measure of cognitive functioning represent the underlying construct of intelligence rather than English language proficiency or cultural knowledge (Rhodes, Ochoa, & Ortiz, 2005).

Practitioners must also weigh evidence supporting the proposed use of the measure. In practice, assessment data are often used to make decisions related to screening, diagnosis or classification, or progress monitoring. Decisions at any stage are best informed by data collected using multiple methods (e.g., interviews, tests) and from multiple sources (Reschly, 2013). Standardized measures that are appropriate for one purpose may not be appropriate for others. In the following sections we briefly highlight the types of evidence required across these decisions and provide examples specific to IDD.

Screening

Screening tools are brief techniques designed to identify those who likely have a condition from those who most likely do not (Glascoe, 2005). Screening may be conducted by pediatricians, educators, or other qualified professionals. In clinical and educational settings, screening measures may guide referrals or target early intervention services (McKenzie & Megson, 2012; Sonnander, 2000). Resulting decisions are commonly to conduct more comprehensive evaluation, provide early intervention, or provide no further services.

Screening tools must be resource efficient and appropriate for the population being screened. Screening tools are evaluated based on evidence of traditional forms of reliability and validity but also on the accuracy of the resulting decisions based on their scores. If we consider IDD as a dichotomous outcome (i.e., disabled or non-disabled), screening measures result in four possible classifications: true positive, true negative, false positive, and false negative. True positives and true negatives reflect accurate classifications of disabled or non-disabled. False positives occur when individuals are identified as disabled who were not; potentially resulting in over referrals and wasted evaluation resources. False negatives occur when individuals are identified as non-disabled when they were in fact disabled. False negatives are typically considered the most undesirable outcome as intervention efforts may be delayed (McKenzie & Megson, 2012; VanDerHeyden, 2011). These four classifications can be used to calculate indices of sensitivity (i.e., probability true positives are correctly identified), specificity (i.e., probability true negatives are correctly identified), positive predictor values (i.e., proportion those identified as disabled who were correctly identified), and negative predictive values (i.e., proportion of those identified as non-disabled who were correctly identified). In order to maximize efficiency, screening tools have lower reliability and validity than more comprehensive measures. Still, researchers suggest that sensitivity of 0.70–0.80 and specificity of 0.80 are necessary (Glascoe, 2005).

Research on screening tools specific to IDD is still emerging (McKenzie & Megson, 2012). Screening tools could be used to identify individuals at risk for IDD or for identifying risk of autism spectrum disorders (e.g., Sappok et al., 2014) or other disorders (e.g., Hermans & Evenhuis, 2010; Mindham & Espie, 2003; Myrbakk, von Tetzchner, & Bodfish, 2008) for individuals with IDD. As a complete review of screening tools is beyond the scope of this chapter, instead we highlight recent research on a potentially promising measure. We use this example to draw attention to the types of evidence practitioners could seek when selecting screening measures rather than to endorse one measure over another.

McKenzie and colleagues have published a series of recent studies evaluating the Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q). The CAIDS-Q is a 7-item measure of literacy, support needs, self-care, and social relationships. The individual or someone with sufficient knowledge of the individual's background can complete the CAIDS-Q. The CAIDS-Q has adequate evidence of reliability and validity (McKenzie & Murray, 2015). Moreover, researchers have found acceptable sensitivity and specificity values for estimating the full-scale IQ of children ages 6–8 (McKenzie, Murray, & Murray, 2013) and ages 8–18 (McKenzie & Murray, 2015; McKenzie, Paxton, Murray, Milanesi, & Murray, 2012). Evidence also suggests the CAIDS-Q total score can be used to estimate functional ability (Murray, McKenzie, Booth, & Murray, 2013). Taken together, the CAIDS-Q provides an efficient way for estimating a child's IQ and functional ability and could be used to signal the need for more comprehensive assessment. These results in support of the CAIDS-Q as a promising evidence-based screening tool; however, it is important to note this evidence does not support the use of the CAIDS-Q for targeting early intervention services or for differentiating between IDD and other similar disorders.

Diagnosis and Classification

Diagnosis of intellectual and developmental disabilities, or classification in educational settings, is based on deficits in intellectual functioning, adaptive behavior, and age of onset (Schalock et al., 2010). Decisions related to diagnosis can have far reaching consequences for the services, supports, and legal protections offered to individuals (Reschly, 2013; Schalock & Luckasson, 2013). Evidence-based assessment requires the use of well-researched, psychometrically adequate measures of cognitive functioning (e.g., Woodcock–Johnson Tests of Cognitive Abilities; Schrank, Mather, & McGrew, 2014) and adaptive behavior (e.g., Adaptive Behavior Assessment System—III, Harrison & Oakland, 2015; Diagnostic Adaptive Behavior Scale, Balboni et al., 2014). To guide interpretation, practitioners must also evaluate the relevance of the norming sample and the developmental sensitivity of the measure in relation to their client (Hunsley & Mash, 2010).

Reschly (2013) provided an excellent review of the necessary considerations for diagnosis of IDD. Considerations include IQ cut off scores, the age of test norms, differences between maximum performance and typical (i.e., day-to-day) functioning, and the limitations inherent in the selected measures. Practitioners must also consider client characteristics such as age, cultural background, educational history, or language proficiency when interpreting testing results. For example, evidence supports the relative instability of IQ scores at early ages (e.g., under 5; Sattler, 2008), which warrants caution when interpreting test performance. IQ measures that include a nonverbal index may be warranted when the client has speech or language issues. Similarly, adaptive behavior scores should be interpreted in the context of cultural norms.

Inferences regarding intellectual functioning or adaptive behavior should not be made solely on the results of standardized testing (Reschly, 2013; Schalock et al., 2010). Test results should be considered along with other evidence gathered in the evaluation (Reschly, 2013). Substantial advances in our knowledge regarding the etiology of IDD have identified a number of risk factors that are related to intellectual functioning (see Witwer, Lawton, & Aman, 2014). Identification of prenatal (e.g., nutritional deficiency), perinatal (e.g., gestational age, birth weight), or postnatal factors (e.g., infections, lead exposure) may contribute to our understanding about the client's functioning. Moreover, assessments of adaptive behavior should include direct observations of adaptive behaviors and interviews with respondents who know the client well (Schalock et al., 2010).

Treatment Monitoring

Monitoring response to treatment is an important assessment activity once a diagnosis or classification is made. The selection of progress-monitoring measures is dependent on the target skills. Following the principles of evidence-based assessment, measures should have theoretical and empirical support linking the scores with the intended constructs (Hunsley & Mash, 2010). Measures used to monitor treatment effectiveness should be brief, repeatable, and sensitive to changes in client functioning over time. Resulting data may be used to inform the continuation or modification of the supports being provided. In addition to the traditional forms of validity and reliability, evidence should demonstrate the measures result in data that can inform accurate decisions regarding treatment effectiveness. Practitioners in educational settings often use decision rules to interpret the resultant data from treatment monitoring. Practitioners should use decision rules that are based on empirical evidence, which may always be the case—even for rules that are widely disseminated (Ardoin, Christ, Morena, Cormier, & Klingbeil, 2013).

School Settings

In educational settings, targets may include academic achievement, social competence, classroom behavior, or communication skills. Diverse professionals with their respective specialized training (e.g., school psychologists, speech/language pathologists [SLP], special education teachers, occupational therapists [OT], transition specialists) may work either collaboratively or independently in identifying effective assessments that best target a client's needs and track progress in their respective domain.

In many settings it may be common for the SLP or special educator to assist in selecting available oral language curriculum based measures (CBMs), such as the Test of Narrative Retell (Petersen & Spencer, 2012) or the Narrative Assessment Protocol (Pence, Justice, & Gosse, 2007). The school psychologist may choose social competence oriented outcome measures that focus on student self control and their self regulation (Gettinger & Stoiber, 2006; Stoiber & Gettinger, 2011) such as the Social Competence Performance Checklist (Stoiber, 2004) or on direct behavior methods, such as Direct Behavior Ratings (Christ, Riley-Tillman, & Chafouleas, 2009). In addition, professionals can team together to identify CBMs that are known and used across both disciplines' scope of practice, including emergent literacy indicators (e.g., Individual Growth and Development Inventory-II; Early Childhood Research Institute on Measuring Growth and Development) and early literacy indicators (e.g., oral reading fluency; Hasbrouck & Tindal, 2006; vocabulary and reading comprehension; Gettinger & Stoiber, 2012; 2014). While garnering input from professionals from multiple disciplines to select outcome measures in a domain such as literacy or social competence may seem redundant, each discipline may have a unique perspective on the types of measures and decisions deemed as most useful for the particular situation. Whereas SLPs may contribute based on their knowledge of the language or vocabulary demands of the assessment, the OT may assist regarding the value of daily living indicators, and the school psychologist may generate ideas on the value of academic or social-behavioral requirements incorporated into the assessment protocol (Justice, 2006; Stoiber, 2014).

Adult Clients

The quality-of-life (QoL) construct appears germane to the discussion of monitoring the effectiveness of supports provided to adults with IDD (Brown, Hatton, & Emerson, 2013; van Loon et al., 2013). A focus on one's QoL emphasizes the alignment of support services to the client's goals and desired outcomes (Luckasson & Schalock, 2013) or family well-being (e.g., Hu, Summers, Turnbull, & Zuna, 2011). Recent research has focused on establishing QoL as a framework for assessing client outcomes and measuring the effectiveness of supports (Schalock, Keith, Verdugo, & Gomez, 2011; Verdugo, Schalock, Keith, & Stancliffe, 2005).

Schalock et al. (2011) cogently summarized research validating the QoL framework. Briefly, researchers have developed and validated a cross-cultural framework that includes three factors: independence, social, and well-being (cf. Verdugo, Navas, Gomez, & Schalock, 2012). Within these three factors are a set of eight domains (e.g., interpersonal relations, social inclusion) and indicators (e.g., community participation) that could be used to generate specific items to assess client outcomes. Importantly, QoL measures should include information from self-report and direct observation of client functioning as there is a weak correlation between the two formats (Schalock et al., 2010; van Loon et al., 2013).

Research on QoL measures has primarily focused on individuals with mild disabilities with a recent study of the San Martin measure providing an important exception (Verdugo, Gómez, Arias, Navas, & Schalock, 2014). Li, Tsoi, Zhang, Chen, and Wang (2013) systematically reviewed nine instruments for measuring QoL amongst individuals with IDD. Psychometric evidence for the measures varied considerably with the Choice Questionnaire (Stancliffe, 1995) and Quality of Life questionnaire (Schalock & Keith, 1993) having the most promise (cf. Cummins, 1997; Townsend-White, Pham, & Vassos, 2012).

Support for the importance of the QoL construct and framework exists, however, more research is needed before QoL measures can be considered evidence-based assessments for monitoring treatment effectiveness. This specific characteristic of QoL is an active area of inquiry and we fully expect that evidence of traditional forms of reliability and validity will continue to emerge for QoL measures. Future empirical work could also investigate whether QoL measures are sensitive to changes in client functioning in response to treatment and the likelihood of practitioners being able to adequately interpret the QoL scores to inform treatment modification.

Other Considerations

In this chapter, we address the history and rationale behind EBPs, their relevance concerning individuals with IDD, and criteria for identifying EBPs for use in practice; we also present EBPs specifically related to assessment. The following topics are viewed as also worth consideration by those providing evidence-based services to individuals with IDD, but a full treatment of them is outside the scope of this chapter. A brief introduction to the issues of early childhood special education, inclusive education for children with IDD, and professional development is included here to provide additional context for systems in which EBPs for IDD are implemented.

EBPs Applied to Early Childhood Special Education

The majority of studies demonstrating improved outcomes from implementing EBPs with youth have occurred in primary and elementary grade regular and special education classrooms. The knowledge-base on effective EBP implementation practices and policies for preschool aged children, similar to the evidence base for secondary level practices, is less developed and still emerging (Greenwood et al., 2011; Lieberman-Betz, Vail, & Chai, 2013; Odom, 2009). Nonetheless, most scholars in early childhood special education (ECSE) believe EBPs hold considerable promise with young and preschool aged children who are at risk, or have identified cognitive, language, and/or IDD (Coleman, Roth, & West, 2009; Greenwood et al., 2011; Odom & Wolery, 2003; Sandall, McLean, & Smith, 2000; Smith et al., 2002). Part C of the federal IDEIA provides funding for states to provide comprehensive systems of services for children in need of ECSE (Hebbeler, Spiker, & Kahn, 2012). However, as is true with much of special education law, the details of these services are left up to the individual states to determine. Children under the age of 3 may be able to receive these services if they are experiencing developmental delays in cognitive, physical, communication, social or emotional, or adaptive development; or if there is a diagnosis of a physical or mental condition that is likely to result in such a delay (National Dissemination Center for Children with Disabilities, 2012; IDEA §632, 2004).

Developmental delay therefore represents a largely heterogeneous group of children with diverse conditions. As such, it is often necessary to identify the area in which a developmental delay is present before identifying what EBPs may be available for ECSE. Under IDEA, states may choose to expand the broad disability category of developmental delay up through age 9, though states are not required to do so and may instead use other special education disability categories (IDEA §300.111, 2004).

One consideration in applying EBPs to early childhood regards the dosage, duration, scope, and form of the intervention. The time available for preschoolers to receive greater individualized instruction, for example, may be more restricted as preschool programs vary in length from half to full day and children often attend less than 5 days per week. Services also may be home-based, rather than center-, school-, or community-based. Depending upon the funding source and type of early childhood program (e.g., federally supported Title 1 or funded through programs such as Early Head Start or Head Start, district-or state-funded early childhood special education classroom, home and/or community-based program) and the child's developmental level (3 year old vs. 5 year old), the policies and resources for EBP implementation may vary widely. In addition, considerable controversy surrounds what constitutes evidence-based practices in ECSE, with some educators less willing to incorporate a focus on academic skill development such as early literacy. In some early childhood programs providing young children who have significant delays or cognitive disabilities with individualized tutoring in early literacy skills such as letter recognition or vocabulary may be viewed as in conflict with the goal of using play or more activity-based approaches to facilitate development and learning, or as not being developmentally appropriate (Greenwood et al., 2011).

Other challenges for effective implementation of EBPs in early childhood settings, including ECSE include (a) fewer reliable and valid measures for assessing and monitoring progress, (b) inconsistent standards specifying expected child outcomes, (c) poorly defined intervention change variables (such as the teaching cycle or which environmental features such as aspects of the home and classroom environment need to be incorporated), (d) considerable variability in program features and program quality, (e) lower professional status and specific training of early childhood aides and/or parents who may serve as the interventionist, and (f) fewer available and appropriately trained personnel to conduct interventions (Ball & Trammell, 2011; VanDerHeyden & Snyder, 2006). As a result, numerous system, funding, and philosophical policy issues present challenges for implementation of EBPs in early childhood settings in general, and in ECSE programs more specifically (Greenwood et al., 2011).

Another consideration for EBP implementation in early childhood regards what evidence-based criteria should be used to examine effective practices. For example, in ECSE, Odom and Wolery (2003) put forth eight foundational tenets aimed at unifying special education theory with best practice. These foundational tenets are considered to exemplify strong ECSE programs, and include features unique to early childhood such as: (a) families and homes are primary nurturing contexts, (b) strengthening relationships is an essential feature of early intervention, and (c) transitions across programs are enhanced by a developmentally investigative adult (Odom & Wolery, 2003). Lieberman-Betz et al. (2013) used the eight ECSE foundational tenets as a framework to examine best practices in multi-tiered applications in preschool settings. In general their review based on the ECSE evidence-based practices showed that the five programs reflected most of the ECSE EBP criteria (four of five included six or more EBP features, one study incorporated all eight criteria). In particular, Lieberman-Betz et al. found consistencies in ECSE evidence-based practices across the five reviewed programs, such as children learn through acting on and observing their environment, adults mediate children's experiences to promote learning, and children participate in more developmentally advanced settings to foster successful and independent participation in such settings. One EBP feature, "families and programs are influenced by the broader context" (Odom & Wolery, 2003, p. 166) was only apparent in two programs. Thus, the authors suggest a focus on program characteristics that are reflective of the child's age and development, such as more family-centered and sensitive components, might emerge as unique features to consider when designing and implementing EBPs within early childhood service delivery.

Inclusive Education

Many students with SDD, or identified as IDD in later grades may be provided services in self-contained special education classrooms. Inclusion of these students in general education classrooms, however, is considered a best practice, if not an EBP on its own.

Inclusive education first emerged as a prominent movement in US education research and practice in the 1980s (Danforth & Naraian, 2015). The justification for inclusion has largely been theoretical and philosophical in nature, and the inclusion of students in regular education classrooms is often done to reduce the marginality of students identified as having disabilities (Doré, Dion, Wagner, & Brunet, 2002). As such research on inclusion is often in the position of trying to validate policies already in place (see Danforth & Naraian, 2015 for a conceptual article on the approach such research should take). Complicating the issue, school visits and observations have revealed that many schools who report they are following an inclusion model for special education have yet to move students with disabilities into their general education classrooms. Thus, actual implementation this change in service-delivery might require overcoming significant obstacles from school culture and disengaged leadership (Mamlin, 1999; Stoiber, Gettinger, & Goetz, 1998).

Despite these complications, a large body of research has supported inclusion as a special education approach, however the outcomes of inclusion for students with IDD has been far less explored (Dessemontet, Bless, & Morin, 2012). In Freeman and Alkin (2000) review of academic achievement outcomes of students with IDD in inclusive classrooms compared to segregated classrooms, they were able to identify only nine empirical studies. Nonetheless, researchers have consistently reported that including children with IDD into the general education classroom does not negatively impact on the academic achievement of their typically developing peers, which has been a common concern voiced against inclusion (Dessemontet & Bless, 2013). Further, some evidence suggests that the more time IDD students spend in inclusive classrooms the more positive the outcomes (Freeman & Atkin).

Practitioners who are tasked with aiding students with IDD in the general education classroom may want to focus their efforts at identifying practices aimed at building fundamental and foundational skills teachers identify as critical for these students to be successful. These skills include following instructions given by the teacher, obeying classroom rules, staying on task for short periods of time, appropriate social competencies, and friendship-making skills (Kemp & Carter, 2005).

Professional Development in Evidence-Based Practices

To promote professionals' and paraprofessionals' implementation of EBPs with individuals with IDD, professional development (PD) activities aimed at their knowledge and use of EBPs appears as an important priority. The purpose of the PD is to help those individuals who work with IDD populations do the right thing by applying EBPs in a manner that accommodates the needs and abilities of individuals with IDD; but also to get it right in terms of how the EBP is implemented and sustained effectively. For example, in light of the example of promoting inclusion as an EBP, PD would likely be beneficial regarding ways to alter environments (e.g., classrooms, community settings) to accommodate students with IDD's possible coexisting social and behavioral concerns. Although this PD focus should assist professionals and paraprofessionals in their work with individuals with IDD in the inclusive settings, the instructional/ecological changes would likely be beneficial in promoting appropriate behavior and improved academic performance in all students. This emphasis of the PD on regular education practices represents a shift from the notion that only those individuals with identified disabilities need support through targeted and intensive intervention strategies. Rather, due to recent estimates of 10–20 % of students requiring social and behavioral support, regular educators become key players in enhancing both regular education and students with IDDs' academic and behavioral outcomes by adapting environmental and learning conditions to the needs of all students thus increasing the likelihood that the EBP procedures will be implemented.

Professional development also would appear useful that explicitly addresses methods for adhering to key component strategies of an EBP when faced with other competing demands. In this regard, it is especially important to ensure that the EBP is aligned with other school, district, or community setting initiatives and that attention is given to approaches to reinforce and sustain the EBP structure. As noted in our section on assessment, making sure that data are collected and used to inform decision-making as a pervasive practice facilitates long-term adoption of new practices, including EBPs (Cook & Odom, 2013; Stoiber, 2014). There is a substantial body of evidence to suggest that even when an EBP was applied successfully and produced intended results, it remained difficult to sustain once the researchers have left and the funding disappeared (Fixsen et al., 2013; Stoiber & Gettinger, 2015). To foster ongoing buy-in with the EBP it is important to identify what outcome is most valued by the school, community setting, or institution (Klingner et al., 2013). Researchers typically provide resources such as PD that includes coaching, monitoring of intervention integrity, and other staff support (e.g., graduate students who tutor lowest-performing students or coaches who help facilitate small groups), which may not be readily available in programs without the researchers' assistance. For this reason, it is important to develop a shared vision within and across the institutional setting including collaborative conversations between researchers and practitioners regarding the type of PD support that is required prior to implementation of the EBP, as well as what type and level of PD is necessary to ensure continuation of the EBP.

Conclusion

Evidence-based practices are receiving significant attention in education and related fields. Linked to the topic of EBPs is a robust line of inquiry on implementation science which targets efforts to diffuse, translate, and disseminate evidence-based and evidence-informed practices. Further, the press for widespread application of EBPs in the school and community for individuals with disabilities confirm its status as a high priority for improving outcomes with this population. Thus, EBPs should not be viewed simply as a "trend."

Despite the high level of interest in the implementation of EBPs in service delivery with individuals with disabilities, the research base on EBPs with individuals with IDD is still evolving. In addition, many critical research and application questions regarding optimal evidence-based practices in serving individuals with IDD remain. Some critical questions that readily emerge include the following: What steps should be taken in selecting EBPs for individuals with IDD when there does not exist reliable sources to easily access them? How should unique differences in individuals with IDD be accommodated when adapting an EBP found to work with individuals with other disabilities (e.g., SLD, speech and language delays) or without disabilities? What outcomes should be prioritized (e.g., social competence development, a foundational skills such as reading environmental sight words, or a daily living functional skill) as most important to address in selecting and implementing an EBP? What is the optimal duration that an individual with IDD should receive an EBP when data suggest that the individual's performance has not changed?

Given the current status of knowledge surrounding EBPs in the discipline of IDD, attention should be given to guidelines that practitioners may use to assist their decision-making when selecting EBPs. Thus, we have provided a framework that highlights considerations practitioners may incorporate in selecting intervention and instructional practices. In addition, for EBPs to benefit individuals with IDD it is necessary to examine evidence-based assessment procedures that are linked to EBP selection and implementation decisions. Such assessment methods play an important role both in determining who should receive what EBP, how the practice may need to be adjusted to produce the intended outcome, and whether an individual with ID is responding to the EBP as expected. The current zeitgeist emphasizing accountability in serving individuals with IDD also suggests that it should be valuable to consider other specific EBP application issues to assist schools and institutions in moving toward improved EBP implementation. We highlight several considerations viewed to be foundational for more cohesive and integrated EBP practices. These include the application of EBPs in early childhood settings and for use in inclusion.

We also call for an obvious need for explicit and feasible professional development that incorporates a shared vision for launching and sustaining EBP implementation with individuals with IDD. Here we note the advantage of researcher- and practitioner-informed decisions regarding the kinds of support required for optimal implementation. The specific proposals for improving EBP implementation with individuals with IDD require empirical testing to determine whether they are feasible along with how the knowledge generated from EBP implementation with individuals with IDD can be more effectively refined and disseminated. In this regard, it is important for university-based trainers to collaborate with field-based practitioners in facilitating EBP selection/implementation and to examine essential content for PD.

By design, EBP implementation involves multifaceted considerations, and thus requires input from a broad range of potential contributors. Clearly, multiple types, designs, and lines of research are essential to successfully understand which EBPs will work most effectively, with whom, and under what conditions. Through the implementation of collaborative inquiry procedures and processes, we believe EBPs for individuals with IDD will continue to evolve and flourish. The amount of work outlined for furthering EBP use with individuals with IDD may appear daunting. Yet this is an exciting time for researchers and practitioners to join together in the design and implementation of EBPs with individuals with IDD. In doing so, we expect EBPs to have a significant impact in making real change in the systems serving individuals with IDD, and most importantly, in improving their lives.

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Functional Assessment

4

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Introduction

Operant behavior is a product of its environment. As a person engages in responses that result in reinforcing consequences, these responses are likely to occur more whereas responses that do not result in reinforcing consequences are likely to occur less. Thus, behavior is learned. It acts on its environment to produce a consequence that strengthens the behavior and increases the likelihood of future occurrence. Appropriate behavior and problem behavior are acquired and maintained in the same manner. Furthermore, when responses are reinforced in the presence of specific stimuli, the responses are more likely to occur in the presence of these stimuli. These stimuli, called discriminative stimuli (S^Ds), have stimulus control over the behavior. Finally antecedent events (motivating operations or MOs) can alter the reinforcing value of stimuli and thus influence the behavior that produces those stimuli. Antecedent events that increase the reinforcing value of stimuli are called establishing operations (EOs) and antecedent events that lessen the reinforcing value of stimuli are called abolishing operations (AOs). Information on the antecedents (S^Ds and MOs) and reinforcing consequences of a behavior helps us understand why the behavior is occurring (e.g., Cooper, Heron, & Heward, 2007; Lennox & Miltenberger, 1989; Miltenberger, 2016; O'Neill, Albin, Storey, Horner, & Sprague, 2014). This is the information one gathers in a functional assessment.

Because operant behavior is controlled by its antecedents and consequences—the contingencies of reinforcement—the goal of a functional assessment is to understand these contingencies. These reinforcement contingencies can be classified into four main categories—social positive, social negative, automatic positive, and automatic negative. This taxonomy, as described in the next sections, differentiates contingencies based on (1) the presentation or removal of a stimulus following the behavior (i.e., positive vs. negative reinforcement) and (2) whether the presentation or removal is socially mediated or is a direct result of the behavior acting on the environment (i.e., social vs. automatic reinforcement) (e.g., Iwata, Vollmer, Zarcone, & Rodgers, 1993; Miltenberger, 2016).

Social Positive Reinforcement

Social positive reinforcement occurs when, contingent on a response, a reinforcing stimulus (i.e., attention, tangible item, or event) is presented by

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another individual and this strengthens the response. This process can be seen when teaching new skills; correct responses are strengthened after the contingent delivery of a tangible reinforcer or attention. Social positive reinforcement contingencies can also be responsible for the acquisition and maintenance of problem behaviors. Examples of these contingencies can be a parent giving candy to a child who is engaging in a tantrum to get him to stop, or a teacher turning to a student and providing attention in the form of scolding after he aggresses towards one of his peers. Although providing the tangible item or attention temporarily terminates the undesirable response, the reinforcing effect results in an increased future probability of that response in that context.

Social Negative Reinforcement

Social negative reinforcement occurs when, contingent on a response, an aversive stimulus is removed by another individual and its removal strengthens the response. Social negative reinforcement contingencies are further categorized as *avoidance* or *escape*. Social negative reinforcement contingencies can shape and maintain both desirable and undesirable behaviors. For example, it is an escape contingency if a graduate student who is studying asks his roommate to turn his loud music off and the roommate does so (removal of the aversive event by another individual). However, it is an avoidance contingency if the next time the student has to study, he asks his roommate to not turn the music on that day (*avoiding* the aversive event). Both of these contingencies strengthen a desired communicative response. Alternately, these contingencies can shape and maintain undesired behaviors, as is the case when a student engages in a tantrum that results in a teacher terminating an academic task (*escape*) and in future situations the student engages in a tantrum as the teacher gathers the materials but before the assignment is presented (*avoidance*).

Automatic Positive Reinforcement

In automatic positive reinforcement, a response directly acts on the environment to produce a reinforcing stimulus and this strengthens the response; the reinforcing stimulus is not delivered by another person. Both desired and undesired responses can be strengthened through automatic positive reinforcement. For example, automatic positive reinforcement is involved when a person goes to the refrigerator and takes out a preferred food item to eat, or when individuals engage in leisure activities, such as reading, watching television, or playing video games. Furthermore, behavioral excesses such as stereotypy and self-injurious behavior are commonly maintained by automatic positive reinforcement. In individuals diagnosed with developmental disabilities, response classes such as stereotypy or self-injury can produce reinforcing stimulation that maintains the behavior independent of any social consequences. For example when a child with autism flicks his fingers in front of his eyes, it can produce visual stimulation that reinforces the behavior or when an adult with intellectual disability engages in head banging, it can produce tactile stimulation that reinforces the behavior. In each case, the behavior is maintained by the stimulation it produces and not by the action of another individual.

Automatic Negative Reinforcement

In automatic negative reinforcement, a response acts directly on the environment to terminate aversive stimulation and this strengthens the response. Paralleling social negative reinforcement, automatic negative reinforcement can be further described as either *escape* or *avoidance*. These contingencies can reinforce desired responses, as is the case when a cook immediately pulls his hand back after touching a hot pan thus removing the painful stimulation (*escape*), and uses an oven mitt to pick up the hot pan in the future to prevent the painful stimulation (*avoidance*). Automatic negative reinforcement can also be responsible for reinforcing undesirable behaviors as when a child with autism runs out of noisy classroom thus terminating the aversive noise (*escape*) and refuses to enter the noisy classroom in the future (*avoidance*). In each case the termination of or avoidance of the noise resulted directly from the child's problem behavior (not the actions of others) and reinforced the behavior.

Functional Treatments

With the development of functional assessment methods to identify the environmental determinants of problem behaviors, functional treatments could be identified to address the specific contingencies that maintain the behaviors. A functional treatment is one that addresses the antecedents that evoke the behavior and/or the reinforcing consequences that maintain the behavior. The three functional treatments for problem behavior, developed on the basis of functional assessment results, are extinction, differential reinforcement, and antecedent manipulations (e.g., Iwata et al., 1993; Miltenberger, 2016).

Extinction

Extinction consists of withholding the reinforcer that previously maintained a response contingent on the emission of the response (e.g., Iwata, Pace, Cowdery, & Miltenberger, 1994). As the occurrence of problem behavior is no longer followed by the reinforcer, the contingency between the behavior and reinforcer is weakened and thus the future probability of the response is decreased. In other words, if the problem behavior is no longer reinforced, it will stop occurring. For example, if the functional assessment identifies that a child's aggressive behavior is maintained by social positive reinforcement in the form of attention, extinction would consist of withholding attention contingent on an aggressive response. Likewise if aggressive behavior was maintained by termination of aversive tasks, extinction would consist of no longer terminating tasks following the behavior.

Differential Reinforcement

The second functional approach to treatment of problem behavior is to deliver the functional reinforcer following an alternative behavior, or the absence of the problem behavior, while withholding the reinforcer for the problem behavior. These procedures are called differential reinforcement of alternative behavior and differential reinforcement of other behavior, respectively. By reinforcing an appropriate response with the reinforcer maintaining the problem behavior, but on a richer schedule of reinforcement, the desired behavior should increase and replace the problem behavior. For example, if the functional assessment identifies that a child's aggressive behavior is maintained by social positive reinforcement in the form of attention, differential reinforcement may consist of providing more, higher quality attention when the child asks for attention and withholding attention when the child emits the problem behavior.

Antecedent Manipulations

The third functional approach to treatment based on functional assessment results is to manipulate antecedent events (EOs and S^Ds) that evoke the problem behavior or to increase response effort for the problem behavior. If the EO or the S^D for the problem behavior is eliminated, the problem behavior is less likely to occur. Likewise, if response effort is increased for the problem behavior relative to desired alternative behavior, the problem behavior is less likely to occur. For example, consider the case of a child (Cody) with autism who strikes a classmate sitting nearby. The aggressive behavior occurs only with this classmate when Cody has not received teacher attention for an extended period of time. When Cody strikes the classmate, she cries and the teacher responds with scolding and explaining (attention) that reinforces Cody's aggressive behavior. The proximity of the classmate is an S^D and extended time without teacher attention is an EO for the aggressive behavior that is reinforced by attention. In this case a number of antecedent manipulations are possible. The teacher can remove the S^D and increase response effort by moving the victim to a seat far away from Cody. In addition, the teacher can eliminate the EO by providing frequent noncontingent attention to Cody so there is no longer an extended period without attention to evoke the problem behavior.

The functional treatments described above require information about the antecedents and consequences of the problem behavior. Without that information, it is difficult to arrange contingencies to alter the antecedents and consequences to decrease the problem behavior and establish alternative behavior. Functional assessment is the method by which we gain that information. In the sections that follow, three approaches to conducting a functional assessment are described (e.g., Iwata et al., 1993; Lennox & Miltenberger, 1989; Miltenberger, 2016; O'Neill et al., 2014). Indirect assessment involves gathering information from caregiver recall through interviews and questionnaires. Direct assessment involves direct observation and recording of antecedents and consequences as they occur in relation to the problem behavior. Functional analysis involves manipulating antecedents and consequences to demonstrate their influence on the problem behavior.

Indirect Assessment

The first step in the functional assessment process is the indirect assessment. During an indirect assessment, the researcher or therapist meets with caregivers and asks a series of questions to gather information about the client, problem behavior, and events related to the problem behavior. The defining characteristic of indirect assessments is that information is gathered from the caregivers based on their recall of the behavior and related events.

Indirect assessment methods are widely used in practice (Ellingson, Miltenberger, & Long, 1999). These methods consist of interviews, rating scales, and questionnaires. They include questions about the topography of the target behavior, the frequency, duration, and intensity with which it occurs, the preceding (antecedent) stimulus events, and the following (consequent) stimulus events. From the information gathered through indirect assessments the behavior analyst can develop hypotheses about the antecedents that evoke the problem behavior and the consequences maintaining the behavior (aka, the function of the behavior). It is important to note that indirect assessments can lead to hypotheses about function, but that a functional analysis is necessary to demonstrate experimental control and confirm the hypothesized function.

Various instruments have been developed to standardize the indirect assessment process such as the Motivation Assessment Scale (MAS, Durand & Crimmins, 1988), the Functional Analysis Screening Tool (FAST, Iwata, DeLeon, & Roscoe, 2013), the Questions About Behavioral Function (QABF, Matson, Bamburg, Cherry, & Paclawskyj, 1999). The research on the validity and reliability of these instruments is mixed, with some findings showing that indirect instruments have high agreement with functional analyses and can lead to effective treatment (e.g., Matson et al., 1999; Matson, Tureck, & Rieske, 2012), and others reporting the opposite (e.g., Iwata et al., 2013; Zarcone, Rodgers, Iwata, Rourke, & Dorsey, 1991). Higher correspondence between indirect assessment instruments and functional analyses was found when there was agreement on the function identified by the instruments across multiple (4–5) raters (Smith, Smith, Dracobly, & Pace, 2012). Nonetheless, the data supporting the use of only indirect assessments as a basis for treatments is mixed at best, and more studies are necessary to empirically support them as a basis for treatment development.

Due to the mixed reliability and validity of indirect assessments, researchers have warned against their use as a sole functional assessment method for identifying the maintaining variables and developing functional treatments (e.g., Iwata et al., 2013). Nonetheless, indirect assessments are an important part of the functional assessment process; they provide information that can be useful in the development of direct assessments or functional analyses. Information learned about the topography of behavior and likely antecedents and consequences can identify the events to be recorded and best time and place for direct observation, and help the behavior analyst develop the conditions to be included in a functional analysis. For example, Kennedy and Itkonen (1993) used the results of a functional assessment interview to identify particular setting events, including waking up late or taking a particular route to school, that appeared to be related to higher rates of problem behavior in school. The setting events identified through the interview were later confirmed to be related to higher rates of problem behavior when direct observation data were collected on the frequency of problem behavior and the occurrence of the setting events.

Rather than rely on questionnaires or rating scales, we recommend that the behavior analyst conduct a thorough interview to start the functional assessment process. Behavior analysts should ask open-ended questions that allow the person interviewed to describe in detail the topography of the target behavior and the events that occur before and after (e.g., Hanley, 2011, 2012; Miltenberger, 2016; Miltenberger & Fuqua, 1985; Veltum & Miltenberger, 1989). A thorough functional assessment interview provides a more comprehensive account of the antecedents and consequences of the problem behavior than can be derived from a questionnaire or rating scale. In addition, the interview helps the behavior analyst establish a working relationship and build rapport with caregivers or implementers. Behavior analysts should ask questions that evoke answers that provide as much detail as possible about the behavior of interest and the context in which it occurs (see Table 4.1 for a list of functional assessment interview questions). The detailed information gathered from a thorough interview should be used to develop a hypothesis about the antecedents and consequences and to develop direct observation procedures and functional analysis procedures to confirm or alter the hypothesis developed from the interview.

Table 4.1 Behavioral assessment interview questions

What are the behaviors of concern?
For each behavior, define how it is performed, how often it occurs, and how long it lasts
When, where, and with whom are behaviors most likely? Least likely?
What activity is most likely to produce the behaviors? Least likely?
Does the behavior typically occur when the individual is alone or around others?
What does the person get as a consequence of the behaviors?
What does the person avoid or escape from as a consequence of the behaviors?
What amount of physical effort is involved in the behaviors?
What expressive communication strategies does the person use?
What events, activities, objects, people does the person appear enjoy?
What appropriate behaviors or skills does the person perform that could occur in place of the problem behaviors?
Identify the treatment programs that have been tried and how effective they have been

Direct Assessment

Direct assessment (also called A-B-C recording, Miltenberger, 2016) involves direct observation of the target behavior in relevant contexts and documentation of naturally occurring environmental events that precede and follow the problem behavior. Direct assessment can be accomplished through narrative recording, checklist recording, or interval recording (Miltenberger, 2016). In narrative recording, the observer writes a description of each instance of the behavior and the events that precede and follow the behavior. In checklist recording, the observer has a checklist of possible target behaviors, antecedents, and consequences. Each time the behavior occurs, the observer checks the behavior and antecedent and consequent events associated with it. In interval recording, the observer identifies specific target behaviors and antecedent and consequent events to be recorded. During the observation period, the observer then marks the occurrence of the behavior and each event in consecutive intervals, resulting in data on the timing of the events in relation to the behavior. Another form of direct assessment is a structured descriptive assessment (to be described later, Freeman, Anderson, & Scotti, 2000). The goal of direct assessment is to identify environment–behavior relationships and formulate hypotheses about the antecedents and consequences that are functionally related to the behavior. Although direct assessment is more rigorous than indirect assessment because it involves direct observation of the behavior as it occurs rather than recall of the behavior, it yields data that are correlational and thus cannot demonstrate a functional relationship (Mace & Lalli, 1991). Nonetheless, when a direct assessment identifies patterns in the antecedents and consequences of the behavior and this information is consistent with the hypothesis from the indirect assessment, it increases the confidence that the information is accurate and can form the basis for developing functional treatments (Miltenberger, 2016; Repp & Karsh, 1994).

An early application of direct assessment was described by Bijou, Peterson, and Ault, (1968) who proposed procedures for documenting environment–behavior interactions. Bijou et al. presented four general guidelines for increasing the effectiveness of these assessments. First, the authors suggest a thorough description of the environment in which the behavior of interest occurs, including an account of the physical and social climate and the observable events that occur within it, noting any changes that may take place throughout the assessment period. Second the authors recommend describing the behavior, antecedents, and consequences in observable terms, organizing this information temporally in such a way that a relationship between events can be derived, and creating a recording system that can capture the desired dimension of behavior. Third, the authors recommend assessing interobserver agreement and finally, identifying a method for gathering and analyzing the data. This model proposed a type of narrative recording in which environmental events are separated into antecedents (A), behavior (B), and consequent events (C), and recorded as they occur. The information gathered from the narrative then allows the behavior analyst to create a recording system in which codes are assigned to specific antecedent, behavior, and consequent events, thus facilitating observations. Once the data have been assembled, conditional probabilities can be calculated to describe the findings.

Conditional probabilities identify the likelihood of occurrence of one event relative to another (e.g., Repp & Karsh, 1994). For example, Repp and Karsh (1994) conducted direct assessment of antecedents and consequences of problem behavior in a classroom setting and found that attention reliably followed the problem behavior. They developed the hypothesis that attention was reinforcing the problem behavior, developed treatment to address this hypothesis (teachers withheld attention for problem behavior and delivered attention for desirable behaviors), and showed that the functional treatment was successful. Lerman and Iwata (1993) calculated the conditional probabilities of self-injurious behavior (SIB) in relation to antecedent and consequent events for six adults with intellectual disabilities. The authors computed the proportions of SIB occurring before and after the presentation and removal of attention and instructions, generating eight conditional probabilities. Conditional probabilities were calculated by dividing the number of intervals containing SIB in the presence or absence of an environmental event by the total number of intervals scored with SIB. Lerman and Iwata did not find strong correspondence between the functions suggested by these conditional probabilities and subsequent functional analyses.

Lalli, Browder, Mace, and Brown (1993) used the direct assessment method described above in a classroom for three students diagnosed with intellectual disabilities. The researchers recorded antecedents, consequences, topographies of each target behavior, and the type and content of instruction. The data gathered from observation sessions were then used to identify environmental events that were correlated with instances of problem behavior in order to develop hypotheses that were subsequently tested using functional analyses. The results showed that there was correspondence between the functions obtained from direct assessments and functional analyses. Similarly, Mace and Lalli (1991) used this direct assessment approach to develop a hypothesis about the function of the bizarre speech exhibited by an adult male diagnosed with intellectual disabilities. However, Mace and Lalli (1991) found inconsistencies between the results obtained from the two assessments, as the direct assessment suggested that bizarre speech was maintained by either positive or negative reinforcement and the functional analysis showed that bizarre speech was solely maintained by positive reinforcement. These results are consistent with other studies which suggest that the results of descriptive assessments may not correspondence with the results of functional analysis (e.g., Camp, Iwata, Hammond, & Bloom, 2009; Lerman & Iwata, 1993; Thompson & Iwata, 2007).

Structured Descriptive Assessments

Although a disparity in the functions identified by direct assessments and functional analyses is sometimes seen (e.g., Lerman & Iwata, 1993; Mace & Lalli, 1991), it is possible that conducting a functional analysis may not be feasible due to a lack of experienced implementers or a controlled environment. Therefore, a method for increasing correspondence between assessment procedures may prove useful. The structured descriptive assessment (SDA) proposed by Freeman et al. (2000) attempts to improve correspondence by arranging environmental events that evoke problem behavior instead of waiting for naturally occurring opportunities for the behavior to occur. It is important to note that only antecedent events are programmed, consequences occur naturally. Contriving the number of antecedents that occur during an observation session can yield a better sample of environment–behavior relations.

Freeman et al. (2000) conducted SDAs at a school and group home with two children diagnosed with intellectual disabilities. Antecedent events were programmed during the assessment sessions but therapists were instructed to respond to problem behavior as they typically would. For example, to test if task demands evoked problem behavior, the researchers asked the therapists to present demands every 2 min but to respond to the problem behavior as usual. The data obtained from the SDAs were then compared to the results of a functional analysis to assess agreement between the procedures. The authors reported congruence between the functions derived from both assessment procedures. Anderson and Long (2002) expanded on these findings by comparing the results obtained from SDAs to those of an analogue functional analysis and evaluating whether hypotheses derived from the SDAs would lead to effective treatment. Sessions were conducted during a low attention condition, a difficult task condition, a condition in which a preferred tangible was not available, and a play condition with no demands and substantial attention. The results of this study show that the functions identified by both assessments matched for three out of four participants. The assessment data for the participant whose results did not agree suggested two different functions, however, both functions had to be addressed in treatment to fully decrease problem behavior in all contexts. Based on these findings, the authors propose that the SDA may be a feasible substitute or complement to the functional analysis. In a more recent study Anderson, English, and Hedrick (2006) extended the application of the SDA to four typically developing children. The authors exposed the participants to three or four 10-min conditions similar to those described by Anderson and Long (2002). Responses per min as well as conditional probabilities were calculated for each participant to evaluate interactions between environmental events and problem behavior and develop functional interventions, however, unlike the previous studies, functional analyses were not conducted. The results were congruent with those of the previous studies; the results of the SDA were useful in developing hypotheses about environment–behavior relations, yet an evaluation of conditional probabilities was necessary to generate a more thorough understanding of functional relations. For example, the results of the SDA for one participant hypothesized adult attention as a maintaining variable, but upon further analysis of conditional probabilities, both peer and adult attention were identified.

The findings mentioned above are promising because SDAs represent a structured form of direct assessment that examines behavior in the environment in which it occurs, as the behavior analyst manipulates stimuli that naturally evoke the behavior, so the natural consequences can be observed in this context (Freeman et al., 2000). Further evaluation of the SDA approach is warranted. Although the functions identified by the SDA matched those obtained by the functional analysis as reported by Freeman et al. (2000) and Anderson and Long (2002), these represent only two studies examining the correspondence between these assessments and thus further replications are needed to demonstrate the generality of these findings. However, Anderson et al. (2006) did use an SDA to identify the maintaining variables and used this information to develop a successful intervention. Another limitation is that the SDA does not manipulate consequences; rather, caregivers are instructed to respond to the problem behavior as they typically would under natural circumstances. As such, the results of the SDA lead to hypotheses about the reinforcing consequences but do not demonstrate a functional relationship. We believe the SDA could be strengthened by manipulating consequences as well as antecedents when possible. For example, if the teacher is asked to present difficult tasks as part of an SDA, the teacher could also be asked to terminate the task following instances of the problem behavior. This condition could then be alternated with easy tasks and no termination of demands following problem behaviors. Differences in the level of problem behavior between conditions would confirm the influence of the antecedents and consequences on the problem behavior. It might be noted that this could make the SDA much more like a functional analysis than an SDA, and would greatly increase its similarity to the trial-based FA, which is discussed later.

Scatterplots

Scatterplots are a type of direct assessment used when patterns of behavior in the natural environment are the primary interest (Touchette, MacDonald, & Langer, 1985). A scatterplot is used to identify the timing of the behavior rather than the antecedents and consequences of the behavior, and therefore, the scatterplot is not a functional assessment procedure. This method requires uninterrupted observation of the problem behavior across multiple consecutive time intervals, with each interval typically lasting a half hour or less. Data are then plotted on a grid to show when the behavior is most likely to occur. For example, a filled cell may represent the occurrence of the behavior at a high frequency, a cell with a slash may represent the occurrence of the behavior at a low frequency, and an empty cell may mean the behavior did not occur during that observation period. Scatterplots are simple to conduct and yield a visual representation of the data almost immediately without the need for extensively trained observers. However, unlike the functional assessments discussed above, antecedent and consequent events are not recorded and thus the results obtained cannot be used to develop hypotheses about the function of the target behavior. However, because these results identify time of day correlated with the occurrence of problem behavior, they help inform further assessments (Touchette et al., 1985). For example, a direct assessment of antecedents and consequences can be scheduled at the time the scatterplot shows the behavior is most likely to occur. Furthermore, if problem behavior is likely to occur during a time of day associated with a particular activity (e.g., math), that information may be useful when designing a functional analysis. For example, a math task may be included in the escape condition. Furthermore, this assessment procedure can be tailored to fit a variety of settings (e.g., schools, homes, centers).

Summary

There is substantial research on the use and effectiveness of direct assessment. The primary characteristic of all types of direct assessment is the emphasis on direct observation of the target behavior and related events. Observations must continue until all antecedents and consequences that reliably precede and follow the problem behavior have been surveyed and a clear pattern of antecedents and consequences is discerned. When conducting a direct assessment there is some flexibility in the way data are organized and analyzed, such as narrative A-B-C recording, A-B-C checklists, SDAs, percentage of occurrence, or conditional probabilities. We believe it is essential for the direct assessment to be conducted (or overseen) by a competent behavior analyst with a thorough understanding of behavior principles and environment–behavior relationships.

Perhaps the main limitation of direct assessment is the absence of experimental manipulation of potentially reinforcing consequences. It is important to clarify that direct assessments can only identify correlations, the temporal pattern of antecedents and consequences in relation to the behavior, not functional relationships between environmental events and the target behavior. Freeman et al. (2000) attempted to address this limitation by introducing the SDA, and although promising, further research is needed as only a few studies using this procedure have been conducted thus far and only antecedents are manipulated in the assessment. In addition, although several studies have shown correspondence between results of direct assessments and the results of functional analyses, several studies have also demonstrated poor correspondence between the results obtained from direct assessments and functional analyses (e.g., Thompson & Iwata, 2007). This lack of correspondence may the due to several factors (Camp et al., 2009). First, it may be difficult to identify maintaining consequences if the behavior is intermittently reinforced; second, if behaviors occur in bursts or at high rates consequences are likely to follow a behavioral episode instead of each instance of problem behavior. For example, Marion, Touchette, and Sandman (2003) conducted a study with 45 individuals diagnosed with developmental disabilities and found that the event most likely to follow SIB was another occurrence of the behavior itself instead of any other environmental consequence. Third, certain topographies of behavior that are harmful to the individual or others (SIB, aggression) may be followed by consequences that are not necessarily the ones maintaining the behavior. To illustrate this phenomenon, Thompson and Iwata (2001) analyzed the direct assessment data obtained from 27 participants and found that attention followed problem behavior in 88.9 % of all cases. A follow-up study conducted by the same authors in 2007 using a subset of the cases reported in 2001 showed that when compared to the results of a functional analysis, attention was the maintaining consequence in only 25 % of the occasions. Similar results were also obtained by St. Peter et al. (2005). Interestingly, Camp et al. (2009) reported direct assessments are more likely to match the results of functional analyses when the function is automatic reinforcement. And finally, it is possible that relevant stimuli are not present during observations because caregivers may remove S^Ds or EOs that evoke behavior to decrease the likelihood of its occurrence when they know they are being observed (Anderson & Long, 2002).

Even though the lack of experimental manipulations is a limitation, the utility of direct assessments cannot be overlooked. A well-conducted direct assessment can be an important part of the functional assessment process because an indirect assessment alone is never sufficient for the complete assessment of behavior-environment relations as they occur in the natural environment (e.g., Miltenberger, 2016; O'Neill et al., 2014). A well-conducted direct assessment results in the development of hypotheses that can aid in the development of functional analyses and lead to treatment development. Careful observations may also detect precursors to the problem behavior that may be part of the same functional class. This is particularly useful when problem behaviors are so severe that they cannot be allowed to occur (more information on how to address this situation below) (e.g., Mace & Lalli, 1991). Given the variety of direct assessment approaches available, sufficient time should be devoted to selecting the appropriate method. A good starting point suggested by Fisher, Piazza, and Roane (2011) is to evaluate what the behavior analyst would like to accomplish by completing the assessment, considering that direct assessments are flexible and can be adapted to study a variety behavioral phenomena. Furthermore, behavior analysts should assess the availability of resources such as trained observers or data collectors, equipment (e.g., paper/pencil, laptops), and of course, an experienced individual capable of organizing and interpreting the data.

Functional Analysis

A final approach to conducting a functional assessment is the functional analysis (FA). The term functional analysis refers to an assessment strategy in which the behavior analyst experimentally manipulates antecedents and consequences to demonstrate a functional relationship between these environmental events and behavior. Unlike indirect and direct assessment methods which can lead to a hypothesis about the maintaining variables, the FA establishes a functional relationship, confirming the variables that are maintaining behavior. Whereas indirect assessments rely on self-report and direct assessments rely on observation of the natural occurrence of the target behavior and related events, the FA manipulates antecedent events (S^Ds and EOs) to evoke the behavior and delivers consequences differentially for these responses. If responding is differentiated across conditions with differing antecedent events and programmed consequences (demonstrating experimental control), functional relationships between the behavior and environment are demonstrated.

A potential criticism of the FA approach is that it purposefully evokes problem behavior. It may seem that evoking and reinforcing the very behavior that is targeted for decrease would be an unsafe assessment method, particularly when dealing with topographies such as self-injury. However, the philosophy behind this approach is that a temporary increase in the target behavior, when necessary safety precautions are in place, is tolerable and can confirm the hypothesized functions from indirect and/or direct assessment methods, leading to potentially more effective treatment. This approach can be analogous to skin allergy testing, in which a number of allergens are placed on a person's skin in different locations to see to which allergens produce a reaction. The temporary hives and other potentially dangerous symptoms occur in the presence of a physician who can respond appropriately. The temporary discomfort and potential danger of being exposed to an allergen is outweighed by confirming the person's allergy in a safe environment and developing the most effective treatment. The same logic can be applied to the FA approach, and in fact, in a review of 99 cases of FAs on self-injurious behavior, Kahng et al. (2015) concluded that rates of injury related to the FA were low, and when injuries occurred they were not severe. When the most appropriate FA strategy is chosen and necessary precautions (such as protective equipment) are employed, the FA is a relatively safe, and very precise, assessment method that can identify functional relationships and lead to effective treatment.

Iwata, Dorsey, Slifer, Bauman, and Richman (1982/1994) developed an experimental analysis to assess the variables maintaining self-injurious behavior. They exposed participants to a series of conditions in a multielement design (as described later). This study demonstrated an effective approach to assess the function of the behavior that was extremely influential in advancing functional analysis methodology (Mace, 1994). However, it is important to clarify that one of the most critical contributions of this publication is not the set of procedures described by the authors (e.g., analogue setting, specific conditions, multielement design, data analysis method), but rather the approach they employed; systematically manipulating antecedents and consequences to demonstrate functional relationships between environmental events and the behavior of interest.

Essential Features of Functional Analyses

In a functional analysis, the behavior analyst manipulates antecedents and consequences to identify which environmental events are functionally related to the behavior. In this approach, the behavior analyst arranges one or more test conditions and one or more control conditions. Although several variations of functional analyses have been proposed and will be described in later sections of this chapter, there are three essential features of the test condition and control conditions in a functional analysis. The first essential feature of the functional analysis is the manipulation of a potential reinforcer to see if it increases the behavior. In the test condition, the potential reinforcer (i.e., attention, tangible, escape) is delivered on a continuous reinforcement schedule following every instance of the behavior. In the control condition, that reinforcer is not delivered if the problem behavior occurs.

The second essential feature is the manipulation of motivating operations (MOs) (Laraway, Snycerski, Michael, & Poling, 2003). In particular, in a test condition of a functional analysis, the behavior analyst presents an EO to evoke the behavior. The EO is specific to the reinforcer being tested in the test condition. For example, if attention is being tested, the EO would consist of deprivation in which no attention is provided before the occurrence of the problem behavior. If escape from aversive activities is being tested, the EO would consist of the presentation of an aversive activity. In a control condition, the behavior analyst presents an AO for the behavior so the behavior is less likely to occur. If attention is being tested, the AO would consist of noncontingent attention; if escape is being tested, the AO would consist of the absence of the aversive activity or the presence of an easy task.

The third essential feature is the manipulation of a discriminative stimulus (S^D). An S^D evokes behavior by signaling that reinforcement is available in its presence, and as such, functional analysis test and control conditions must have unique S^Ds that facilitate differential responding in each condition. For example, different therapists might conduct different functional analysis conditions or the conditions might be conducted in different rooms to facilitate stimulus control. Stimulus control among conditions can also be enhanced if the same therapist wears a different color t-shirt or uses distinct materials in each condition (Connors et al., 2000). The presence of these different S^Ds will signal which contingency is in effect and suggest the availability of a particular form of reinforcement for problem behavior.

In summary, a functional analysis consists of one or more test conditions and one or more control conditions. Each test condition tests whether a consequence functions as a reinforcer and therefore consists of an EO to evoke the behavior that produces that potential reinforcer and the delivery of that potential reinforcer each time the behavior occurs. Each control condition consists of an AO that decreases the value of that potential reinforcer and withholding that potential reinforcer if the behavior occurs. Furthermore, each condition is associated with a different S^D. If the problem behavior is higher in the test condition than in the control condition or if it is higher in the test condition than it is in other test conditions, the functional analysis shows that reinforcer to be functionally related to the problem behavior.

Functional Analysis Conditions

The typical functional analysis approach incorporates all three of the essential features mentioned above into a series of four experimental conditions, three that test potential sources of reinforcement for the problem behavior and a control condition. The test conditions are: social positive reinforcement in the form of attention or access to tangibles, social negative reinforcement in the form of escape from task demands or social interactions, and alone (automatic reinforcement). The control condition is a play condition. The currently recommended sequence for these conditions to maximize relevant EOs is ignore/alone, attention, play, and demand if the tangible condition is not included (Hammond, Iwata, Rooker, Fritz, & Bloom, 2013).

Attention Condition

During the attention test condition, attention is delivered following every instance of the problem behavior. To set up this test, the assessment setting is equipped with moderately preferred items (e.g., toys or leisure materials) within reach of the individual. Moderately preferred items are included because research suggests that the availability of highly preferred items results in reductions in attention-maintained problem behavior (Fisher, O'Connor, Kurtz, DeLeon, & Gotjen, 2000; Roscoe, Carreau, MacDonald, & Pence, 2008), and thus, if present, these items would compete with attention as a reinforcer. Further, if the items are placed out of the individual's reach, he/she may engage in other forms of behavior to access these items and the test may produce a false negative result. That is, the assessment may reject attention as a maintaining reinforcer when indeed it is, because the client was engaging in an alternate behavior. To establish the relevant EO for this test, the therapist may interact with the individual for 1–2 min prior to the session but then withdraw attention during the session. The therapist will say that he/she (the therapist) has to do some work and provide no further attention until the problem behavior occurs. The therapist provides attention contingent on every instance of problem behavior and ignores all other responses emitted by the individual (Iwata, Dorsey et al., 1982/1994). To ensure ecological validity, the type of attention provided following the problem behavior should mimic what typically occurs in the natural environment. For example, because it is likely that problem behavior typically results in statements of concern or disapproval, Iwata et al. (1982/1994) followed instances of SIB with physical contact (e.g., hand on the shoulder) and verbal responses such as "don't do that, you're going to hurt yourself." Similarly, Fisher, Ninness, Piazza, and Owen-DeSchryver (1996) demonstrated that a boy's destructive behavior was maintained by verbal reprimands directly related to the problem behavior (e.g., "That hurts") and not unrelated verbal statements (e.g., "It's sunny today"). Kodak, Northup, and Kelley (2007) assessed the effects of six different forms of attention (reprimands, unrelated comments, tickles, eye contact, praise, and physical attention) on the problem behavior exhibited by two children for whom attention had been identified as a maintaining reinforcer. However, unlike the previous studies, verbal reprimands directly related to the problem behavior were not the only form of attention maintaining the behavior; tickles and unrelated comments were also shown to have an effect on the frequency of problem behavior.

Tangible Condition

Although the tangible condition was not initially described by Iwata et al. (1982/1994), access to preferred items has been shown as a possible function of problem behavior (e.g., Hagopian, Wilson, & Wilder, 2001; Lalli & Kates, 1998). Decision-making for whether to include a tangible condition should include careful consideration and selection of potential tangible items to avoid false-positive results (Rooker, Iwata, Harper, Fahmie, & Camp, 2011) To test for social positive reinforcement in the form of access to tangibles, preferred items are selected based on the probability that their removal will result in instances of problem behavior and their contingent delivery will reinforce the behavior. The environment is then set up in such a way that these tangibles are within sight but out of the individual's reach. Prior to the start of this condition, the individual is given a few min to interact with the item. The item is then removed by the therapist, which creates a state of deprivation (EO) that may evoke problem behavior if it has been reinforced by access to tangibles in the past. Contingent on instances of the problem behavior, the therapist returns the item to the individual and allows him/her to interact with it for 30 s while other behaviors are ignored. This procedure is repeated for the remainder for the session. Only the tangible items used in the putative reinforcement contingency should be present to avoid other freely available items interfering with the EO for access to the programmed reinforcer. In addition, to enhance the EO for the tangible items they should not be freely available prior to the session.

Escape Condition

The escape condition is designed to test the effects of negative reinforcement on problem behavior. During this condition, tasks are presented in a least-to-most prompting sequence. Compliance results in brief praise and problem behavior results in a 30-s break from the task (Iwata et al., 1982/1994). To increase the salience of the escape contingency, it is important to use materials and tasks that are exclusive to this condition and increase the value of escape as a reinforcer (EO). As in the test for attention, ecological validity should also be ensured in the escape condition to increase the generality of the findings. This includes selecting tasks and demands that have been associated with problem behavior in the natural environment. For example, problem behavior may be more likely to occur in the presence of tasks that may be considered repetitive or boring or difficult (McComas, Hoch, Paone, & El-Roy, 2000). This point was highlighted by McComas et al. (2000) who found that the problem behavior exhibited by three boys occurred in the presence of different academic tasks. Roscoe, Rooker, Pence, Longworth, and Zarcone (2009) extended these findings by proposing a demand assessment for identifying which tasks are most correlated with problem behavior to be included in the escape condition of the functional analysis. The authors selected 12 tasks for each participant and recorded the frequency of problem behaviors exhibited during each task. The results were then used to select low-probability demands (low-*p*; those associated with lower levels of compliance and higher levels of problem behavior), and high-probability demands (high-*p*; those associated with higher levels of compliance and lower levels of problem behavior), which were then incorporated into a functional analysis. The outcomes of the FA show that for three of the four participants, differentiated responding was only obtained in the presence of low-*p* demands suggesting that the low-*p* demands were an EO for problem behavior maintained by escape from specific tasks. Although the studies described above involved escape from physical tasks, this does not always have to be the case as aversive situations may also take the form of social interactions or questions. For example, Iwata, Pace, Kalsher, Cowdery, and Cataldo (1990) described a participant whose problem behavior was evoked by medical exams and questions regarding physical illnesses. Thus, given that different types of demands may evoke the problem behavior, it is recommended that practitioners conduct interviews and direct observations before starting the functional analysis to determine which demands or tasks are most likely to evoke problem behavior.

Alone Condition

To test for automatic reinforcement during a functional analysis, the individual is generally left alone and observed surreptitiously. The room is barren of any persons, toys, items, or materials that may provide any outside source of reinforcement for the problem behavior or competing behavior. If problem behavior is maintained by automatic reinforcement, high rates of problem behavior can be expected in the alone condition (Iwata et al., 1982/1994). In cases when problem behavior is too severe, a therapist may be present to block instances of problem behavior, however, he/she does not provide any consequences contingent on problem behavior. This modification is referred to as the ignore condition. This condition may also be used if it is difficult to access a controlled environment in which a client can be observed alone. Another variation of the alone condition was described by Piazza et al. (1998) who conducted functional analyses of pica by “baiting” the test room with items safe for consumption. By doing this, the participants are still able to emit the problem behavior in the absence of social consequences but do so with materials that are not harmful to their health.

Control Condition

Lastly, the control or play condition is characterized by an enriched environment in which there are no demands (including questions), the individual has continuous access to preferred items, and non-contingent attention is provided on average every 30 s. In this way, the behavior analyst arranges an AO for attention, tangible items, and escape as reinforcers for the problem behavior. As a result, it is expected that individuals engage in low or zero rates of problem behavior (Iwata et al., 1982/1994).

This condition serves as the control against which responding in all other conditions is compared. Although this arrangement has proven effective as a control condition, Taylor and Carr (1992a, 1992b) and Taylor, Ekdahl, Romanczyk, and Miller (1994) found that for some participants, problem behavior was more likely to occur in the presence of social interactions rather than task demands. Therefore, the play condition may not be the best control when analyzing behaviors maintained by social negative reinforcement in the form of escape or avoidance of social interaction (Kahng & Iwata, 1998). To address this shortcoming, Kahng and Iwata (1998) proposed that the alone condition be used as an alternative in situations in which the presence of a therapist is likely to evoke problem behavior. An important consideration when using the alone in lieu of the play condition as a control is that some topographies of behavior (e.g., aggression) require the presence of another individual. If this is the case, it may be preferable to include the play condition as a control.

Antecedent and Consequence Versus Antecedent Only Approaches

Although the functional analysis model we describe here manipulates antecedents and consequences to show their influence on the problem behavior, another functional analysis approach manipulates only antecedents to identify stimuli that evoke the problem behavior (e.g., Carr & Durand, 1985; Carr, Newsom, & Binkoff, 1980; Durand & Carr, 1987). Carr and Durand (1985) exposed participants to a series of conditions where antecedent events (different levels of task difficulty and attention) were varied. The results established a functional relationship between high levels of task difficulty and problem behavior for some individuals and between low levels of attention and problem behavior for other individuals. Furthermore, treatment in the form of functional communication training (differential reinforcement for verbally requesting attention and assistance) resulted in a decrease of problem behavior for all four children. Despite its potential, a limitation of the AB approach is that it fails to manipulate consequent variables, and as such may not represent the contingencies maintaining the target behavior. Potoczak, Carr, and Michael (2007) compared the antecedent manipulation only (A-B) approach to conducting a functional analysis with the antecedent and consequence manipulation (A-B-C) approach and showed that the ABC approach identified the reinforcer for problem behavior whereas the AB approach did not.

One further limitation with the AB only approach is that the antecedent that evokes the problem behavior might not predict the reinforcer maintaining the behavior. For example, Repp and Karsh (1994) showed that demands were the most frequent antecedent for problem behaviors for two students, suggesting that the behavior may have been reinforced by escape. However, they showed that attention was the reinforcer for the behavior. Romaniuk et al. (2002) also showed that for some children, problem behavior that followed academic demands was reinforced by attention rather than escape. In these cases, information on the antecedent would have led to false inferences about the reinforcing consequences in the absence of information on the consequences.

Beavers, Iwata, and Lerman (2013) reported that 89 % of studies conducting FAs employed the ABC model, 17.2 % of studies used the AB model, and 6.2 % used both. Furthermore, the proportion of studies reporting the ABC model is increasing and the inverse was found for the AB model. This trend is in accordance with best practice, which encourages the use of the ABC model given the minimal differences in effort required to manipulate both antecedent and consequent events (the complete contingency), compared to only antecedent variables.

Variations of Functional Analyses

In the sections that follow, different variations of the functional analysis methodology are described.

Multielement

The multielement FA is perhaps the most widely known, given the far reach of the publication by Iwata et al. (1982/1994) and coverage in several behavior analytic textbooks (e.g., Cooper et al., 2007; Miltenberger, 2016). Although the methodology employed by the authors was an effective application of the experimental assessment, it is important to note that their procedures were only one variation of the FA approach and other methods are also used.

The multielement FA consists of exposing participants to a series of test conditions and a control condition with different antecedent events and programmed consequences (described in the essential features above). The assessment is conducted in a controlled analogue setting where participants are exposed to the conditions in brief (e.g., 10- or 15-min) sessions that are alternated rapidly. The rate of responding (or percentage of intervals in which responses occurred) in each session is then graphed in a multielement design, and a differential rate of responding in one or more conditions relative to the control condition is interpreted as indicative of a particular function of behavior (see Fig. 4.1). The top panel in Fig. 4.1 shows a multielement FA with hypothetical data in which the escape condition produced higher rates of responding than the other conditions, demonstrating that escape is the reinforcer for the problem behavior. The bottom panel shows hypothetical data in which the target behavior is high in all conditions, so a clear function is not identified. However, the high level of the behavior in the extended alone condition suggests that the behavior is maintained by automatic reinforcement because it persists in the absence of social reinforcement (see Extended alone section).

Brief

One variation of the multielement FA is the brief FA. A potential limitation in conducting a multielement FA is that the process can be time intensive. Consequently, researchers have developed an approach that shortens the time necessary to conduct the assessment. Northup et al. (1991) described the brief FA, in which they carried out an entire FA of aggressive behavior, including a treatment test, in less than 90 min. The experimental assessment consisted of an initial phase in which the participants were exposed to a series of two to four conditions similar to those used by Iwata et al. (1982/1994). However, sessions were shorter, lasting 5–10 min with a 1–2 min break in between, and rather than repeated presentation of the conditions, the single presentation was followed by a contingency reversal phase. During the contingency reversal phase, the condition with the highest level of aggressive behavior was repeated for three sessions. However, for the first and third sessions, the contingency was in place for an appropriate alternative response rather than aggressive behavior. Higher rates of the appropriate response and lower rates of aggression during the first and third contingency reversal sessions, and the inverse during the second session, provide further support for the function identified by the initial brief assessment. See Fig. 4.2 for an example of a brief FA.

This brief FA procedure was extensively evaluated by Derby et al. (1992). In a review of 79 cases, problem behavior was emitted during the initial FA phase in 63 % of cases. The low percentage of cases with problem behavior during the initial FA points to a potential limitation with the brief FA; it may only be appropriate when behavior is occurring at a relatively high frequency. However, in cases where problem behavior was emitted, the function was identified in 74 % of the cases, and experimental control was demonstrated in 84 % of the cases through the contingency reversal. Kahng and Iwata (1999) assessed the validity of the initial brief FA phase (one exposure to each of the conditions, without the contingency reversal) by comparing them to full multielement FAs, as well as conducting a within session, min-by-min analysis for the brief FA sessions. Both the brief FA and the within-session analysis had similar correspondence to the full, session-based FA (66 % and 68 % respectively). This research suggests that the brief FA may be a valid methodology for assessing the

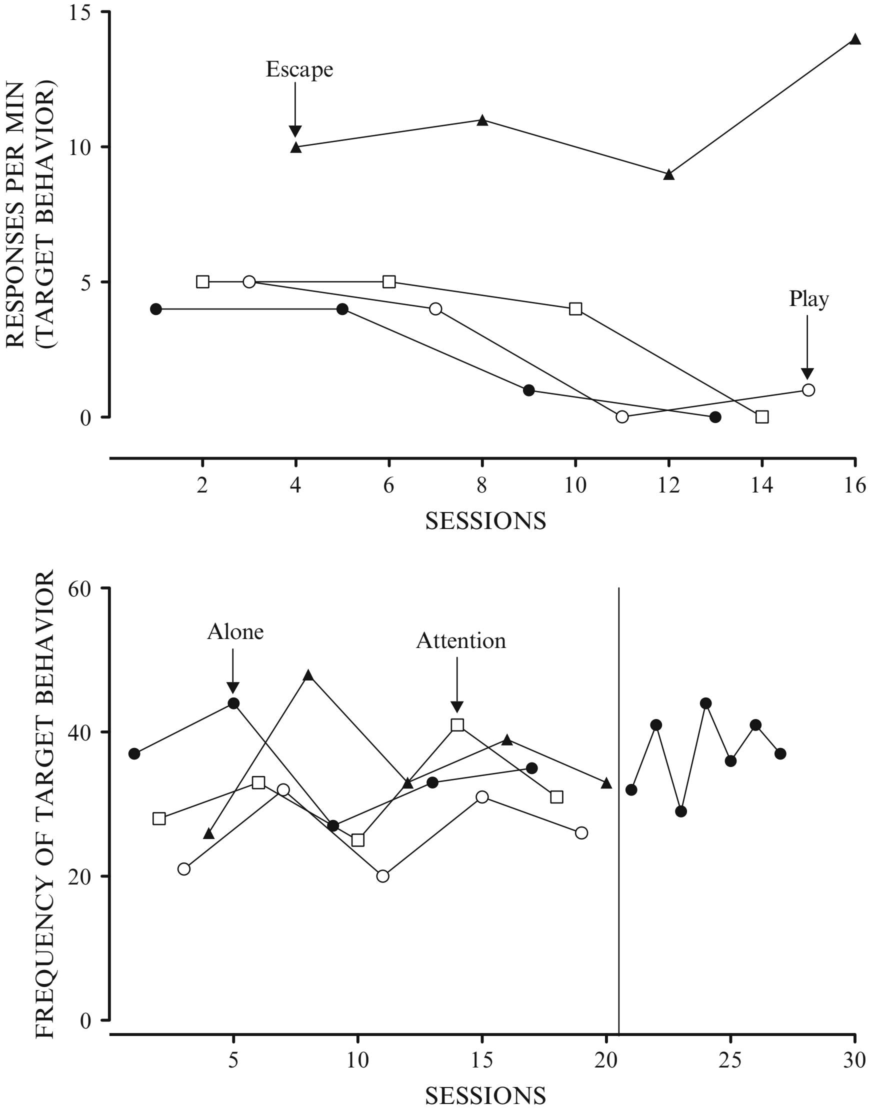

Fig. 4.1 *Top panel* shows a multielement functional analysis with attention, escape, alone, and play conditions. *Bottom panel* shows the same conditions but includes an extended alone phase

function of behavior when time is limited. As suggested by Vollmer, Marcus, Ringdahl, and Roane (1995), if the behavior analyst starts with a brief FA and it results in a clear indication of the function of the behavior, then the behavior analyst can use the information to develop functional intervention. However, if the brief FA does not produce clear results, the behavior analyst can continue with more sessions and conduct a multielement FA as described above.

Single-Test

When a comprehensive interview and direct assessment are conducted correctly, and there is a clear hypothesized function (e.g., agreement between multiple raters in an indirect assessment and a direct assessment), it may be appropriate to conduct a single-test FA (aka, hypothesis-testing FA, Miltenberger, 2016) instead of a multielement FA with all conditions (aka, exploratory FA, Iwata & Dozier, 2008; Miltenberger, 2016).

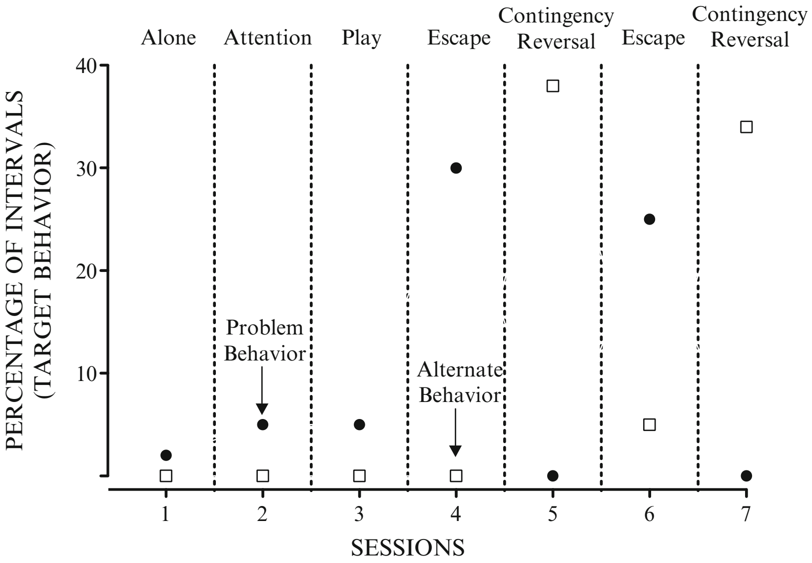

Fig. 4.2 Shows a brief functional analysis with four conditions and a contingency reversal

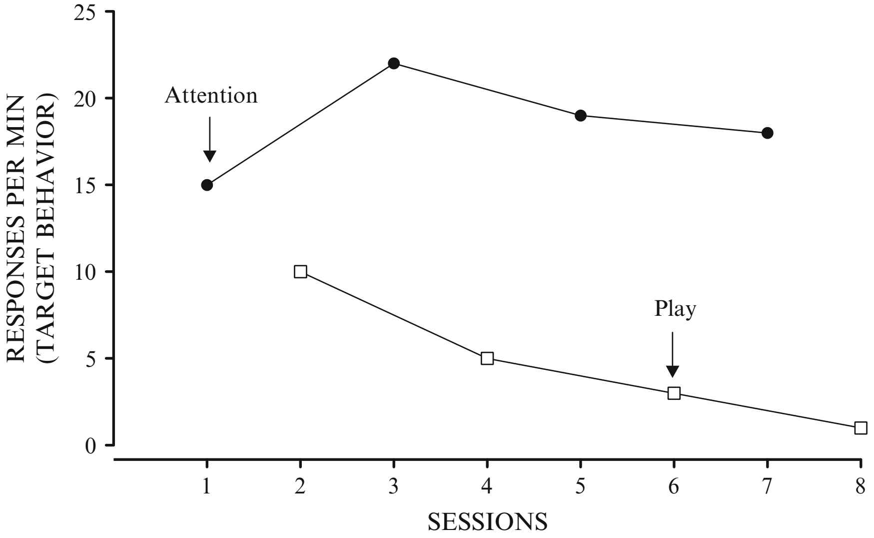

Fig. 4.3 Shows a single-test functional analysis comparing the attention test condition and control (play) condition

In the single-test FA one test condition is compared to a control condition (see Fig. 4.3). Iwata, Duncan, Zarcone, Lerman, and Shore (1994) described the pairwise FA, in which five participants were initially exposed to a multielement FA with various test conditions and one control condition, followed by a pairwise assessment. In the pairwise assessment a series of single-test FAs was conducted in which each test condition was alternated with the control condition. For two of the participants, both the multielement and pairwise FAs showed differentiated responding in one test condition. One participant showed cyclical, undifferentiated responding with both FA approaches. Finally, for the other two participants, the multielement FAs were undifferentiated, and clearer differentiated responding was observed with the single-test approach.

The single-test FA can be a more efficient application of the FA approach than conducting an exploratory FA in some circumstances. Whenever there is a strong hypothesis about the function from previous assessments (indirect and direct), it can potentially save time to only test one function, rather than test multiple functions in an exploratory FA. Although this approach may result in missing untested functions, studies have shown that single-test FAs can identify behavior function when they are the initial FA conducted (e.g., Fisher, Kuhn, & Thompson, 1998). Furthermore, the pairwise application can be useful when an initial exploratory multielement FA does not show clear differentiated responding in one condition. Studies have shown that pairwise analyses can result in a clear identification of function following an initially unclear multielement FA (e.g., Piazza et al., 1997).

Extended Alone

A variation of the single-test FA is the extended alone condition. In this variation, a series of alone (or ignore) sessions is conducted. The rationale behind this method is that if behavior is maintained by automatic reinforcement, responding will persist during the alone sessions. If behavior is maintained by social reinforcement, extinction will cause responding to decrease as the participant progresses through alone sessions. This approach can be employed to confirm a clear hypothesized function of automatic reinforcement, or when following a multielement FA, results are undifferentiated with responding occurring in all conditions (see bottom panel of Fig. 4.1). Querim et al. (2013) evaluated this approach and compared the results of the extended alone FA to full session-based FAs. Out of 30 cases, the prediction of function based on extinction or maintenance during the extended alone sessions had exact agreement with the function (social versus automatic) identified by the FA for 28 of the cases. It should be noted that although an extended alone condition can rule out automatic reinforcement and point to a social function, it does not identify the particular social function.

Trial-Based

Although the multielement FA introduced by Iwata and colleagues (1982/1994) was conducted in an analogue setting rather than in the natural setting, an analogue setting is not an essential feature of the FA approach. As such, Sigafoos and Saggers (1995) proposed the trial-based FA (which they referred to as the discrete trial FA), a variation of functional analysis methodology that increased access to (and potentially the ecological validity of) the experimental approach by embedding discrete trials into natural routines rather than conducting sessions in an analogue setting. The authors first described the use of the trial-based FA to assess the function of aggressive behavior in two children diagnosed with autism in a school setting. Each trial lasted 2 min and consisted of a 1-min test and control segment. Test segments were terminated upon the occurrence of problem behaviors. The results of a trial-based FA are reported as the percentage of trials in each condition in which the problem behavior occurred (see Fig. 4.4). The results obtained by Sigafoos and Saggers (1995) showed a higher percentage of trials with problem behavior during the social positive reinforcement condition (in the form of attention for one participant and tangibles for the other), suggesting that the trial-based FA could potentially identify the environmental variables responsible for maintaining

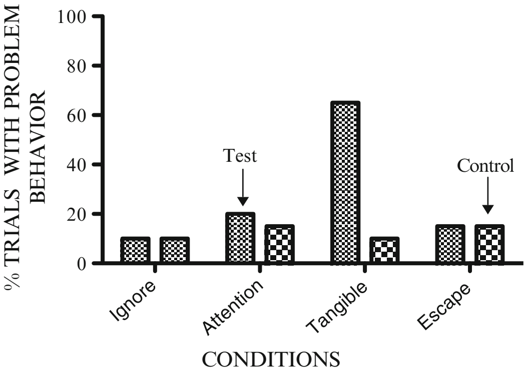

Fig. 4.4 Shows a trial-based functional analysis with four conditions

problem behavior. However, given that a treatment analysis was not conducted following the assessment it is unclear whether the functions identified were indeed correct.

Bloom, Iwata, Fritz, Roscoe, and Carreau (2011) expanded upon and further refined the trial-based FA methodology. The modifications to the trial-based FA proposed by Bloom et al. (2011) included a shift in the order of the test and control segments and extension of trial segments from 1 min to 2 min. Also, Bloom et al. proposed a test for automatically maintained problem behavior. Assessment trials were conducted by therapists in elementary school classrooms during naturally occurring opportunities. For example, free play in the classroom set the stage for tangible and attention trials and instructional periods facilitated escape trials.

During the control segments for attention, a moderately preferred item was available and the therapist provided non-contingent attention to the student. Instances of problem behavior did not produce any consequences. Upon the termination of the control segment, the test began with the therapist telling that student that he/she had "some work to do" and turning away. Contingent on the first instance of problem behavior, the therapist expressed concern (delivering attention) and terminated the test segment. The control segments for tangibles involved the therapist sitting near the student who had access to a preferred item. At this time, all instances of problem behaviors were ignored. Once the test segment began, the therapist removed the tangible item and kept it away from the participant for the remainder of the 2 min. Contingent on problem behavior, the therapist immediately returned the item to the student and terminated the segment. During the control segments for the demand condition, the student was seated in the absence of tangible items or task materials. As in the previous conditions, there were no programmed consequences for instances of problem behaviors. Immediately after the control segment, the test condition began with the therapist placing a demand and guiding the student to comply using least-to-most prompting (this can be modified if a different prompting strategy is used in the setting). If the student engaged in problem behavior, the therapist removed the demand and terminated the test. Lastly, during the ignore trials, the student was seated alone for back-to-back 2-min segments in the absence of preferred items or task materials. Instances of problem behaviors did not result in any consequences or terminate the segments.

Bloom et al. (2011) compared the results obtained by the trial-based FA to those produced by a multielement FA, showing that the outcomes generated by both assessments matched in 6 out of 10 cases or 8 out of 10 cases, depending on how the trials were conducted. These results suggest that the trial-based FA may be a practical approach when analogue functional analyses are not feasible. Since then, a number of studies have replicated the procedure and produced similar findings demonstrating the usefulness of trial-based FAs for identifying the maintaining consequences of problem behavior (e.g., Bloom, Lambert, Dayton, & Samaha, 2013; Lambert, Bloom, & Irvin, 2012; Rispoli, Davis, Goodwyn, & Camargo, 2013; Rispoli, Ninci, Neely, & Zaini, 2014). A few studies have also been conducted demonstrating approaches to teaching residential staff to conduct trial-based FAs (e.g., Lambert, Bloom, Kunnavatana, Collins, & Clay, 2013) and teachers (Kunnavatana et al., 2013; Kunnavatana, Bloom, Samaha, & Dayton, 2013).

Although a review of the trial-based FA literature conducted by Rispoli et al. (2014) reported 59 % perfect correspondence between the trial-based FA and the multielement FA, correspondence rose to 83 % when considering partial correspondence or correspondence following condition modifications It is not clear what factors account for this level of correspondence. Considering the fact that both approaches involve experimental manipulation of antecedents and consequences to show their influence on the problem behavior, both demonstrate a functional relationship between environments events and the target behavior. It is possible that differences can be accounted for by the location of the assessment (analogue versus natural environment), persons involved in the assessment (researchers versus caregivers), or the session format (percentage of discrete trials in which the behavior occurred versus rate of the problem behavior across a session). When a FA is conducted in an analogue setting, a behavior analyst attempts to incorporate into the FA conditions the relevant antecedent stimuli and consequences that are maintaining the behavior in the natural environment. The benefit of the analogue FA is the high degree of control over the experimental variables it affords. However, given that the trial-based FA systematically manipulates the contingencies maintaining behavior in the environment in which it naturally occurs, it may be more likely that an essential feature (e.g., EO, S^D, particular person) that controls the behavior in the natural environment may be present in the analysis. More research evaluating the trial-based FA in relation to analogue FAs is needed to establish the level of correspondence across populations, settings, and target behaviors and identify variables that might contribute to correspondence.

In conclusion, not only does the trial-based FA have high ecological validity as the trials are conducted when the context in the natural routine is appropriate for each condition, but it may also be extremely useful for behavior analysts working in settings where a separate secure location is not available or practical for an analogue FA (e.g., if a teacher in a school does not want a child to be removed from class for the purposes of an assessment).

Latency

Thomason-Sassi, Iwata, Neidert, and Roscoe (2011) proposed the use of latency as the dependent measure for conducting FAs. Using latency as the dependent measure could be advantageous in cases where problem behavior occurs at low rates, or when the behavior poses a risk to participants or others. It could also be useful when the occurrence of the behavior modifies the environment in a way that prevents recurrence of the behavior (e.g., property destruction or removing clothing), or when sessions must be terminated upon the occurrence of the behavior for safety reasons, as is the case with elopement. Thomason-Sassi et al. (2011) compared the results of latency FAs where the session was ended following the first response to multielement FAs using response rate. The results showed correspondence between latency and response rate in the FAs, that is, a short latency to respond corresponded with high response rates. The results show that the use of latency as the dependent variable can be a valid approach to conducting a functional analysis in some cases.

Davis et al. (2013) conducted a latency FA on the elopement behavior of an 8-year-old boy. The participant was exposed to a series of attention, escape, tangible, and play conditions in sessions that were terminated immediately after the consequence for elopement in each condition was delivered. The results of the latency FA showed differentially shorter latencies to elopement during attention and tangible conditions relative to the play condition. Following the latency FA, functional communication training (FCT) addressing the attention and tangible function was evaluated and the latencies to elopement were substantially longer than during baseline sessions. This study provided further evidence that latency can be a valid dependent variable in a functional analysis and treatment evaluation. Carr and Carlson (1993) and Kemp and Carr (1995) also showed the utility of latency to problem behavior as a dependent measure in evaluating treatment for problem behavior

Although limited, the current research supports the use of latency as a dependent measure during FAs that can help overcome practical obstacles when sessions need to be terminated following one occurrence of the target behavior.

Precursor Analysis

Another application of the FA approach that is useful when assessing the function of severe behavior that can endanger the participants or the investigators is the precursor FA. In situations in which a single instance of the target behavior would be dangerous or problematic, conducting an FA on precursor behavior provides a safe and effective approach.

Precursor behavior includes response topographies that reliably precede the target behavior and are often part of the same functional response class (Herscovitch, Roscoe, Libby, Bourret, & Ahearn, 2009). Smith and Churchill (2002) first applied the FA approach to precursor behavior. In the study, precursor responses of the target problem behavior were identified for all participants from caregiver reports and observation. The researchers conducted an experimental analysis with conditions similar to those used by Iwata et al. (1982/1994), initially with the contingencies in place for the target problem behavior, and then with the contingencies in place for the precursor behavior. For all participants, the FA on the problem behavior and the FA on the precursor behavior identified the same function. Additionally, during the precursor FA the problem behavior was rarely evoked.

A limitation of Smith and Churchill's (2002) study was that the precursors were identified in an unsystematic way that depended on self-report. Borrero and Borrero (2008) described a method for systematically identifying precursor responses. First, direct assessments (narrative recording) of the problem behavior and potential precursors were conducted. Then, the researchers calculated the conditional probability of problem behavior given a precursor (occurring within 10 s of each other), the conditional probability of a precursor given problem behavior (occurring within 10 s of each other), the unconditional probability of problem behavior, and the unconditional probability of a precursor. Finally, the authors performed a lag-sequential analysis to identify the probability of a potential precursor during each of the 50 s before and after problem behavior and the probability of problem behavior during each of the 50 s before and after a precursor. Herscovitch et al. (2009) expanded on the findings by Borrero and Borrero (2008) by employing conditional probability analyses to differentiate between several potential precursor responses. To make the process of identifying potential precursors more efficient, Fritz, Iwata, Hammond, and Bloom (2013) conducted a trial-based precursor assessment. During this assessment, the participants were exposed to a series of trials resembling the attention, escape, and tangible conditions in the FA conducted by Iwata et al. (1982/1994). The trials were terminated upon emission of the target behavior, limiting the number of occurrences of the severe problem behavior. Following the trials, potential precursor responses were operationally defined and recorded from the videos using a checklist that categorized responses based on topography as either (a) vocalizations, (b) facial expressions, (c) postures, (d) repetitive motor movements, (e) locomotion, (f) object manipulation, and (g) other problem behaviors. The authors then calculated a series of conditional and unconditional probabilities to identify precursors to the target behavior.

In addition to improving methods for identifying precursor behavior, support for the utility of conducting FA on precursor responses has also grown. A number of studies have demonstrated that FAs conducted on precursor behavior typically agree with FAs conducted on the target problem behavior in the function identified (Borrero & Borrero, 2008; Herscovitch et al., 2009; Smith & Churchill, 2002). This high correspondence suggests that the precursor and the target behavior are members of the same response class. This conclusion is further supported by the findings that when the contingencies are placed on the precursor during the FA, the target problem behavior occurs less frequently, (Borrero & Borrero, 2008; Dracobly & Smith, 2012; Smith & Churchill, 2002) and that functional treatments (DRA) addressing the reinforcer identified as maintaining the behavior by precursor FAs decreased both the target behavior and precursor behavior (Dracobly & Smith, 2012; Langdon, Carr, & Owen-DeSchryver, 2008). Overall, the effectiveness of functional treatments based on FA of precursor behavior and the high correspondence with session-based FAs of the target behavior makes precursor FA a promising assessment method for socially mediated problem behavior.

Biological Influences

When conducting a functional assessment, if there is any reason to believe that the target behavior is influenced by medical or biological variables, behavior analysts should recommend a medical consultation to identify or rule out the influence of such variables (BACB guideline 3.0) and arrange medical treatment if necessary. The influence of biological events on behavior has been shown in a few studies (e.g., Bramble, 1995; O'Reilly, 1997). For example, Bramble (1995) described two cases where rhythmic movement disorder, a sleep disorder consisting of stereotypical behaviors (head-banging and body-rocking) occurring around or within a sleeping period, had an onset correlated with ear infections in early childhood for both boys. It may be that the ear infections were contributing factors for the development of the behavior disorder.

Kennedy and Meyer (1996) evaluated the effects of allergy symptoms and sleep deprivation on the rates and function of escape-maintained problem behavior of three participants. Through indirect and direct assessments, the presence of allergy symptoms was identified as an event related to higher rates of problem behavior for one participant, and sleep deprivation was identified as an event related to higher rates of problem behavior for the other two participants. The researchers conducted FAs both in the presence and absence of the related events (allergy symptoms and sleep deprivation). The results of the FAs indicated that for one participant, problem behavior was maintained by escape only when allergy symptoms were present. For the second participant, escape from demands was identified as the maintaining variable both with and without sleep deprivation; however, the rate of problem behavior during the escape condition was higher when the participant was sleep deprived. For the final participant, escape from demands was identified as the variable maintaining her problem behavior when she was not sleep deprived, however, when she was sleep deprived, her results were undifferentiated with problem behavior occurring across all conditions.

In another example of biological setting events, Carr, Smith, Giacin, Whelan, and Pancari (2003) evaluated the effects of menstrual discomfort on the assessment and treatment of severe problem behavior. The investigators conducted a comprehensive assessment, consisting of interviews, record review, direct observation, and functional analyses. The assessment indicated that problem behavior was related to menstrual discomfort (cramping, fatigue, backache, and upset stomach) and task demands. Specifically, the problem behavior occurred in the demand condition of the functional analysis, but almost exclusively when the women were experiencing their menses. Demands did not evoke problem behavior when they were not experiencing their menses. The authors implemented a multicomponent intervention that addressed both the biological setting event (providing non-drug treatment in the form of heat pads or added rest time contingent on indicators of pain) as well as the escape function (noncontingent reinforcement, FCT to request breaks or assistance with tasks, choice, and redistribution and embedding of demands) which reduced the problem behavior in three participants.

These studies demonstrate that not only should biological factors be considered before conducting an FA, but that biological factors can be considered as potential EOs for problem behavior. They demonstrate that biological factors can influence problem behavior in some contexts but not others, further supporting the usefulness of the FA to understand the interplay between biological factors and contingencies of reinforcement.

Interpreting Results

One interprets the results of a functional analysis by looking for separation in the data paths between the test and control conditions. The rate or percentage of intervals with problem behavior is typically graphed on the y-axis and the number of sessions on the x-axis. Functional analysis results are commonly graphed in multielement or reversal design and interpreted through a visual analysis (Beavers et al., 2013). Perhaps the most important criterion for accurately interpreting the results of functional analyses is ensuring that each test condition is independently compared to the control condition. An elevated rate of behavior in a single test condition compared to the control condition is said to display differentiated responding (aka, separation in the data). For example, high rates of behavior in the attention versus the control condition would be indicative of behavior maintained by social positive reinforcement in the form of attention. Conversely, undifferentiated responding is established when similar rates of behavior are seen across all conditions. Lack of separation in the data may be indicative of poor discrimination between the conditions or suggest the behavior is maintained by automatic reinforcement. A review of the functional analysis research conducted by Beavers et al. (2013) reported that 94 % of the graphs in the studies surveyed showed differentiated responding.

Although authors put forth suggestions for interpreting different patterns of responding as indicative of a particular function (e.g., Iwata et al., 1982/1994), the traditional visual inspection approach is subjective and may be affected by the rater's experience and knowledge and may not be as reliable as it is widely assumed (Hagopian, Fisher, Thompson, & Owen-DeSchryver, 1997). Consequently, Hagopian et al. (1997) demonstrated the need and put forth objective criteria for interpreting FA results. The researchers first had three predoctoral interns interpret 64 FA graphs, and found low inter-rater agreement (0.46). Then, a panel of experts interpreted the same graphs and developed criteria for interpreting FA results (see Hagopian et al., 1997), which resulted in high agreement with the expert panel's interpretation (0.94). Finally, after being trained on the criteria, the agreement on the interpretation by the predoctoral interns increased substantially (0.81). Given the results of this study, it is important for a well-trained behavior analyst to conduct the FA and interpret the results. Furthermore, it may be appropriate, particularly when the behavior analyst interpreting the results of an FA has limited experience, to use the criteria proposed by Hagopian et al. when analyzing FA results.

Within-Session Analysis

Another strategy for interpreting functional analysis results is to analyze within-session patterns of responding. This approach might be useful if there is no separation in the data between test and control conditions during the initial functional analysis sessions. If the rate of problem behavior increases across the session in a test condition, it may indicate the effects of reinforcement and if the rate of problem behavior decreases across the session in a different test condition or control condition, it may indicate an extinction effect. Therefore, when the rate is similar in test and control conditions, within-session patterns may provide some evidence of whether the consequence functioned as a reinforcer (e.g., Vollmer et al., 1995). Figure 4.5 shows the results of a within-session FA in which the behavior is elevated in the attention condition but also in the alone condition that follows. However, the pattern in the alone condition suggests that there may be an extinction effect following carry over from the prior attention condition.

Cooper, Wacker, Sasso, Reimers, and Donn (1990) conducted a functional analysis and then conducted a min-by-min analysis (graphed as the percentage of occurrence of appropriate behavior during each min) of the condition with the highest and lowest percentages of appropriate behavior in order to establish stability in responding within each condition. Their findings demonstrated the utility of performing a within-session, min-by-min analysis of assessment conditions, and suggested that 10-min sessions may be necessary to achieve stability in responding within a session.

Northup et al. (1991) performed a within-session, min-by-min analysis during the contingency reversal phase of the brief FA. Their analysis consisted of graphing the cumulative number of intervals with problem behavior (aggression) and appropriate behavior (sign) across min of the session. The trends in the within-session analysis supported the conclusions drawn from the full session.

Vollmer, Iwata, Zarcone, Smith, and Mazaleski (1993) expanded on the study by Northup et al. (1991) by conducting a min-by-min analysis of all assessment conditions (the first several sessions in a complete multielement FA), and comparing the results of the brief min-by-min assessment to the complete multielement FA for four participants. For the three cases in which the full-length FA produced differentiated responding

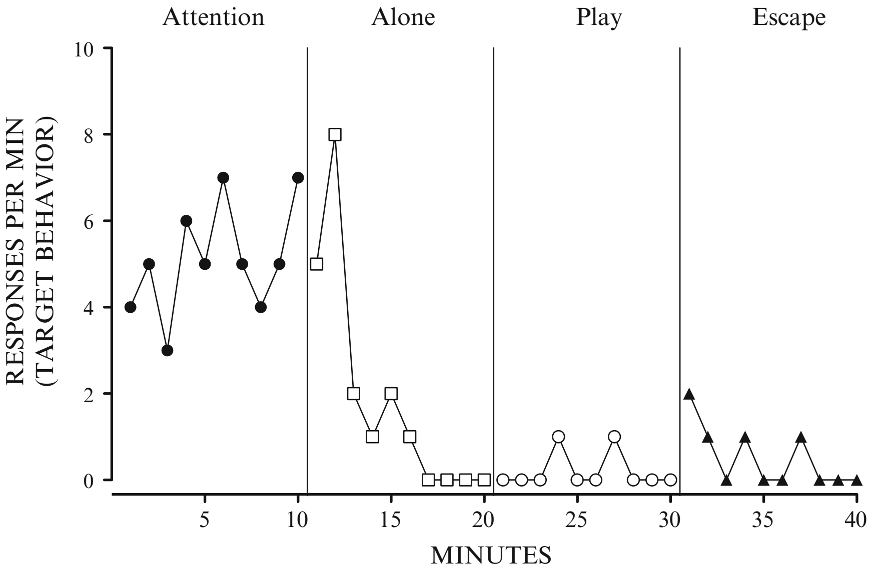

Fig. 4.5 Shows a within-session functional analysis with four conditions

indicating a function of behavior, the within-session min-by-min analysis also identified a corresponding function. These results suggest that conducting a within-session min-by-min analysis can be an efficient way to identify the function of behavior that can make the process quicker than a full-length FA.

Additionally, the authors make the case that analyzing within-session patterns of responding could be useful even when conducting full-length session-based FAs. In the one case in which the full-length FA did not produce differentiated responding in any particular condition, the brief within-session analysis was indicative of an attention function. Although it was unclear whether this was a false positive during the brief assessment, conducting a within-session analysis of the full-length FA that continued to show bursts of responding throughout attention conditions would have strengthened the interpretation of an attention function.

Conclusion

We begin this chapter by making the case for the importance of conducting a functional assessment to identify environmental determinants of problem behavior in order to develop functional interventions. We then review three functional assessment approaches: indirect assessment, direct assessment, and functional analysis. Ultimately, there are two reasons to conduct a functional assessment: one is to produce information on antecedents and consequences that can be used to design functional interventions and the other is to identify a functional relationship between one or more environments events and the target behavior when doing so is essential for research purposes.

When conducting a functional assessment to produce information needed for developing functional interventions, the behavior analyst starts with an indirect assessment, the outcome of which is a hypothesis about the antecedents and consequences that are functionally related to the behavior. The functional assessment is never complete with just an indirect assessment; the behavior analyst must conduct a direct assessment to gather more information or conduct a functional analysis to confirm the hypothesis from the indirect assessment. The goal is to find correspondence between the results of the indirect and direct assessment or between the results of the indirect assessment and functional analysis. When there is correspondence between two approaches, the behavior analyst can use the information to develop functional interventions. The success of the intervention is more evidence that the correct function of the problem behavior was identified in the functional assessment.

If the hypothesis from an indirect assessment does not correspond to the hypothesis from the direct assessment, the behavior analyst has to take steps to resolve the conflict. This may involve further indirect and direct assessment to see if correspondence can be achieved or it may involve a functional analysis. Using one of the functional analysis methodologies described in this chapter, the behavior analyst will manipulate antecedents and consequences to identify the specific variables controlling the behavior.

ABA research demands a higher level of "proof" than does the application of ABA in clinical practice. Researchers must demonstrate experimental control (a functional relationship) by showing that the independent variables (environmental events) they manipulated produced changes in the dependent variables (the target behavior). In the course of conducting research, the behavior analyst may seek to demonstrate a functional relationship between antecedents and consequences and the target behavior to better understand the events that influence the target behavior or to develop the functional interventions to be evaluated. In either case, the behavior analyst must employ a functional analysis as this is the only functional assessment approach that can demonstrate a functional relationship.

Because conducting a functional assessment is an integral part of a behavior analyst's practice, behavioral clinicians should ensure that they have the appropriate training and supervised experience to conduct each of the functional assessment methods and to design functional interventions for problem behavior based on the information derived from the functional assessment. We believe individuals trained in behavior analysis (specifically in the functional approach to assessment and intervention) should oversee the process of conducting functional assessments and developing functional interventions. Designing and implementing functional assessments and functional interventions requires a conceptual understanding of behavioral principles, not just training in how to conduct the procedures. Understanding the concepts and principles of behavior analysis is necessary for interpreting functional assessment results and designing interventions consistent with the behavioral processes unique to the client, the target behavior, and the context. This level of understanding cannot be developed through workshops or in-service training but must come from an academic program that integrates coursework, research, and supervised practice in applied behavior analysis.

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Preference Assessments for Clinical Decision Making

5

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Introduction

The Oxford English Dictionary offers us two definitions of preference that are relevant to this chapter:

1. The action of or an act of preferring or being preferred; a greater liking for one alternative over another or others; predilection and
2. The object of prior choice; that which one prefers.

Schwartz and Baer (1991) suggested that choice was the fundamental behavioral definition of preference. While perhaps lacking in the richness of qualitative description, such a conceptualization affords clinical and experimental utility through precise quantification, comparison, and scaling. In this chapter, we review procedures that have been used to assess preference. Most of the included literature involves individuals with intellectual and developmental disabilities (IDD), though the procedures may be reasonable whether the subject of study has some language deficit, if we are perhaps dubious of their statements, or if we simply require additional and compelling evidence.

When asked about our own preferences, we may have a tendency to speak generally and identify things that are robust against moment-to-moment variance. But formal assessments of preference tend to produce answers that depend on a number of contextual variables including the nature of the assessment, the availability of alternatives, as well as relevant motivating operations and the effort required to obtain the thing in question.

Historically, some authors have made a distinction between one's preference for a stimulus and its reinforcing value based on the effort required to obtain it (DeLeon & Iwata, 1996; Fisher et al., 1992; Pace, Ivancic, Edwards, Iwata, & Page, 1985). That is, the term preference has sometimes been confined to describe the outcome of a procedure in which one or more choices are available and some low-effort behavior such as reaching toward or otherwise approaching an item is assessed. In this sense, preference assessment methodology evolved toward abbreviated methods from which to identify a stimulus likely able to improve some clinically meaningful behavior. A common template for such research has involved the comparison of data generated from two phases: a brief preference assessment, and a longer reinforcer assessment that may (or may not) validate results from the preference assessment (Fisher, Piazza, Bowman, & Amari, 1996).

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Later, some researchers began to show that preference may change depending on effort and ultimately argued for the assessment of stimuli using more than one level of effort, an approach more akin to that typically associated with reinforcer assessments (DeLeon, Iwata, Goh, & Worsdell, 1997; Tustin, 1994). Further, some important methodological improvements in preference assessments, such as the use of concurrent-chains procedures, have features of both preference and reinforcer assessments. What is clear is that both of these procedures can provide useful clinical information and that discussion of both is necessary to provide a full picture of stimulus evaluation procedures available to clinicians. Thus, despite a historical distinction, we will consider both the assessment of preference and reinforcer value for the purposes of this chapter as they share similarly important roles in the selection and evaluation of stimuli for clinical decision making.

In addition to gathering evidence about whether a particular stimulus is preferred, sometimes it may be clinically valuable to know if a stimulus is not preferred and by how much. Parallel to the development of methods for the identification of appetitive stimuli, a less visible line of research has focused on the identification and description of aversive stimuli. Methods for identifying aversive stimuli are often omitted in reviews of preference assessment methods, yet they often differ substantially from their more familiar cousins while being no less clinically relevant. Thus, we will briefly consider them as well.

Reasons for Evaluating Preference

As stated above, one reason for conducting a preference assessment is to identify an item likely to function as a reinforcer. For things like toys or food that can be presented in groups or pairs on a table, preference assessments lead to rapid identification of items likely to function as reinforcers. In this case, the assessment serves as a clinical tool to inform and improve other parts of interventions (e.g., Graff, Gibson, & Galiatsatos, 2006; Repp, Barton, & Brulle, 1983). For this purpose, it is sometimes helpful to distinguish between procedures that identify something as preferred (i.e., yes or no) as compared to those that can identify the degree to which it is preferred. The former tend to be useful as a first step when selecting among a large set of stimuli, while the latter procedures tend to be more involved, but essential when one needs to obtain a ranking for a set of stimuli or to identify a stimulus with some specific level of preference (e.g., the most preferred, but see also McCord & Neef, 2005, for a discussion of considerations when including lower preferred stimuli in assessments).

Other times, assessments are built into learning routines or interventions as important consequences in their own right. Here, the therapist is often less concerned about the particular choices of the participant and more concerned with the effect the choice has on preceding behavior (e.g., that it serves as a reinforcer, see Lerman et al., 1997).

Another reason to incorporate preference assessments into clinical routine is to improve an intervention's acceptability to its consumers, their family, and society at large (Wolf, 1978). Schwartz and Baer (1991) suggested that an intervention's social validity might be expressed by the range of alternatives the client rejects in favor of the one under consideration. Green, Gardner, and Reid (1997) and Green and Reid (1996) reported that including preferred stimuli in clients' daily programs is associated with increases in indices of happiness. In addition to the direct opinions of the clients, Parsons and Reid (1990) found that staff believed allowing clients to choose their own food was important. As per BACB Guidelines for Responsible Conduct 2.10d, client preference should be considered when selecting interventions (Behavior Analyst Certification Board (BACB), 2013) and there is no reason to believe that client preference should not be a consideration for the components of those interventions.

Finally, we may offer individuals choices because we believe that individuals have the right of self-determination (Reid, Everson, & Green, 1999). That is, individuals have a right to choose what they do during the day, whether and what kind of employment they might have, and how to spend their leisure time. For example, Van Houten et al. (1988) argued that individuals have a right to a therapeutic environment that includes access to enjoyable leisure activities. Van Houten et al. suggested that client preference should be considered when selecting items and activities to be part of the therapeutic environment. Because such choices are no less important and are likely governed by the same kinds of relations that govern other kinds of choices, we have a responsibility to bring to bear the considerable technology and empirical findings at our disposal to use the best means available for providing such choices.

Providing the opportunity to choose, and incorporating client preference, represents a means to ensure the exercise of personal liberty for persons with disabilities in the context of habilitative services (Bannerman, Sheldon, Sherman, & Harchik, 1990). Bannerman et al. recommended using preference assessments as a means of incorporating client input regarding how they will be taught, as well as a framework for including client choice regarding what they will be taught. They argued that to do so will not only honor the rights of persons with disabilities, but will improve the effectiveness of training procedures by raising participation levels and task performance accuracy, as well as reducing problem behavior in learning contexts.

Selecting Stimuli to Assess

A variety of different approaches have been developed to systematically identify preference. All of these approaches begin with the therapist making a decision on what sorts of things to assess. Usually, this is largely governed by the purpose the stimuli are to serve. For example, choosing a stimulus for delivery during an instructional context may necessitate convenience (e.g., food or a small toy; see Fisher et al., 1996) or possibly be driven by the behavior being targeted (e.g., an intervention to increase social skills may work better if it is a preferred form of social interaction). One documented approach is to choose stimuli from a wide variety of categories. For example, both Pace et al. (1985) and Fisher et al. (1992) included two stimuli from each of eight categories: food, visual, auditory, temperature, vestibular, social, and olfactory. Using an approach like this might increase the chances of identifying at least one preferred stimulus, although other research has found that including stimuli from more than one category tends to increase sensitivity to inter-category differences at the expense of intra-category differences (e.g., food may often be more preferred than activities; see DeLeon, Iwata, & Roscoe, 1997 and Bojak & Carr, 1999).

Assuming that the therapist has identified the sorts of stimuli to assess, the next step is usually to obtain a list of such stimuli for evaluation. Of course, one should always consider asking the client themselves (e.g., Barrett, 1962). Otherwise, if the client does not possess adequate language skills, this step may involve formal or informal interviews with caregivers (e.g., Parsons & Reid, 1990; Rincover & Newsom, 1985). Caregivers can often prove to be a valuable source of information regarding activities and items clients prefer, especially if the purpose is only to obtain a preliminary list (Green, Reid, Canipe, & Gardner, 1991). Fisher et al. (1996) evaluated clients' preferences for stimuli selected from a standard list against those selected using the Reinforcer Assessment for Individuals with Severe Disabilities (RAISD), which is a structured interview administered to those familiar with the individual being assessed. Alternatively, some have attempted to select stimuli based on their formal similarity with an individual's stereotypy (Rincover, Newsom, Lovaas, & Koegel, 1977). Although Rincover et al. identified effective reinforcers for each participant, formal similarity to a participant's stereotypy did not prove to be a useful predictor.

Two systematic approaches for identifying stimuli to include in preference assessments were described by Kelly, Roscoe, Hanley, and Schlichenmeyer (2014). Kelly et al. were specifically interested in identifying preferred forms of social interaction with individuals with autism spectrum disorder (ASD). Because a hallmark of the disorder includes social deficits, identifying preferred forms of social interactions for individuals with ASD might be difficult, or at best, idiosyncratic. Therefore, the authors used three methods for identifying potential forms of social interactions: a self-developed questionnaire for caregivers, making direct observations of clients interacting socially with others across a variety of different activities, and observing whether and what kind of attention clients requested. After successfully identifying preferred forms of social interactions that were later validated to function as reinforcers, the authors cited the preliminary assessments as a critical step.

After obtaining a preliminary list of stimuli to be evaluated, the next step is to rank them according to relative preference or value. When attempting to find a reinforcer, often we are interested in finding the most effective reinforcer from our preliminary list. Occasionally, we might be interested in finding a stimulus that is only of moderate or low preference (i.e., something that is at least approached occasionally). Such stimuli might be beneficial when we do not want the interaction with the stimulus to compete strongly with ongoing activities or social interaction. For example, the attention condition in functional analyses often includes preferred items, but it is important that preference for such items be assessed because it has been shown that inclusion of highly preferred items can suppress attention-maintained problem behavior, leading to a false-negative outcome (Roscoe, Carreau, MacDonald, & Pence, 2008).

In the rest of this section, we review preference assessment methods beginning first with indirect approaches, moving on to direct approaches, providing discussion of adaptations to assess particular kinds of stimuli, and then provide some methods of conducting reinforcer assessments.

Indirect Assessment: Verbal Report and Questionnaires

The simplest approach is to ask clients or caregivers about the types of stimuli that are preferred (Barrett, 1962; Cautela & Brion-Meisels, 1979; Fantuzzo, Rohrbeck, Hightower, & Work, 1991). Asking takes little time, but unfortunately, it does not always produce reliable or accurate information about preference (Lockhart, 1979) or identify stimuli of useful treatment utility (Northup, Jones, Broussard, & George, 1995). In addition, there are many reasons to be dubious of self-reported preferences. For example, correspondence between self-reports and behavior (say-do correspondence) in typically developing children is low (Guevremont, Osnes, & Stokes, 1986; Risley & Hart, 1968). Moreover, hierarchies of stimulus types obtained verbally may not match those obtained using experiential approaches (cf. DeLeon, Iwata, & Roscoe, 1997; Fantuzzo et al., 1991). Yet the lure of an easily administered approach for identifying preference has not stopped investigators from looking. The appeal of simply asking someone what they like and, conversely, what they do not like is that it seems faster, easier, more cost-effective, and works for a variety of stimulus types (e.g., snacks vs. trips to the zoo). The problem is that all those benefits depend heavily on the validity of verbal report, which has been questioned.

Cautela and Brion-Meisels (1979) evaluated the Children's Reinforcement Survey Schedule (CRSS) in typically developing elementary-aged school children. The instrument consists of 25 items that participants rate on a 3-point scale: *dislike*, *like*, and *like very much*. The authors found only moderate test–retest reliability ($r=0.48$–0.72), with children in older grades showing greater reliability. Daly, Jacob, King, and Cheramie (1984) later assessed the correspondence between teacher- and student-identified items in fifth and sixth graders using the CRSS. They found that correspondence between teachers and students was low ($r=0.32$; range 0.01–0.61).

Green et al. (1988) evaluated staff opinions of client preferences for 12 different stimuli using a 5-point Likert-type scale ranging from 5 (most preferred) to 1 (least preferred). However, when the survey results were converted to rankings for each participant and compared to the results of a single-item approach assessment (described in more detail below), the resulting correlations ranged from −0.33 to 0.11 across the seven clients. These results suggest caregivers do not reliably rank items according to client preferences. A systematic replication by Green et al. (1991)

found statistically significant correlations between staff opinions and client preferences, but for only two out of six participants. Thus, results from these studies suggest that staff may not reliably identify preferred items.

Northup et al. (1995) examined preference for items in an array of toys by presenting the array and asking children diagnosed with Attention Deficit Hyperactivity Disorder (ADHD), “Of all the toys, which one is your favorite?” (p. 99). Northup et al. then compared the identified items to one in which they asked participants to select between two toys at a time, “Would you rather play with [Toy 1] or [Toy 2]?” Although both procedures resulted in the identification of “preferred” items, results of the two procedures had relatively low correspondence (correlations ranged from 0.3 to 0.4).

Fisher et al. (1996) compared client preference rankings obtained using a paired-stimulus procedure to opinions obtained from caregivers using the RAISD. The authors found statistically significant correlations with stimuli that were identified by the caregivers ($r=0.32$), but not for the standard stimuli. One interpretation of the results that also helps to explain the results of Green et al. (1988) and Green et al. (1991) is that caregivers might occasionally predict client preferences for stimuli with which they are frequently observed to interact, but they are unlikely to do so for stimuli arbitrarily identified by an experimenter.

More recently, person-centered planning approaches have gained popularity and attempt to highly weigh clients’ interests when selecting programs and interventions. However, Reid et al. (1999) found that in person-centered plans for four participants, only 33 % of the items mentioned were identified as highly preferred using direct assessments. Thus, results of direct assessments should be weighted more heavily than staff opinion. Northup (2000) examined the accuracy of a reinforcer survey consisting of 42 items rated on a 3-point scale: *not at all*, *a little*, or *a lot*. Results from the survey were then compared to the results of a reinforcer assessment. Correspondence between the survey instrument and the reinforcer assessment was low (57 %).

Despite consistent findings that results from verbal report and questionnaire methods may be enhanced by doing such things as arranging participants to state their preferences between two options at a time, by having the stimuli present (or pictures of the stimuli, e.g., Wilder, Ellsworth, White, & Schock, 2003), or by using older participants (e.g., Bernstein, 1986, Cautela & Brion-Meisels, 1979), ultimately the results may still be of questionable value as they suffer from problems of inter-rater reliability, test–retest reliability, and validity. On the other hand, depending on one’s purpose for assessing preference, the methods may be justifiable. For example, Northup, George, Jones, Broussard, and Vollmer (1996) found that a verbal-choice procedure (in which participants were simply asked to state their preference between two stimuli that were not present) had a false-positive rate of 31 %, meaning that for every ten stimuli identified as preferred, approximately three were unlikely to function as effective reinforcers. A similar false-positive rate was reported by Northup (2000). Similarly, although Cote, Thompson, Hanley, and McKerchar (2007) found that teacher-identified items did not correspond well with the results of direct preference assessments conducted with typically developing preschool children ($r=-0.06$); the teacher-identified items still functioned as reinforcers, but they were less effective than those identified using the direct assessment (see also Schanding, Tingstrom, & Sterling-Turner, 2009). In conclusion, verbal report may suffice if the goal is simply to identify one or more candidate stimuli to be evaluated with more scrutiny later. However, such approaches should not be relied upon as a stand-alone method of assessment due to their low reliability and validity.

Direct Approaches to Preference Assessment

Another approach is to directly observe individuals as they interact with stimuli in their environment. Stimuli with which individuals voluntarily interact are assumed to be preferred over stimuli with which they do not interact. Durations of item interaction can be compared, producing hierarchies of preference (e.g., Kelly et al., 2014). A limitation of this approach is that it only includes stimuli currently present in the environment. If the environment includes minimal stimuli, the range of stimuli assessed will also be limited. It is also possible that a single item may be very preferred, and may consume large quantities of time, either resulting in little information being gathered about the other stimuli present, or extended observations.

Another strategy involves systematic presentation of a variety of stimuli and recording some measure of selection or item interaction. Typically when items are selected, an interaction period is permitted before the next stimulus or set of stimuli is presented. This way, selecting an item results in an opportunity to interact with that item and it is presumed that only items with which the subject wishes to interact will be selected. This approach can be an efficient means to get information about preference for a wide variety of stimuli. The approaches described below have different strengths and weaknesses and are appropriate for different situations.

Single-Stimulus Approach

The single-stimulus approach involves presentation of a series of stimuli, one at a time while a therapist measures the subject's approach or lack thereof (Pace et al., 1985). Once an item is approached, the subject is permitted to interact with it for a period of time (e.g., 5 s). Pace et al. repeated the process ten times for each of 16 stimuli, drawn from a number of stimulus classes (auditory, edible, kinesthetic, olfactory, social, tactile, thermal, and visual). Data on the percentage of trials each stimulus was approached were presented as an index of preference. When Pace et al. measured the effectiveness of high-preferred stimuli versus low-preferred stimuli when delivered as a consequence for a response, they found a correlation between preference and reinforcer effectiveness. The single-stimulus approach provides information about whether or not the subject prefers a stimulus over nothing. However, when items are presented by themselves, there may be no disincentive for approaching them, so long as they are not aversive. That is, the question becomes, would you rather interact with this item or do nothing? In the data reported by Pace et al., five of the six participants approached two or more items 100 % of the time. In some cases, an individual will always approach particular stimuli, and never approach others. This procedure may result in hierarchies with some stimuli at 100 % and others at 0 %, with no means to differentiate the relative degree of preference for those stimuli always selected.

Although the single-stimulus preference assessment was designed to identify preferred stimuli, under some circumstances it may also be useful to know which items are never approached. Because failure to approach an item suggests that the subject prefers having nothing over interacting with that item, items approached on 0 % of trials may be assumed to be low quality or possibly even aversive. Single-stimulus preference assessments have been used for this purpose. For example, Bourret, Iwata, Harper, and North (2012), and Koehler, Iwata, Roscoe, Rolider, and O'Steen (2005) both used single-stimulus preference assessments to identify low-quality or nonpreferred stimuli.

In order to conduct a single-stimulus preference assessment, a list of potentially preferred items should be identified. Individuals who regularly interact with the subject may be queried, items may be selected from the subject's environment, or both. Then, a space should be prepared that is free of distraction or other items in the same class as the items included in the assessment. Each of these items should be presented in isolation, and an opportunity to approach the item presented should be provided on each trial. In some cases, a prompt is provided to the participant indicating that he or she can approach the item if desired at the beginning of the trial, (e.g., "You can have it if you like."). Care should be taken to not provide a demand to the participant to approach the item, lest approach responses come under control of the prompt rather than features of the approached item. The duration of the opportunity to approach should be consistent across trials. For example, each trial can start with a 5-s opportunity to approach the item. Whatever duration for this opportunity is used, care should be taken to ensure that the subject's motor skills would reasonably permit an approach response during that opportunity. For example, longer opportunities might be provided for individuals with less efficient motor skills. Approach should result in access to the item, as a natural consequence of reaching for it and the nature of the interaction with the item can vary depending on the nature of the item. In the case of an edible item, the participant should be permitted to consume the item. Small quantities of edible items should be available on each trial to minimize the impact of satiation across trials having an effect on the outcome of the assessment. In the case of nonedible items, like leisure materials, a standard duration of access should be provided following each approach. This duration can vary. For example, Pace et al. (1985) used only 5 s, but longer durations can also be used, such as 30 s or 1 min, as long as the duration is held constant across trials. The nature of the items being assessed may lend themselves better to shorter or longer durations. Then, the item should be removed, marking the end of that trial. Another trial can begin immediately, with the presentation of a new opportunity to select another stimulus. After each stimulus has been presented once, the process is typically repeated multiple times. Data are collected on each trial, indicating whether or not the subject approached the available item. The percentage of times the stimulus is selected in the assessment is calculated by dividing the number of times each stimulus was approached (the numerator) by the number of times it was presented (the denominator) and multiplying the resulting value by 100. Typically, this percentage for each stimulus is graphed on a histogram with each bar representing a different stimulus.

The information gained from a single-stimulus preference assessment is adequate when the goal of the assessment is to identify an item that is not aversive and that is preferred over nothing. However, if the goal of the assessment is to identify the relative preference for one item over another, the single-stimulus preference assessment may not yield the desired information, despite the hierarchies obtained by Pace et al. (1985), which relied on variation of approach versus non approach across trials for each stimulus. If such variation does not exist, approach percentages may cluster around 100 and 0 % (Mazaleski, Iwata, Vollmer, Zarcone, & Smith, 1993). Opportunities for selection in the single-stimulus approach are between a single item and nothing and, as such, are not ideally suited to determine preference differences across stimuli. In order to obtain a preference hierarchy, it is useful to include opportunities to select between concurrently available stimuli. Finally, because "better than nothing" is such a low bar, items identified as "preferred" by single-stimulus approaches may not necessarily function as reinforcers (Paclawskyj & Vollmer, 1995).

Paired-Stimulus Approach

One approach of differentiating between stimuli that is more sensitive than Pace et al.'s (1985) single-stimulus approach is to present stimuli in pairs until every stimulus has been presented with every other stimulus. The procedures for doing so are very similar to those described above except that two items are presented concurrently (and every stimulus is presented along with every other stimulus at least once, and always an equal number of times), instead of one at a time, and a subject is prompted to select between the two. Attempting to select both simultaneously is blocked, but all other procedural details described above are also relevant to this approach.

Fisher et al. (1992) compared this approach (which they referred to as a forced-choice procedure) to the single-stimulus approach using 16 stimuli across the same eight classes as those investigated by Pace et al. (1985). Replicating the results of Pace et al., Fisher et al. found that the single-stimulus approach failed to differentiate between at least two stimuli in each of the eight participants. More importantly, Fisher et al. found that the paired-stimulus (PS) procedure allowed for differentiation between those highly preferred stimuli. Thus, the main advantage of the paired-stimulus preference assessment (PSPA) over the single-stimulus preference assessment is the production of a hierarchy of preference. Because the subject has the opportunity to choose between each stimulus as presented with every other stimulus, a hierarchy that shows the degree to which each stimulus is more or less preferred than the other stimuli included in the assessment is produced.

However, one disadvantage of the PSPA is the number of trials, and ultimately time, required to conduct it. Presenting each of the 16 stimuli that were used in Fisher et al. with each of the others requires 120 total trials. Although Fisher et al. provided access for only 5 s, more recent studies have used a minimum of 30 s. Thus, the procedure might take up to an hour using more recent standards of access. Of course, the total assessment time can be reduced by including fewer stimuli and including stimuli that are reportedly preferred (e.g., through caregiver interviews) may decrease the likelihood of not identifying a preferred item.

More generally, a disadvantage of the PS approach (including approaches involving choices between more than two options) as compared to the single-stimulus approach is that its success depends on the participants' skill-level insofar as they are able to examine the available options. The absence of such skills may be visible if no clear preference emerges among a wide variety of stimuli. In such cases, a single-stimulus approach may be more reasonable. Another disadvantage is that the necessity of removing and withholding stimuli following each trial may result in the occurrence of problem behavior (Roane, Vollmer, Ringdahl, & Marcus, 1998).

At this point, it may be useful to include a note about position-biased responding, or side bias. Some individuals tend to select exclusively from either the left or the right position. If a stimulus is always presented on the right or the left, variations in selections may be under control of the side bias, rather than the features of the stimuli presented. This represents a serious concern when the information gleaned from the preference assessment is inaccurate and clinical interventions are developed that depend on accurate information about relative preference for one stimulus over another. For example, if contingencies are arranged to favor a desirable behavior without extinction for problem behavior (in situations in which extinction is contraindicated), it is important to know which stimuli are of high quality so that they can be provided for desirable behavior over other stimuli of low quality that are concurrently available for undesirable behavior. Side biases can be detected by using data sheets that include a feature to indicate the side on which each stimulus should be presented each trial. The data sheet can have names or representative numbers presented on the left or the right and these positions can correspond with the positioning of both stimuli during each trial. Each stimulus can be presented on either side an equal number of times, in the sequence indicated by the data sheet. Then, data collectors can circle the stimulus (or the number representing the stimulus) selected and if all selections are made on one side or another, it will be easily detected by visual observation of the distribution of circled names or representative numbers on the data sheet.

Bourret et al. (2012) attempted to eliminate side bias in five individuals with disabilities who typically selected from one side to the exclusion of the other during choice opportunities. Three of their subjects began to select from either side when one of the two stimuli presented was of known poor quality (i.e., non-preferred as identified during a single-stimulus preference assessment in which they were never approached). The remaining two subjects' selections continued to be under the control of position instead of stimulus quality. These two subjects were also exposed to a condition in which more of a stimulus was available on one side versus the other. Magnitude differences also failed to produce selections towards the unfavored side. Unbiased selections were produced following the inclusion of an error correction feature in which selection towards the side associated with bias were blocked and the participant was prompted to select the other side five times without access to the selected item. Following this intervention, selections came under control of the consequences of selection, rather than the position on which items were presented.

This study is relevant to the present discussion for two reasons. First, it suggests a number of interventions that may be tried if position-controlled selections interfere with obtaining information about preference. Second, it suggests that in at least some cases, side bias may be observed when there is not enough difference in preference across stimuli included in an assessment. That is, indifference regarding the consequences of selection for one stimulus over another may result in a side bias that may be eliminated when different stimuli are included in the assessment, ones for which a greater difference in preference exists.

Multiple-Stimulus Approaches

Despite the existence of position-biased responding in some individuals, the PSPA is a commonly used and well-established approach to identifying preferred items as well as relative preference for those items. Although reliable and a marked improvement over lengthy observations in the environment, PSPAs can be cumbersome, depending on the number and nature of the stimuli assessed and the duration of access time between stimulus presentations. The multiple stimulus preference assessment is an adaptation that takes less time, but still results in a hierarchy of preferences.

The multiple stimulus with replacement (MSW) preference assessment was developed by Windsor, Piche, and Locke (1994). They presented six items in an array and allowed subjects (adults with disabilities) to select from that array. The stimuli used were edibles (food and drink) and item position was rotated across trials. Following each selection from the array, the therapist replaced the consumed item. The process was repeated ten times. They compared that approach to a PS approach in which each item was presented with only one other item across 30 trials (10 opportunities to select each item). Highly preferred items were correlated across both assessments, but more consistent preference was demonstrated across administration in the PS format than in the group presentation format. Despite the lower reliability observed in the MSW approach than in the paired approach, a benefit of the MSW approach was that it took one half to one third as long as the paired approach to administer. It is interesting to note that staff predicted which stimuli would be most preferred prior to both assessments, but the staff's specific rankings of the rest of the stimuli were not significantly correlated with the results of either the MSW or the PS assessments.

One strength of the PS format that is missing from the MSW may account for the differences in outcomes between the MSW and PS assessments. That is, the PSPA pairs each item with every other item, forcing a ranking of those items. The replacement of selected items from the array after they have been selected in the MSW allows the subject to select the same item again and again. This may result in preference for some items while obscuring preference for other items.

An adaptation to the MSW that is designed to eliminate this weakness is the multiple stimulus without replacement (MSWO) preference assessment, developed by DeLeon and Iwata (1996). This approach is identical to the MSW except that after a particular item is selected, it is not replaced, thus forcing the subject to make a selection from an array that does not include the previously selected item(s). Relative preference is obtained by dividing the number of times each item was selected by the number of times it was presented in an array. In this fashion, the subject's selection data demonstrate a hierarchy of preference. DeLeon and Iwata compared the PSPA, the MSW, and the MSWO approaches and found moderate to high rank-order correlations between the MSWO and PSPA approaches. The time required to conduct the MSW and MSWO preference assessments was comparable. Items from the middle of the preference hierarchy obtained by the MSWO and PSPA functioned as reinforcers in a subsequent assessment when made contingent on arbitrary responses. These items had not been selected in the MSW assessment, presumably because preference for highly preferred items obscured preference for them.

Therefore, it appears that the MSWO is a procedure that combines the advantages of a PSPA (a reliable hierarchy) and the MSW (efficiency).

DeLeon and Iwata (1996) repeated the MSWO preference assessment five times. Higbee, Carr, and Harrison (2000) replicated the procedure, but repeated the assessment three times instead of five. When the stimuli identified as most highly preferred were used as consequences in a subsequent reinforcer assessment, they increased behavior to above baseline levels. However, there was some inconsistency between MSWO rankings and relative effectiveness of each stimulus during the reinforcer assessment, suggesting that there may be an improvement in reliability of the results when five versus three repetitions are conducted. In order to test this possibility, a study could be conducted in which an MSWO is repeated five times and then the stimuli selected as high, moderate, and low preference from each could be compared during a reinforcer assessment. It should be noted that any of the other previously described assessments could be repeated, either to determine the degree to which preference remains consistent or two improve the likelihood that momentary variability will not adversely effect outcomes.

An important variation on multiple-stimulus approaches is the free-operant preference assessment. Roane et al. (1998) presented 10–11 items in a circle in front of participants and observed their interaction for 5 min. Participants were free to manipulate the items, or no items, and at no point during the session were items withdrawn. Observers recorded the percentage of 10-s intervals each item was touched or held by the participant. The authors found that stimuli interacted with more often functioned as more effective reinforcers. In comparison to results from PSPAs, the free-operant approach sometimes identified different items, but it was associated with shorter assessment times and fewer instances of problem behavior (which tended to occur during the PSPA when items were removed between trials).

Regardless of the number of times the assessment is conducted, and whether or not selected stimuli are replaced before subsequent trials, multiple stimulus preference assessments share a common feature, that items are presented in an array, rather than individually or in pairs. In order to conduct a multiple stimulus preference assessment, distractions should be eliminated. As in the procedures for conducting single- or paired-stimulus preference assessments, included items can be determined using a number of approaches. Once determined, all included items are typically presented one at a time prior to the start of the assessment so that the participant can experience them. This pre-assessment sampling may be especially important when novel stimuli or stimuli not commonly encountered by the subject are used in the assessment.

The number of trials in the assessment should match the number of stimuli included in the assessment. On the first trial, all the stimuli should be arranged in an arc-shaped array such that each stimulus is equidistant from the participant and an opportunity to select one of the items should be provided. The duration of this opportunity may vary as per the suggestions provided above for other types of preference assessments but should be held constant across trials. It may also include a prompt to select one's favorite item from the array. Selection typically results in access to that item. If the item is edible, the participant should be permitted to consume the item. If the item is a leisure item, the participant should be permitted to interact with the item during an access period. As in the previously discussed preference assessments, access duration should be held constant across selections.

After the first trial, procedures vary depending on whether conducting an MSW or MSWO assessment. If conducting a MSW, each trial will include the same total number stimuli, but will vary in terms of the position of each stimulus. When replacing the previously selected stimulus, the therapist should rotate the position of all stimuli in order to make position-controlled responding detectable. If conducting an MSWO assessment, each trial will include one fewer item than the previous trial, as the participant selects items and they are not replaced. An exception to this is if the participant does not select any item on a trial. Then, the assessment will continue for the same number of trials as the number of items included. Data are collected on the item selected on each trial. The number of times an item is selected is divided by the number of times it was available (which will be the same across stimuli in the MSW but will vary across stimuli in the MSWO). The resulting value is multiplied by 100 to yield a percentage of trials on which each item was selected. As with the single- and paired-stimulus preference assessments, these data may be presented in histograms, in which each bar represents a stimulus.

Another stimulus modality that clinicians may wish to assess using preference assessments is olfactory. Pace et al. (1985) included two olfactory stimuli in their array, coffee and flowers. These stimuli (coffee beans and a hibiscus flower) were placed inside a closed coffee can or plastic container, respectively. Some participants approached both olfactory stimuli on a high percentage of trials, but their reinforcing effectiveness was not evaluated. Both Bloom (2008) and Wilder et al. (2008) assessed the reinforcing efficacy of olfactory stimuli and found reinforcement effects. Bloom et al. used cotton balls soaked with aromatic/essential oils or scented candle shavings inside glass saltshakers or film canisters. All olfactory stimuli corresponded to food flavors (e.g., peppermint, strawberry, coconut). Wilder et al. used solid room fresheners, some of which were scented with food flavors (apple, vanilla) but lavender and rain scents were also included. Thus, precedent has been made for inclusion of olfactory stimuli in a variety of natural and synthetic forms using a variety of sources and delivery techniques.

Assessing Preference for Activities and Interventions

Often it may be desirable or necessary to evaluate an individual's preference toward an extended activity. However, activities are different from the kind of simple tangible or edible stimuli most often used in preference assessments in some important ways other than mere convenience. First, activities usually vary a lot each time they are experienced (e.g., no two games of hide-and-seek are the same). Second, the delay between choosing a particular activity and its peak subjective experience weakens the ability of choosing to be influenced by such moments. Third, it is difficult to identify a stimulus that might be presented in a choice context that adequately summarizes the combination of these effects. These are problems for stimulus evaluation procedures because, to be useful, participant selections need to be under the control of the consequences for approaching. For familiar toys or food items, this is quite reasonable because the contingencies for approaching and manipulating (or consuming in the case of edibles) tend to be very immediate and reliable. For example, approaching and consuming an M&M™ results in the same flavors, textures, and sweetness every time. Even for unfamiliar foods or toys, the contingencies between approach and the subsequent interaction are so reliable that the appearance of the stimulus itself readily acquires discriminative control. There is an additional layer of complexity when choices are not tightly controlled by the consequences for approaching: there may appear to be no preference, or preference may develop according to more immediate variables (the appearance of the cards as opposed to the activities depicted in the cards). For example, subtle differences in effort or the perceptual abilities of clients may become apparent through side biases (as outlined above). Together these effects interact to make assessing preference of activities more difficult.

Using Representative Items

One approach to addressing the aforementioned problems is to continue to include them in preference assessments, but present them in the form of a representative stimulus. Both Pace et al. (1985) and Fisher et al. (1992) included activities (swinging in a swing and a therapist rocking the participant's chair) in their assessments, but did not provide detail about how they were included such as specifying how they were presented and how participants indicated a selection. Presumably, an actual swing could be placed on a table, but a human-sized rocking chair might be cumbersome. Both studies could have placed toy-sized representative figures of both a swing set and a rocking chair and used them in place of whatever they did use.

Use of representative items has been examined in a number of studies, although not necessarily for the purposes of assessing preferences for activities (e.g., Graff & Gibson, 2003; Higbee, Carr, & Harrison, 1999). Collectively, these studies suggest two features that might enhance the validity of preference assessments conducted using representative items: providing the stimulus immediately following selection (more discussion of this is provided in the following section), and possession of picture-to-object and object-to-picture (or their equivalent) matching to sample skills. However, such skills may not always be sufficient.

Another approach is to use photographic or pictorial images or written words on cards as representative of activities. This might be especially useful in situations in which an activity is not immediately deliverable following a selection. For example, Daly et al. (2009) used index cards with the written name of an activity, such as going to the library, walking around the school or playing in the gym in an MSWO preference assessment with four children with behavior disorders who were receiving special education services (but who were not necessarily intellectually disabled). The procedures described by Daly et al. are not strictly a concurrent-chains schedule because the activities were not provided contingent upon selection during the MSWO preference assessment, although the most preferred activities were validated as reinforcers for completing math problems in a subsequent assessment.

The term concurrent-chains schedule is used to refer to arrangements in which specific sets of conditions (e.g., schedules of reinforcement, activities, availability of responses) are associated with specific contexts, each of which is signaled by the presence of unique stimuli. Each context is referred to as a link (i.e., a link in a chain). When used to assess preference, two or more links are usually arranged in sequence: an *initial link* in which two or more responses are available (a *concurrent operant* arrangement), and one or more *terminal links* in each of which a particular activity is available depending on the response requirements met in the initial link. For example, one might consider standing at the payment booth of a movie theater as an initial link in a concurrent-chains schedule. At the payment booth, I can name one of the available movies and pay the attendant (the *response requirement*). I am then permitted access to movie theater in which the movie I indicated is shown (the *terminal link*). In concurrent-chains schedules, access to the terminal link might function as a reinforcer for behavior in the initial link. If a concurrent-operant arrangement is in place in the initial link, then it is also possible to describe the distribution of behavior across the available options as preference. Thus, the procedure captures aspects of both preference and reinforcer value.

In the simplest arrangements, response-requirements in the initial link are usually low (e.g., fixed-ratio [FR] 1). For example, touching an item once might be sufficient to result in access to an activity associated with that item. Ratio schedules are often used when it is desirable to know that one alternative is preferred more than another, however small of a difference in preference there may be. This is because ratio schedules often result in *exclusive preference*, wherein the participant only selects his or her most preferred option. This kind of result is reasonable if one considers that any response toward the less-preferred option means foregoing a more-preferred option: what incentive is there to ever select the less-preferred option? More sophisticated approaches might involve arranging variable-interval schedules (where the first response following an unpredictable amount of time that hovers around some average results in access to the terminal link) in the initial link. Variable-interval schedules tend to engender a pattern of responding indicative of the *degree* of preference for one alternative over another.

Many aspects of the direct preference assessments discussed thus far fit the metaphor of a concurrent-chains schedule. But the term is sometimes invoked explicitly in some of the studies below that assess preference for activities or interventions. For example, responses in the initial link described by Hanley, Piazza, Fisher, Contrucci, and Maglieri (1997) produced access to a room where a particular intervention, with its own response requirements and associated schedules of reinforcement, were in effect.

It is useful to conceptualize some forms of preference assessment as concurrent-chains schedules because doing so allows us to anticipate a wide-range of effects observed in basic laboratories ranging from those due to delays to reinforcement, magnitude (or the duration), response requirement, schedule, and effort. From this framework, we can be more confident that the preferences we measure are valid when selections among activities result in access to those activities immediately and always. Some examples of the applied work on assessing preferences using concurrent-chains schedules are described below and underscores some of these points.

Mithaug and Hanawalt (1978) described the first systematic use of a concurrent-chains schedule to evaluate preference for activities, or in their case, vocational tasks. Preferences for vocational tasks (sorting, assembling paper booklets and other items, and stuffing envelopes) were assessed in three adults with intellectual and developmental disabilities. Representative items from the tasks were presented to subjects in pairs and approaches produced access to the selected task for 7 min. Items were presented in random pairs, with the exception that the previously selected item was presented with a new item until it had been paired with everything else at least once.

As stated earlier, a concern raised when assessing preference for activities is that their remoteness comes with a reduced ability to affect choice. One way to enhance control by the activity is to provide it following selections. But providing the activity immediately following selection does not necessarily guarantee that preference is not due to some idiosyncratic feature of the stimuli presented to clients during choice-making. Thus, although Mithaug and Hanawalt (1978) identified clear preferences, it is still difficult to know whether those preferences can truly be attributed to the activities and not the objects representing them.

Mithaug and Mar (1980) addressed this concern in a subsequent study in which preferences for items were initially identified using the procedures described above and, then in a subsequent phase, the consequences for choosing items were flipped. That is, selections toward an item that was previously preferred now resulted in access to an activity that was previously not preferred, and vice-versa. During this condition, preference shifted away from the activity that had previously been preferred and toward the activity that had previously been non-preferred. These findings highlight the importance of providing consequences for making sections and the procedure offers one example of how to obtain additional evidence that selections are indeed under control of the activities being selected.

Hanley et al. (1997) used a similar concurrent-chains procedure to assess client preferences for two function-based interventions: functional communication training (FCT) and noncontingent reinforcement (NCR). Preference was assessed by presenting clients with three switches, each covered with a colored sheet of construction paper designated according to one of the treatments or a control (no consequence). The location of the switches was determined pseudo-randomly to help detect side-biases. Selections to either of the treatment switches resulted in 2 min of access to a room where the selected treatment was in effect. Results showed that both participants preferred FCT over NCR.

Hanley, Iwata, and Lindberg (1999) used photographs to represent activities such as riding a bike outside or watching cars drive by from the patio with four adults diagnosed with moderate to profound intellectual disabilities. The assessment involved a forced choice among three pictures. Two photographs showed activities that were believed to be enjoyable and the third showed a control activity that was believed to have little or no reinforcing value. Initially, participants did not receive access to the activities depicted contingent on selection and generally their selections indicated indifference. Following this condition, contingent access was provided for selections. In this condition, clear preferences did emerge between activities, suggesting that contingent access is necessary for this type of preference assessment.

It may be that the differences obtained by Daly et al. (2009) and Hanley et al.'s no-consequence condition were due to differences in participant characteristics. Nonetheless, results from Hanley et al. offer empirical support for providing consequences for selections during preference assessments. Another important result from Hanley et al. appeared for one participant, who initially showed a preference for Art (when choices did not result in selections), but whose preference shifted toward Music once selections resulted in access to the thing selected. This result suggested that preference, defined as a clear choice of one alternative over another, may not be sufficient because it may only reveal a preference for the photo representation (e.g., perhaps the photo of Art was more attractive than the photo of Music). Thus, when assessing preference for activities, it may be important to show that choices are sensitive to the activities themselves.

Hanley, Piazza, Fisher, and Maglieri (2005) conducted a very interesting study in which a concurrent-chains schedule was implemented to allow clients to choose between one of three treatment rooms. Each room contained one of the following interventions: FCT, FCT plus Punishment, and Punishment alone. Both participants showed a clear preference for FCT plus punishment over either FCT or Punishment alone. This study is interesting because it underscores that following one's own intuitions about what a client is likely to prefer may not always be the most valid approach.

An alternative to words or pictures on cards to represent items is the use of brief video clips. Snyder, Higbee, and Dayton (2012) compared the results of two preference assessments: one with toys and one with videos of an unfamiliar child playing with the same toys with six preschoolers diagnosed with autism. The stimuli were presented in pairs using the Fisher et al. (1992) PSPA procedure and selections resulted in 15 s of access to the selected stimulus (the toy in the tangible assessment and the toy depicted in the video in the video assessment). Both assessments produced the same top-ranked item and for four of the six participants, the same bottom-ranked item. A subsequent reinforcer assessment was not conducted.

Assessing Preference for People and Social Interactions

Relative to the assessment of food or tangible stimuli, the adaptation of preference assessments toward the identification of social interactions is a relatively newer target of examination. Although some of the seminal studies on preference assessment included forms of social interaction among other stimuli, very little procedural detail was provided to indicate how they were presented in stimulus arrays, or delivered as consequences. One early precursor involved assessing preference for particular individuals or staff members.

Sturmey, Lee, Reyer, and Robek (2003) assessed client preferences for staff. Staff were seated in pairs facing clients and clients were instructed to, "Go to whom you want to play with" (p. 104). When clients approached staff within 1 min, staff provided a brief interaction that involved talking, brief physical contact, or both. Procedures differed slightly across participants, with some receiving of up five presentations of each pair of staff (but not necessarily all combinations of staff), and others being presented with pairs of staff once, but interactions following client approaches lasted 30 s. The results produced preference hierarchies similar to those found in studies involving paired-preference assessment procedures (e.g., Fisher et al., 1992) for five of seven participants. However, no subsequent tests were performed to confirm the preferences.

Rapp (2005) examined preference among different caregivers in a young boy with intellectual disabilities who also engaged in problem behavior. Following procedures similar to those described by Sturmey et al. (2003), caregivers were presented in pairs by seating them across the room from the client. At the beginning of the session, the client was escorted to the center of the room. The caregivers were instructed to change seats every 60 s. An approach was scored according to whichever caregiver the client came into proximity with first at the beginning of the session, and then again after caregivers changed seats. Approaches were scored whenever the client came in proximity to one of the caregivers. In any given session, only one caregiver was instructed to talk to the client contingent on approaches to that caregiver (approaches to the other caregiver resulted in no programmed consequences). Results showed that the client's approaches depended on both the caregivers available at any given time and the consequences provided by those caregivers. Thus, the data (in terms of the percentage of time spent in proximity) clearly demonstrated that the client preferred attention from one caregiver to the other.

Smaby, MacDonald, Ahearn, and Dube (2007) assessed the reinforcing efficacy of three kinds of social interactions (tickles, head rubs, and praise) in children with autism spectrum disorders (ASD). Each session consisted of a baseline period in which responses (placing a poker chip in the therapist's hand, or touching the therapist's hand) resulted in no programmed consequences, and a social consequence period in which responses produced access to one social consequence delivered for 2 s. The results showed that some social consequences supported consistently higher rates relative to baseline than other social consequences, providing evidence at least some of the stimuli functioned as reinforcers. Although rates of responding on FR-1 schedules such as those used by Smaby et al. (2007) are not typically interpreted as a direct measure of preference, they do speak directly to the ability of the consequence to reinforce the behavior that was increased. Thus, Smaby et al.'s method is more akin to a reinforcer assessment, but given that the social interactions were not present to be selected (as in a choice assessment of tangible stimuli) any concern that responses are occurring for reasons other than the social consequences can be addressed by comparing rates of behavior across the baseline and consequence conditions. One disadvantage of the procedure is that Smaby et al. provided only one exposure to each social consequence per day, necessitating at least 2 days of assessment.

Nuernberger, Smith, Czapar, and Klatt (2012) assessed preference for social interactions in children with ASD using pictures. Pictures were presented to participants in an MSWO format (described in more detail above). Approaches to any of the pictures resulted in 15-s access to the depicted form of social interaction and removal of that photo from the array prior to the next presentation. This continued until all of the stimuli had been selected or the child made no selection within 15 s of stimulus presentation, whichever happened first. Nuernberger et al. obtained clear preference hierarchies in all three participants. A subsequent reinforcer assessment revealed that stimuli identified as preferred for two of the three participants resulted in the highest levels of responding on a sorting task. One potential limitation of Nuernberger et al. is that all of the participants could receptively and expressively identify the photos used in the assessments. Therefore, it is not clear to what degree the assessment would accurately describe preference in individuals without such skills.

Kelly et al. (2014) compared a paired pictorial-choice procedure and a single-response format similar to that described by Smaby et al. (2007) except that it also included a photo-representation of a social interaction. In addition to photos of social interactions, a control photo was included in the assessments. Approaches to photos of social interactions resulted in those interactions being delivered for 2–5 s while approaches to the control photo resulted in no attention for 2–5 s. Because some forms of attention involved a necessary delay between participant approach and delivery (e.g., the therapist having to stand up and walk around the participant to deliver a pat on the back), all forms of attention were delivered following a 2-s delay. Kelly et al. then repeated each assessment three to seven times and examined the degree to which results of each were consistent across time (test–retest reliability). The authors found that the paired-choice procedure produced consistently more reliable results as compared to the single-response procedure. This finding echoes similar result, obtained with food and tangible stimuli showing that paired-stimulus approaches have reasonable reliability (DeLeon & Iwata, 1996). In a subsequent phase, the authors also demonstrated that most forms of social interaction identified as preferred using the paired-choice procedure also functioned as reinforcers.

Given the unclear role of prerequisite skills, it may sometimes be desirable to present stimuli in a way that matches how they occur naturally. Clay, Samaha, Bloom, Bogoev, and Boyle (2013) did exactly this by using procedures similar to those described by Rapp (2005) and Sturmey et al. (2003) wherein different therapists were presented in pairs. The procedures differed from previous studies because each therapist delivered a different form of social interaction contingent on client approaches. After obtaining clear hierarchies of social interactions, the therapists previously associated with most- and least-preferred social interactions switched what they delivered. Thus, if participants' preferences changed to select the person now delivering the most-preferred social interaction, this provided evidence that participants' preferences were valid. In addition, a subsequent reinforcer assessment showed that the most-preferred social interactions functioned as reinforcers.

The available evidence suggests that identifying preferred forms of social interactions is best accomplished using a procedure that involves choice (Kelly et al., 2014). Currently, it is not clear whether, and to what degree, prerequisite skills are necessary when using pictures to represent social interactions. Clearly, pictures are effective for some individuals. For other individuals, it is possible that procedures in which clients choose between different people who deliver different consequences like those described by Clay et al. (2013) may be necessary.

Aversive Stimulus Assessments

As with preferred stimuli, there is value in assessing whether or not a stimulus is likely to be aversive. This may prove useful when selecting activities or tasks to include in the escape condition of a functional analysis of problem behavior or as an antecedent for a communication training intervention to teach individuals to request breaks from aversive activities or as part of a positive punishment contingency. The literature on this sort of assessment is more limited but researchers have used a number of strategies to identify non-preferred or aversive stimuli.

A simple approach is to ask clients. Northup et al. (1996) evaluated a modified version of the Child Reinforcement Survey (Fantuzzo et al., 1991) to include questions regarding aversive stimuli in children with ADHD. For example, participants were asked to rate how much they preferred to "Get out of…" (p. 203) educational activities like math and reading according to a 3-point scale: *not at all*, *a little*, or *a lot*.

A more direct approach involves presenting stimuli and measuring some aspect of behavior. Green et al. (1988) used a stimulus assessment similar to Pace et al. and assessed participant responses to identify stimuli that, when presented in a single-stimulus format, would lead to a participant engaging in either an approach or an avoidance response (e.g., moving away from a stimulus or making a negative-affect vocalization). Green et al.'s focus was on identifying potential reinforcers and so they did not confirm whether or not the avoidance responses were indicative of whether or not particular stimuli were aversive in a negative reinforcement or a positive punishment contingency.

Another approach is to measure the occurrence of problem behavior in the presence of a stimulus. McCord, Iwata, Galensky, Ellingson, and Thomson (2001) and Buckley and Newchok (2006) both examined problem behavior in the presence of auditory stimuli. In both studies, sounds were played for 5 min and were turned off for 30 s contingent on the occurrence of problem behavior. Once aversive sounds were identified, interventions were developed to reduce problem behavior in the presence of those sounds. The purpose of these assessments were to identify relevant antecedents for problem behavior for the purpose of designing interventions to address problem behavior maintained by escape from those antecedents. However, aversive stimuli have also been assessed for other purposes.

Fisher, Piazza, Bowman, Hagopian, and Langdon (1994) evaluated procedures to be used in a positive punishment contingency (e.g., water mist, hands down). They implemented each procedure multiple times in a session and conducted one session per stimulus. Observers recorded negative- and positive-affect vocalizations and physical-avoidance responses. Then, a hierarchy was established by adding the negative-affect vocalizations and the physical-avoidance responses, and then subtracting the positive-affect vocalizations to produce a value that could be compared across stimuli. This approach to assessment was then validated in a punishment-based treatment, as the most avoided stimuli in the assessment were the most effective when used in a positive-punishment contingency.

Zarcone, Crosland, Fisher, Worsdell, and Herman (1999) measured similar responses to identify stimuli, the removal of which would reinforce behavior. They used multiple approaches to identify stimuli, including the use of the Negative Reinforcement Rating Scale (NRRS), which they administered to parents. Then they presented the stimuli one at a time and trained a response the participant could use to terminate the presented stimulus. Using latency as a dependent variable, Zarcone et al. generated a hierarchy of stimuli. This hierarchy was validated when the stimuli associated with the shortest latencies to the escape response were subsequently presented in a positive punishment contingency and resulted in the greatest reductions in problem behavior from baseline.

Call, Pabico, and Lomas (2009) also used the NRRS, but for a different purpose. They measured latency to the first instance of problem behavior, rather than to an alternative response. Then they used the stimuli (task demands) identified as most and least aversive in the escape condition of a functional analysis of problem behavior and found that more aversive demands were associated with higher rates of problem behavior than less aversive demands.

The authors of these studies used a range of approaches to identify aversive stimuli for a variety of clinical purposes. Some used indirect approaches, like interviews, or direct approaches that involved presenting stimuli and measuring participant responses. Unlike preference assessments, which typically measure approach or selection, aversive stimulus assessments use other responses as a parallel. These might be negative-affect vocalizations, physical-avoidance movements, and trained mands for escape and/or problem behavior. The occurrence of these responses suggests that the stimuli that evoked them are aversive and may be used in negative reinforcement or positive punishment clinical interventions.

Reinforcer Assessments

Many people probably misuse the term reinforcer to mean, "a stimulus that I hope will make my intervention effective," "a stimulus that I hope will increase behavior," or "a preferred stimulus that I hope will increase behavior." Indeed, when caregivers are questioned about whether they have ever tried reinforcement, they may respond in the affirmative, but further questioning may reveal that they only tried one stimulus without having either direct or indirect evidence that it actually functioned as a reinforcer under any circumstances. Reinforcement-based interventions can fail for a variety of reasons, not least of which has to do with the effectiveness of the chosen "reinforcer." Preference assessments provide some clues as to whether stimuli are likely to function as reinforcers, but often the evidence they provide is indirect.

Therefore, when things are not working, it may be prudent to conduct a reinforcer assessment to provide clear evidence that at least the stimuli included in the intervention function as a reinforcer. This allows the clinician to focus on adjusting other parameters of the intervention. In addition, reinforcer assessments might be used to provide direct evidence that one stimulus in particular is the most effective reinforcer out of those being considered. Many of the studies described so far included some form of reinforcer assessment. Below we describe three types of reinforcer assessments along with their merits.

Single-Operant Reinforcer Assessments

Following a preference assessment, Pace et al. (1985) conducted a single-operant reinforcer assessment to confirm whether preferred stimuli (defined as those stimuli that were approached on at least 80 % of trials) provided contingently resulted in more correct responding than non-preferred stimuli (defined as those stimuli approached on 50 % or fewer trials). At the beginning of each trial, participants were provided with one of five instructions: reaching across the table, making eye-contact with the therapist, raising a hand, touching the therapist's hand, and saying "eat." During a no-reinforcement baseline, compliance with the instruction produced no programmed consequences (i.e., the therapist behaved as if nothing happened). During the test conditions, compliance within 5 s of the instruction resulted in 5 s of access to the stimulus being tested. A session consisted of ten trials.

Reinforcement effects were demonstrated using a reversal design. Although the specific order of conditions varied across participants, most participants experienced a baseline, a preferred stimulus test, a non-preferred stimulus test, a return to baseline, and a return to the preferred stimulus test. The results showed that preferred stimuli were associated with a higher percentage of correct responses as compared to baseline, suggesting the preferred stimuli functioned as reinforcers. In some cases, the percentage of correct responses obtained when using non-preferred stimuli was greater than that observed during baseline, suggesting that at least some of the non-preferred stimuli also served as reinforcers. In those cases, preferred stimuli were associated with greater levels of correct responding than non-preferred stimuli, suggesting that preferred stimuli functioned as more effective reinforcers when compared to non-preferred stimuli.

Typically, clinicians would begin a single-operant reinforcer assessment by selecting some topography of behavior to reinforce. Because the purpose of the assessment is to learn something about the strength of the stimulus, it is usually desirable to select a response that is already in the client's repertoire, or a very simple response that is easily acquired. Doing so makes it possible to rule out skill or training deficits in the event that no reinforcement effect is found. An important consideration is the schedule of reinforcement. Most often, FR-1 schedules are used to for the purposes of reinforcer assessment, where each occurrence of the target response results in immediate delivery of the stimulus. This allows the client to rapidly contact the contingency and is ideal for producing acquisition. Recently, investigators have begun examining other schedules (see Roane, 2008 and Tustin, 1994 for reviews), including arrangements where schedule changes occur within session (e.g., progressive ratio schedules). Although progressive ratio (PR) schedules are technically also single-operant arrangements because only one response option is available at any given time, we will make a distinction for the purposes of this chapter because until recently most applied work involving single-operant reinforcer assessments consisted of only FR-1 schedules. Progressive ratio schedules will be discussed separately below.

Usually, single-operant reinforcer assessments are conducted in sessions that last a fixed amount of time and the outcome is the number or rate of responses emitted by the client. Occasionally, it may be desirable to divide the session into a fixed number of trials. For example, if the target response is completion of a task that must be delivered by another person (e.g., imitation, matching to sample). In such cases, the outcome is the number or percentage of trials in which the correct response was emitted.

Also, in order to obtain empirical evidence as to whether a stimulus functions as a reinforcer, the behavior that produces it must be shown to increase relative to the level observed under some control condition. Often, a no-reinforcement control is used, where behavior results in no programmed consequences (i.e., the therapist behaves as though the response did not occur). But other reasonable control conditions include noncontingent reinforcement (NCR, or providing the stimulus on some dense fixed-time schedule, independent on the occurrence of behavior, e.g., every 30 s), and differential reinforcement of other behavior (DRO, or providing the stimulus continent on periods of time in which the behavior does not occur). Thompson, Iwata, Hanley, Dozier, and Samaha (2003) evaluated these control conditions and found that no reinforcement was generally associated with the most rapid demonstration of reinforcement effects with few negative side effects.

The single-operant approach can be a rapid means of testing whether a stimulus functions as a reinforcer, but subsequent work has shown that it may not be ideal for selecting between reinforcers of varying effectiveness or value. For example, Roscoe, Iwata, and Kahng (1999) compared rates of responding when low- and high-preferred stimuli were provided contingent on behavior in both a single-operant and concurrent-operant arrangement. They found that often responding tended to be about the same in the single-operant arrangement regardless of the stimuli being provided. It might be that when given the opportunity to earn a reinforcer or not, subjects are likely to work regardless of whether the reinforcer is "amazing" or "fine." This problem with using single-operant reinforcer assessments is reliable and has been replicated many times (Catania, 1963; Lerman, Kelley, Vorndran, Kuhn, & LaRue, 2002; Taravella, Lerman, Contrucci, & Roane, 2000). Under such conditions, a concurrent-operant reinforcer assessment may be more revealing of relative value.

Concurrent-Operant Reinforcer Assessments

Concurrent-operant reinforcer assessments differ from single-operant assessments in that at least two response options are available, and (usually) each response option produces a different consequence. The relative value of one stimulus is inferred from the degree to which clients choose to engage in the response that produces it over others. In this way, concurrent-operant reinforcer arrangements are similar in form to paired-stimulus preference assessments. The difference lies in the amount of work required to obtain a stimulus. Response requirements are usually very low (e.g., reaching toward a stimulus) in preference assessments, but reinforcer assessments usually require some meaningful amount of work (e.g., completion of an academic or self-care task). Many factors important to clinical decision-making can influence responding in concurrent-operant situations (see Fisher & Mazur, 1997 for a review), but for our purposes we are most interested in describing how the procedure can be used to detect differences in reinforcer value.

Roscoe et al. (1999) compared relative rates of responding in a concurrent-operant arrangement for high- and low-preferred items. The specific topography of behavior varied across participants. Some participants were required to emit a response by touching either of two microswitches, whereas others were required to write on either of two pads of paper. At the beginning of each session, participants were presented with two response alternatives, behind each of which a plate was placed containing either the high-preferred or low-preferred items. Responses resulted in immediate access to the associated food items according to a FR-1 schedule. Participants were able to engage in either or both of the responses as much as they wanted. Rates of responding on the two alternatives were compared to each other, and to a no-reinforcement baseline in which the preferred items were not visible. The results of Roscoe et al. show clear evidence that the high-preferred stimulus was a reinforcer (by comparing rates of responding on task that produced it during the reinforcer test and baseline), and that it was a more effective reinforcer than the low-preferred item. Generally, all of the participants exclusively engaged in the response that produced the high-preferred item, while engaging in little to no responding on the alternative that produced the low-preferred item. A subsequent test showed that when available by itself on an FR-1, the low-preferred item maintained an equivalent level of responding. Importantly, the concurrent-operant arrangement detected a very clear difference in reinforcer value.

Like single-operant reinforcer assessment, concurrent-operant reinforcer assessments are best conducted in sessions of fixed duration, or a fixed number of trials. Outcome measures may include the rate of responding on each alternative, or the percentage of responses emitted on each alternative.

In concurrent-operant arrangements, it is important to signal in some consistent way that each alternative is associated with a different stimulus. Roscoe et al. (1999) did this by placing each item on a plate behind each response alternative. Other investigators have done things such as using different colored work materials. Either one of these options makes it possible to vary the location of each alternative across trials or sessions. It is important to vary the location of the alternatives at least occasionally to rule out a preference for one stimulus appearing because, for example, the client happens to be right-handed. Such side-biases are usually not insurmountable, but their role should be ruled out if possible.

An argument might be made that if differences are not apparent on single-operant FR-1 schedules, then although they might exist on concurrent-operant schedule, they may not be clinically significant. This is not an unreasonable claim, especially if the response is topographically identical to that used in a the clinical situation, and other contextual variables such as the length of the session, the schedule of reinforcement, the presence of discriminative stimuli, etc. remain the same. However, often reinforcers are likely to be used in contexts much broader than those assessed and so any evidence that one stimuli is likely to be more valuable than another may be clinically significant but only under conditions that do not emerge until later. For example, Keyl-Austin, Samaha, Bloom, and Boyle (2012) evaluated the effectiveness of highly and moderately preferred stimuli as reinforcers using a single-operant schedule. They found that like Roscoe et al. (1999), responding was similar for the two items until sessions were conducted for 20 or more minutes. It was only in the last 10 min of a 30-min session that small differences in preference led to performance differences. Data such as these suggest that even minor differences in preference might be clinically significant for programs carried out for hours or days.

Progressive Ratio Reinforcer Assessments

As discussed previously, Keyl-Austin et al. (2012) found that the differences in the rates of behavior emitted by clients to produce moderately and highly preferred stimuli did not differ until clients had already been working steadily for 20 min. One possible interpretation of this finding is that the value of a stimulus decreases with exposure (e.g., satiation) and at some point, the effort required to earn the stimulus begins to compete successfully with its value and the rate of behavior begins to decline. If true, then another reasonable way to assess the value of a stimulus is to modify the work required to earn it (see Tustin, 1994 for a review). One approach is to increase the amount of work required to earn a stimulus within a single session until the client stops working. This arrangement is called a progressive ratio schedule (Hodos, 1961; see Roane, 2008 for a review) and the last schedule requirement completed is often referred to as a *break point*.

An advantage of PR schedules over other reinforcer assessment methods is that they provide a clear index of how much a person is willing to work to earn a given reinforcer. As such, they have unambiguous face validity. In addition, the question of how much work a person will do to earn one reinforcer is different from the question of how much work will they do when each bit of work results in reinforcer access. The latter question is what results of single-operant FR-1 reinforcer assessments address, and as discussed earlier, responding under single-operant FR-1 schedules can obscure differences between stimuli resulting from ceiling effects (i.e., clients may work as quickly as they can as long as they are earning *something*). In addition, there may be cases where rates of responding under FR-1 differ, but in a direction opposite of that described by break points on PR schedules (see Hursh & Silberberg, 2008). For example, assume we are interested in comparing the reinforcer value of two stimuli: A and B. It might be that under FR-1, we find that A is associated with higher rates than B, but that under FR-20, the opposite is true. If one conceptualizes ratio requirements as analogous to task difficulty, then such findings suggests that stimuli associated with higher break points might more reliably maintain responding on difficult tasks (e.g., things not yet mastered).

In addition, break points on PR schedules have been found to be predictive of treatment efficacy. Roane, Lerman, and Vorndran (2001) compared the effectiveness of interventions like NCR and DRO when incorporating stimuli associated with different PR break points. The authors found that stimuli associated with higher break points led to greater and more reliable reductions in problem behavior.

Like single-operant reinforcer assessments, PR schedules begin with the identification of some simple response to target. Ideally, this is something already in the client's repertoire. Next, it is necessary to decide how the schedule requirement should increase within session. A variety of progressions have been used in the literature. For example, Roane et al. (2001) used the following progression with one participant: FR-1, FR-1, FR-2, FR-2, FR-5, FR-5, FR-10, FR-10, FR-20, and FR-20. Generally, larger steps result in higher breakpoints and less evidence of satiation (Hodos & Kalman, 1963). Whatever progression one selects, it is important to be consistent when making comparisons across stimuli.

Unlike single- and concurrent-operant arrangements, it is important that one not use fixed session durations with progressive ratio schedules. Instead, one should end the session after some fixed period of time without responding (Hursh & Silberberg, 2008; Tustin, 1994). This is important because ending the session before the client has hit a break point would likely obscure differences across stimuli. For example, Roane et al. (2001) ended PR sessions after 5 min elapsed without the participant responding.

It is worth noting that PR schedules have been suggested to be aversive and therefore should not be used with protected populations so long as they show no "clear offsetting benefits" (Poling, 2010, p. 348,). In support of this argument, Poling (2010) cited Dardano (1973), who reported data showing that pigeons would peck a key that produced time-out from a PR schedule and that the rate of key pecking increased with increasing ratio sizes. In general, such findings are in line with other work on fixed ratio schedules showing that animals sometimes prefer to be in signaled periods of time-out just after completing a large ratio (Azrin, 1961). If work in a PR schedule is viewed as analogous to demands, then the notion that escape from those demands might function as a reinforcer should not be surprising to clinicians. Escape from demands is one of the most common reinforcers for problem behavior (Beavers, Iwata, & Lerman, 2013).

If in fact clients find PR schedules aversive (this has yet to be shown in humans), there are likely procedures that could be implemented to reduce the aversiveness. One possibility is to use procedures similar to those reported by Dardano (1973) to allow participants to take brief breaks. Dardano's own data suggested clients might be most likely to do this just after completing a large ratio requirement. Thus, the breaks would likely not interfere with a run of work. Also, although PR schedules are a relatively new assessment procedure, there is already direct evidence that they produce clinically relevant data (e.g., Roane et al., 2001). Finally, clients should have opportunities to tell us what they like and dislike themselves, including as pertaining to clinical assessments and interventions based on those assessments. As results from Hanley et al. (2005) illustrated, where clients actually preferred interventions involving punishment to those without it, client preferences may not be so easily anticipated in advance.

Conclusion

There are a variety of reasons for conducting stimulus evaluation procedures like those discussed previously, of which only one is the identification of effective reinforcers. Stimulus evaluation procedures like preference and reinforcer assessments continue to play critical roles in service delivery and research. Obtaining meaningful data necessitates careful selection of stimuli to be assessed, weighing the time and resources required by the assessment procedure with the value of the data to be obtained, and careful implementation. A multitude of procedures have been developed to measure preference and refinement continues in the field to better identify preferred stimuli, relative preference, and effective reinforcers. This evolution of systematic methods increases the availability of clinical tools that assess client preference and choice, and to incorporate them into treatment development.

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Prevention of Severe Problem Behavior

6

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Introduction

Despite the many reports of successful treatment of severe problem behaviors in individuals with intellectual and developmental disabilities (e.g., Kahng, Iwata, & Lewin, 2002), children and adults with problem behaviors not classified as severe remain untreated or unsuccessfully treated in institutions, group homes, schools, and family homes around the country. Severe problem behaviors include self-injurious behavior, aggression toward others, and other types of destructive behavior that is forceful and/or dangerous, or health or life-threatening, that has resulted in or has a high probability of hospitalization, social isolation, and/or serious injury, immediate death or delayed death. Not all self-injurious behavior is severe, but a brief review of any research journal on developmental disability suggests that virtually all behavior disorders are severe from the vantage point of families and caregivers.

Children and adults exhibiting non-severe problem behaviors are at risk of severe problem behaviors if they fail to receive treatment that works. It seems likely they will progress to the classification of *severe* problem behavior. Children who do not exhibit severe problem behaviors may be at risk as well, if they have other characteristics that place them at risk.

"How does one prevent something that has not happened? Therein lies the problem." The late Don Baer spoke these words many years ago at an ABAI Convention as he so adroitly began as a discussant to respond to several papers on prevention of problem behaviors. As usual, when he said so, Baer was articulating one of the essential issues in a critical area of behavior analysis.

Prevention is a multifaceted term as used in this chapter. There are multiple emphasized areas. One focus surrounds actions to preclude the likelihood of severe problem behaviors from emerging. An example of prevention includes providing genetic counseling to the parents of a child diagnosed with Lesch–Nyhan syndrome (Rojahn, Schroeder, & Hoch, 2008). The prevention terminology suggested by Rojahn et al. (2008) is referred to, but not necessarily labeled as primary, secondary, or tertiary.

One focus of prevention is on early detection and intervention of problem behaviors to prevent them from deteriorating and becoming severe

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problem behaviors. Schroeder et al. (2014) assessed risk factors related to the prevalence of severe problem behaviors including self-injury, aggression, and stereotypic behavior with young children. Based on their results, they stressed the importance of early identification and treatment to decrease the chances of problem behaviors becoming more severe and resistant to intervention. Other prevention strategies include, but are not limited to, conducting functional behavior assessments, developing individualized behavior treatment programs based on the function of behavior, antecedent control, preference assessments, and evaluating communication and social skills.

Functional Analyses and Prevention

Functional analyses are widely employed in addressing self-injurious behaviors (Beavers, Iwata, & Lerman, 2013; Hanley, Iwata, & McCord, 2003) and other severe problem behaviors. Based on a review of functional analysis research, behavior treatment was noted to be effective at reducing self-injury if a functional analysis was used (Kahng et al., 2002). Iwata, Kahng, Wallace, and Linderg (2000) considered the role of functional analysis methods to have a preventative function and explained how it enables us to design better treatment programs. They noted that: (1) functional analysis enables researchers to better delineate the antecedent conditions (establishing operations, discriminative stimuli) under which behavior occurs and to alter them so that problem behavior is less possible; (2) functional analysis identifies the source of reinforcement that has to be eliminated so extinction can be used; (3) the same reinforcer that maintains the problem behavior can be employed to increase alternative behaviors; and (4) results of a functional analysis will reveal those reinforcers deemed unnecessary.

Despite advancements in assessment and intervention, self-injurious behavior and other severe problem behaviors still exist; thus, emphasis must be placed on prevention of severe problem behaviors, particularly with young children before they start engaging in severe problem behaviors. Preventive actions taken to preclude the possibility of problem behavior from emerging in the first place directly address the mediating systems in the individuals' environment that contribute to the formation of problem behaviors. It is carried out prior to the onset of problem behaviors in order to eliminate or reduce their chances of occurrence and can be applied to the families, schools, and communities in general.

Training and workshops on ABA provided to parents, caregivers, and schoolteachers that lead to increased competence of the systems in the community are examples of prevention. Conducting environmental hazard and risk assessments concerning the levels of chemical exposure in residential settings for individuals with disabilities are examples of prevention. The contaminants in the environment can cause subtle changes in human brains associated with health and behavioral problems (Newland, 2013), and individuals and children with developmental or intellectual disabilities are particularly vulnerable (Del Bene Davis, 2009). Therefore, it is imperative to protect these individuals from environmental hazard.

Individuals with intellectual and developmental disabilities are at a relatively high risk of developing maladaptive behavior due to the lack of effective communication between the individuals and their caregivers, a history of inappropriate reinforcement delivered contingent upon maladaptive behaviors, and the absence of reinforcing contingencies occurring in the immediate environment surrounding the individuals (Cooper, Heron, & Heward, 2007). The effects of treatments for such purposes have been extensively researched and documented in the behavioral literature. The general finding is that intervention strategies based on the function of the problem behavior are effective in decreasing problem behaviors and thus improving the quality of life for these individuals.

In recent years, researchers (e.g., Schroeder, Bickel, & Richmond, 1986; Singh, 1997) have recognized the critical importance of preventing the development of problem behavior for those individuals who are at risk. These individuals are often in groups and formulating a group prevention strategy may be important. Thus, the prevention of problem behavior can also be analyzed from the physical and social environment impacting the individuals. In other words, what are the characteristics of the environment that shaped the problem behavior in the first place? Van Houten et al. (1988) reported on The Task Force appointed by ABAI on "The Right to Effective Treatment." These guidelines were tasks and the first essential task for the behavior analyst is to organize "a physical and social environment that is safe, humane, and responsive to individual needs" (p. 111).

Behavioral Inoculation Skills Training

Hanley, Jin, Vanselow, and Hanratty (2014) taught skills as a method of prevention of problem behavior, such as waiting for delayed access and tolerance of adult denials to access preferred items or activities by engaging in alternative or less preferred activities to prevent future problem behaviors. Luczynski and Hanley (2013) reported that teaching functional communicative skills not only resulted in improvement in social skills, but also successfully prevented the occurrences of problem behaviors for preschoolers at risk. Skills taught included requesting attention from the teacher, denial of requests, delay tolerance, and requesting preferred materials.

Preferred Stimuli

Besides enrichment of the physical and social areas of an environment, methods and procedures that address the individual's environment to decrease or prevent the occurrence of problem behavior using preference assessments have been reported in the literature. For example, Foster-Johnson, Ferro, and Dunlap (1994) found that implementing preferred activities reduced the levels of inappropriate behaviors (e.g., disruptive, stereotypy) and increased the levels of appropriate behaviors (e.g., on-task) for students with intellectual disabilities in classroom settings. Ringdahl, Vollmer, Marcus, and Roane (1997) reported that simply providing preferred stimuli within eyesight, making them available and easily accessible to the individuals functioned to decrease the occurrence of self-injurious behaviors for some of the participants. However, additional differential reinforcement procedures had to be implemented along with the presence of preferred stimuli in order to decrease self-injury in some participants.

Although the availability and presentation of preferred stimuli or activities could prevent or reduce problem behavior to some extent for some individuals, this arrangement may not be sufficient for other individuals without reinforcement for alternative behaviors. As highlighted by Piazza, Roane, and Karsten (2011), research on preferences has advanced rapidly and demonstrated that preference assessments now include evidence of the utility of providing clients more opportunities for choices to (a) assess client preference for positive reinforcement preferences (Hanley, Piazza, Fisher, Contrucci, & Maglieri, 1997), (b) choose between punishment and extinction aspects of behavioral intervention (Hanley, Piazza, Fisher, and Maglieri (2005), (c) choose systems of motivation (Heal & Henley, 2007), and (d) express preferences for functional communication training, non-contingent reinforcement, or extinction in treatment of severe problem behavior.

Function-Based Treatment

Based on the operant paradigm, the empirical evidence of functional analysis methodology suggested the following possible functions that serve to maintain problem behaviors: social attention, escape from demand, and automatic reinforcement (Iwata, Dorsey, Slifer, Bauman, & Richman, 1994). The empirically supported preventive strategies based on each function are briefly listed as follows.

Treatments for Problem Behaviors Maintained by Social Attention

Behavioral treatments for problem behaviors maintained by social attention usually involve extinction (e.g., planned ignoring) or punishment (e.g., time out) in conjunction with other strategies (Grow, Carr, & LeBlanc, 2009; Hanley, 2011). The strategies recommended include (a) differential reinforcement of alternative behaviors, (b) functional communication training, (c) non-contingent reinforcement, and (d) restructuring the routines (e.g., environmental changes).

In differential reinforcement of alternative behavior, any appropriate behaviors that are alternative to problem behaviors are differentially reinforced by social attention under a predetermined schedule. Functional communication training teaches individuals specific communication skills to effectively obtain social attention. In non-contingent reinforcement, social attention is delivered on a fixed-time schedule regardless of the individual's responses. The strategy of restructuring the routines can be utilized in group settings where attention to each individual is diverted. To maximize social attention for individuals, for example, smaller groups are organized, and peer tutors can be assigned (Grow et al., 2009).

Treatments for Escape-Maintained Problem Behaviors

For escape-maintained behaviors, the preventive strategies recommended are (a) activity choice, (b) curricular and instructional revision, (c) demand fading, (d) differential negative reinforcement of alternative behavior, (e) functional communication training, and (f) non-contingent escape (Geiger, Carr, & LeBlanc, 2013; Hanley, 2011).

Once the functional behavior assessment reveals that problem behaviors are maintained by escape, it is important to reassess and rearrange the relevant environmental variables addressing this particular function. In activity choice, the individuals are presented with various task options for them to choose from. Curricular revision involves examining the appropriateness of goals of tasks and instructional procedures based on individuals' skill levels (Wolery & Winterling, 1997). This is one of the most important aspects for behavior analysts to assess when problem behaviors are maintained by escape. Demand fading involves the withdrawal of aversive tasks associated with severe problem behaviors and gradual reintroduction. Functional communication training involves teaching individuals to request for breaks from tasks in a socially acceptable manner. In differential negative reinforcement of alternative behavior, escape from tasks is provided when appropriate alternative behaviors are displayed, while in differential negative reinforcement of other behaviors, contingent escape is provided when zero responding of problem behaviors occurs for a specified period of time. Non-contingent escape offers opportunities to escape from tasks under timed schedules independent of problem behaviors.

Treatments for Problem Behaviors Maintained by Gaining Access to Tangible Items

When problem behaviors are maintained by gaining access to tangible items, treatments typically involve functional communication training and non-contingent reinforcement (e.g., Hagopian, Wilson, & Wilder, 2001). Functional communication training teaches the individuals to request access to preferred items or activities appropriately. It can be offered in the forms of verbal requests or mands, signs, pointing, using picture cards or augment devices. In non-contingent reinforcement, making preferred tangible items and activities available to the individuals enriches the environment.

Treatments for Problem Behaviors Maintained by Automatic Reinforcement

Problem behaviors maintained by automatic reinforcement are the most difficult to treat primarily due to the fact that the source of reinforcement is unknown and therefore cannot be controlled or manipulated, and it is readily available to the individuals (Vollmer, 1994). Thus, the assessments identifying the source of automatic reinforcement are critical when selecting effective treatments for automatically reinforced problem behaviors. According to Hagopian et al. (1997), a functional analysis may provide indirect evidence as a preliminary step to determining if the problem behavior is maintained by automatic reinforcement. If the rates of problem behaviors are relatively high in the alone condition while relatively low in play or high stimulation conditions, it is indicative that the problem behaviors are maintained by automatic reinforcement. If the problem behaviors are equally high or variable across all conditions, it also suggests automatic reinforcement as a potential source in maintaining behaviors.

Treatments for Problem Behaviors Maintained by Automatic Positive Reinforcement

For problem behaviors maintained by automatic positive reinforcement, preventive treatment strategies include environmental enrichment using the results of preference assessments (e.g., Vollmer, Marcus, & LeBlanc, 1994), differential reinforcement of alternative or other behaviors combined with environmental enrichment (e.g., Ringdahl et al., 1997), and the use of highly preferred matched stimuli to replace problem behaviors (e.g., Piazza, Adelinis, Hanley, Goh, & Delia, 2000). Environmental enrichment involves providing preferred items or sensory stimulation available to the individuals. However, when environmental enrichment alone does not decrease problem behaviors effectively, individualized differential reinforcement procedures may be implemented. Matched stimuli refer to the stimuli that provide sensory stimulation similar to the positive reinforcing properties provided by problem behaviors. When a preference assessment indicates a highly preferred item or activity with matched function for an automatically reinforced problem behavior, it is more likely that engaging in the activity or manipulation with such a stimulus will effectively compete with problem behaviors and thus replace them. Perhaps the most difficult part of this treatment is to identify the potential source of reinforcement for each individual, because no reliable assessment tools are currently available for such detection. Detailed observations and logical guesses may be necessary when selecting matched stimuli.

Treatments for Problem Behaviors Maintained by Automatic Negative Reinforcement

Problem behaviors maintained by automatic negative reinforcement are probably the most difficult to treat with current available knowledge. Once medical personnel identify the source, treatments may involve instructing the individuals to communicate pain or to apply prescribed external or internal medication. However, the source of pain is not always identifiable and treatable for individuals with intellectual or developmental disabilities (Vollmer, 1994). Most treatments for negative automatically reinforced problem behaviors involve punishment procedures (e.g., response blocking) and sensory extinction is the only preventive strategy that is currently recommended (Vollmer, 1994). Sensory extinction uses protective equipment to block problem behaviors and thus reduce or eliminate them. However, Vollmer (1994) also recommended contingent application of protective equipment in order to reduce the time wearing them.

Some correlational studies based on the pain hypothesis of severe SIB have reported that individuals with disabilities tend to display observable nonverbal signs of pain behaviors (e.g., Courtemanche, Schroeder, Sheldon, Sherman, &

Fowler, 2012; Symons, Harper, McGrath, Breau, & Bodfish, 2009). Courtemanche et al. (2012) recommended using Non-Communicating Children's Pain Checklist (McGrath, Rosmus, Canfield, Campbell, & Hennigar, 1998) as a continuous measure to assess individuals with intellectual disabilities who cannot report pain. They reported a correlation between pain-related behaviors and self-injury. Despite the correlation found in these studies, the researchers did utilize functional analyses to distinguish whether self-injury was maintained by social mediation or automatic reinforcement. However, once the results of functional analysis reveal that the problem behaviors are potentially maintained by negative automatic reinforcement, it may be helpful to train staff members to observe signs of pain-related behaviors in clinical settings.

Early Identification and Preventive Treatments

Researchers have reported early emergence of problem behaviors, such as aggression, self-injury, and stereotypy in infants and young children diagnosed with severe or profound intellectual disabilities, autism, and have poor receptive and expressive communication (McClintock, Hall, & Oliver, 2003). The severity of problem behavior is more likely to increase with age and carry over into school years, adolescence, and adulthood (Dunlap et al., 2006; Richman, 2008). Therefore, it is imperative to identify infants and young children who are at risk of developing severe problem behaviors and provide early intervention services to these individuals and their families as early as possible. Studies have suggested the use of screening and evaluation tools, such as The Parental Concerns Questionnaire (Mayo-Ortega et al., 2012; Schroeder et al., 2014), the Bayley Scales of Infant Development (Bayley, 2006), Communication, Symbolic, and Behavior Assessment Scale (Wetherby & Prizant, 2002), and the Behavior Problems Inventory (Rojahn, Matson, Lott, Esbensen, & Smalls, 2001).

Early Identification and Risk Factor Evaluation

Most studies have evaluated risk factors associated with children aged 3 years and older; however, Schroeder et al. (2014) assessed 12 risk factors associated with severe behavior disorders with young children aged 4 months to 48 months. They employed screenings, interdisciplinary evaluations, and follow-ups to evaluate children who were at risk for being intellectual and developmentally disabled. They found eight factors (i.e., age, communication, intellectual level, diagnosis, family income, gender, parent education, and visual impairment) were related to scores on the Behavior Problem Inventory (Rojahn et al., 2001) for subscales of Aggression, Self-Injury, and Stereotyped Behavior. Early identification of children at risk for severe behavior problems is important to help prevent development of chronic treatment-resistant problems. Resurgence of behavior problems has shown to be a problem that may need to be addressed with long-term treatment (Wacker et al., 2011, 2013). Children at risk for severe behavior problems may need long-term intervention and follow-up. Early identification and treatment can enhance reduction and possible prevention of problem behaviors from becoming more severe.

Once infants or young children are identified as at risk or a diagnosis is obtained, these children and their families should receive services and supports to meet their needs. This section emphasizes individualized early intervention services and treatments addressing the environmental variables surrounding the individuals and their families.

Functional Assessment

The functional analysis methodology has been utilized to identify functions of problem behaviors at an early stage and develop treatment plans for young children (Kurtz et al., 2003; Reeve & Carr, 2000; Wacker et al., 1998). For example, Wacker et al. (1998) reported that the results of functional analysis suggested the majority of problem behavior exhibited by these children were maintained by social mediation (21 % positive reinforcement, 46 % negative reinforcement, and 18 % multiple functions). They trained parents to implement differential reinforcement procedures and reported that problem behaviors decreased during treatment while appropriate social interactions increased during follow-up observations. Reeve and Carr (2000) used functional analysis to identify mild attention-maintained problem behaviors displayed by preschoolers and compared the treatment effects of functional communication training versus expressive language training on these children in school settings. They reported that the problem behaviors displayed by children in the functional communication training group remained low while the problem behaviors increased in intensity and frequency for children in the expressive language training group, and did not decrease until they were trained with functional communication training.

Kurtz et al. (2003) reported a study of 30 cases of young children (mean age of 17 months), with or without a diagnosis prior to age 5 years, who had early onset of self-injury and other problem behaviors. After the results of functional analysis were obtained, individualized treatment plans were developed accordingly. Most of the children were given functional communication training supplemented with extinction, punishment, differential reinforcement, or non-contingent reinforcement procedures. Parents were trained to implement the treatment, and the mean percentages of behavioral reduction in self-injury and other problem behaviors were 95 % and 87 %, respectively. The results from these studies provide empirical support for the application of functional analysis with young children to determine the environmental causes of their problem behaviors and develop effective treatment plans at an early stage. In addition, parents and teachers can be trained to implement effective treatment procedures.

Ecological Assessment

The functional analysis protocol (Iwata et al., 1994) has been widely used to identify functions of problem behavior (Beavers et al., 2013; Hanley et al., 2003). At times, target behaviors are maintained by variables not tested in the standard protocol. For example, several idiosyncratic factors have been identified in the research literature (Hagopian, Rooker, Jessel, & DeLeon, 2013; Hanley et al., 2003; Schlichenmeyer, Roscoe, Rooker, Wheeler, & Dube, 2013).

Ecological validity may be a concern, in that behavior problems can serve different functions depending on the context (Lang et al., 2009). Context of the functional analysis may impact the rate of the target behavior observed. In situ hypothesis testing, which may be conducted in the natural environment (Cipani & Schock, 2011), involves switching between baseline and a functional treatment, and comparing the rate of target behavior between conditions. When target behaviors occur at a low frequency, a trigger analysis can be used (Cipani & Schock, 2011). With a trigger analysis, the suspected antecedent condition (i.e., discriminative stimulus and motivating operation) is presented and the percent occurrence of the target behavior is recorded. A trial-based functional analysis can also be conducted effectively in the natural environment (Bloom, Iwata, Fritz, Roscoe, & Carreau, 2011; La Rue et al., 2010). Telemedicine techniques can also be used to conduct a functional analysis in the desired environment (Barretto, Wacker, Harding, Lee, & Berg, 2006).

Given that the functional analysis involves presenting stimuli that evoke target behaviors, some problems may be too severe for such an approach to be ethical. Functional analyses have been conducted on precursor behaviors to develop effective treatment (Fritz, Iwata, Hammond, & Bloom, 2013). Dracobly and Smith (2012) employed descriptive assessment and conditional probability analyses to identify precursors to severe infrequent self-injury. Lerman and Iwata (1993) formulated conditional probability equations to analyze descriptive data. Pence, Roscoe, Bourret, and Ahearn (2009) demonstrated how a descriptive assessment could be helpful prior to conducting a functional analysis. A descriptive assessment can be employed to examine the relationship between behavior and environmental events. Observation of setting events, antecedents, behaviors, and consequences can be conducted in the natural environment. Biological, physiological, medical, and health factors can also be assessed (Kennedy & Meyer, 1996; O'Reilly 1995, 1997; Zarcone, Napolitano, & Valdovinos, 2008). For example, prior to behavioral assessment and treatment of pediatric feeding disorders, other evaluations addressing oral motor skills, swallowing, and nutrition might be conducted (Piazza & Roane, 2009). In other cases, the prescription of medication can impact responding (Kelley, Fisher, Lomas, & Sanders, 2006).

As the goal of prevention is to detect and treat problem behaviors from early on to preclude or minimize adverse effects, intervention services that provide an enriched environment and skill acquisition programs are of particular importance, because these programs can be implemented with the absence of problem behaviors in any setting. In addition, some of the young children identified as high-risk for problem behaviors may not yet exhibit problem behaviors or the problem behaviors are minor at an onset stage, occurring only occasionally. In these cases, functional analysis may not be warranted, but their physical and social environment must be optimized in order to prevent the occurrence of potential problems.

As described in the previous section, some of the treatment strategies involving the manipulations of relevant motivating operations can also be applied at the level of prevention. For example, non-contingent reinforcement (e.g., attention, free time) can be used to create a positive learning environment. In the natural home or school settings, it is commonly observed that children typically receive more adult attention when they display problem behaviors than when they are playing or working independently. Non-contingent reinforcement is easy to implement and ensures that children receive adequate amount of positive reinforcement, so they are not under a state of deprivation for attention or free time.

Environmental Enrichment

Environmental enrichment is designed to maximize reinforcement rates in the environment, including the provision of preferred or developmentally appropriate toys, objects, and activities, making them easily accessible to children. These items or activities can contain multi-sensory stimulation that facilitates interactions between children and their environment. In other words, environmental enrichment serves as a motivating operation that increases the opportunities for children to engage in appropriate activities. Preference assessments can be conducted to determine the preferred stimuli for each individual when arranging environmental enrichment. The implementation of non-contingent reinforcement or environmental enrichment can also be conceptualized as providing competing stimuli to problem behaviors as a means to gain access to preferred items or activities. When such a need is met, many children choose to engage in appropriate activities, rather than exhibiting problem behaviors. However, a study by Boe (1977) demonstrated that merely providing toys for aggressive children is not a panacea. In this study, Boe found that more floor space plus non-contingent reinforcement produced the best outcomes.

Other treatment strategies involving motivating operations include offering activity choice opportunities for children and designing skill acquisition programs suitable to each child's current levels. These strategies can be utilized to minimize the potential aversive effects associated with task demands that might trigger the occurrences of problem behaviors. Differential reinforcement procedures are commonly used in skill acquisition as well as behavior reduction. Reinforcement is delivered contingent on the emission of the target responses. Functional communication training is often taught as an alternative to problem behaviors for obtaining desired consequences.

For children at risk for or with developmental disabilities, mand training is recommended as an essential part of early language training (Greer & Ross, 2008; Sundberg & Partington, 1998). Once children learn to appropriately request for access to adult attention, preferred items or activities, functional communication training containing adequate social skills for preschoolers (e.g., waiting, tolerance of denial or delayed consequence), can be systematically taught in group settings (e.g., Luczynski & Hanley, 2013). Indeed, the responsibility of behavior analysts is to develop effective skill acquisition programs appropriate to each individual's level, so the individuals are empowered with skills for adequate functioning in the environment they live.

Antecedent Control Strategies

Smith and Iwata (1997) pointed out the importance of antecedents in prevention and control of problem behaviors. Antecedent manipulations can serve as prevention by altering the physical or social environment to decrease or preclude the possibility of problem behaviors. By manipulating discriminative stimuli, motivating operations, setting events, or components of a behavioral chain associated with the problem, the probability of the target behavior should decrease (Mayer, Sulzer-Azaroff, & Wallace, 2014). For example, if loud noise was identified as the trigger preceding aggression then reducing noise should facilitate a reduction in aggression. Antecedent strategies can include adding a discriminative stimulus for reinforcement for desired behavior and a discriminative stimulus for extinction for the problem behavior. Changing response effort for the target behavior can also have an impact (Friman & Poling, 1995).

Use prompting strategies or antecedent control techniques may decrease or prevent problems. These techniques include verbal, gestural, or physical prompts, modeling, instructions or rules regarding behavior, activity schedules, redirect to engage in desired behavior, making the environment more reinforcing for appropriate behavior, choice of stimuli, providing preferred stimuli, interspersal techniques of mix easy and difficult tasks, breaking down tasks, adding visual cues, response cards to indicate a break or desired stimuli, and social stories (Gray & Garand, 1993; Johns, Skinner, & Nail, 2000; Lee, Sugai, & Horner, 1999; Mayer et al., 2014; Munro & Stephenson, 2009).

The Matching Law and Conditioned Reinforcement

The findings from basic science suggest at least two concepts—the matching law and conditioned reinforcement—that are of clinical significance and can offer treatment strategies relevant to reduction and prevention of problem behavior for individuals with developmental disabilities.

The matching law states that animals, including humans, respond proportionately to the degree of reinforcement available for each option (Herrnstein, 1970). When applying the matching law to humans in the applied settings, the individual's behavior is conceptualized as choice among alternatives under concurrent schedules of reinforcement available in the individual's environment (McDowell, 1988). Descriptive analyses of observations in natural environments has confirmed the matching relation of response allocation between two alternatives for severe problem behaviors (e.g., aggressive and self-injurious behaviors) and appropriate behaviors (e.g., communicative behavior) displayed by individuals with various developmental disabilities (e.g., Borrero & Vollmer, 2002; Hoch & Symons, 2007; Martens & Houk, 1989; Oliver, Hall, & Nixon, 1999).

In their mathematical analysis, Myerson and Hale (1984) suggested using a variable interval (VI) schedule as an alternative to treat problem behavior maintained by either VI or variable ratio (VR) schedule in applied settings. However, empirical support for this assertion is needed. One study that experimentally manipulated VI concurrent schedules of reinforcement in clinical settings demonstrated a matching relation between alternatives for destructive behaviors and desirable behaviors exhibited by individuals with developmental disabilities (Borrero et al., 2010). Although the intervention of problem behaviors suggested by the matching law usually involves adding a schedule of reinforcement for an alternative (e.g., appropriate behavior) without altering the contingencies for the target behaviors (McDowell, 1988), Borrero et al. (2010) pointed out that simply providing a stronger reinforcement schedule for an alternative may not reduce a problem behavior to a desired level in clinical settings. Therefore, they implemented differential reinforcement of alternative behavior plus an extinction contingent upon the occurrence of the target behavior to further reduce the behavior to lower levels of occurrence.

All of the above-mentioned studies involving demonstrations of a matching relation between response alternatives in applied settings consisted of problem behaviors already exhibited by the individuals and used or suggested treatments by increasing reinforcement rates for appropriate behaviors in order to decrease inappropriate ones. In most cases, the effectiveness of reinforcers is determined by the results of functional analysis. However, it is possible that the matching law has practical implications for prevention of the occurrence of problem behavior for individuals with developmental disabilities in applied settings. First, it is helpful for a behavior analyst to conceptualize an individual's choice behavior of response alternatives under concurrent schedules in a natural environment. Second, when organizing the physical environment, it is important to eliminate all aversive conditions surrounding the individual and consider every possible source of reinforcement for the individual. Third, the design of any skill acquisition and social or leisure activities should enrich the individual's environment with maximum rates of reinforcement.

With maximized rates of reinforcement, an individual is supposed to function adequately at his or her level of independence without the need to display any problem behaviors. However, this is not always observed for every individual in the applied settings, even if a positive environment is created with all potential sources of reinforcements. As discussed above, some individuals may not be interested in engaging with stimuli, activities, or interactions that are presumably reinforcing to most people. These individuals seem to be isolated due to a lack of ability to make contact with their environment and thus have a tendency to engage in behaviors that do not result in reinforcement consistently. Researchers in basic science observed the same phenomenon in animals have suggested conditioned reinforcement as an explanation (e.g., Dunn & Spetch, 1990).

In applied settings, Lalli, Mauro, and Mace (2000) conducted three experiments to replicate the basic laboratory research with human behavior. Experiment 1 and 2 replicated the same procedures with animals and obtained similar results showing a preference for unreliable reinforcement under certain conditions in which the presented stimuli with a longer duration may have functioned as conditioned reinforcers. Experiment 3 further tested the hypothesis of conditioned reinforcement effects for preference of unreliable reinforcement with a 7-year-old girl with developmental disabilities hospitalized due to severe aggression. The functional analysis indicated that the girl's aggression was maintained positively by access to tangible items. The researchers assigned the reliable reinforcement schedule with aggression and the unreliable reinforcement schedule with mand, both associated with an experimenter delivering the reinforcers in conjunction with specific verbal statements. The results were consistent with previous findings, that the girl preferred the unreliable schedule (mand) over the reliable one (aggression), suggesting that the presence of the experimenter along with the verbal statements associated with the tangible items may have functioned as a conditioned reinforcer.

The demonstration of conditioned reinforcement effects in the behavior of individuals with developmental disabilities has significant value in applied settings. Once the conditioned reinforcement is in effect, the individual may prefer the conditioned stimuli with a thinner reinforcement schedule over a reinforcer with a richer schedule. Therefore, this may explain why an individual exhibits problem behaviors maintained by an unreliable reinforcement schedule more often than emits a socially acceptable response (e.g., mand) that consistently results in reinforcement.

Nonetheless, rather than simply providing explanations for observed phenomena, conditioned reinforcement has several important implications with regard to the prevention or reduction of problem behaviors by individuals with developmental disabilities in applied settings. In applied research, a stimulus–stimulus pairing procedure has been developed to condition toys and books as reinforcers for children with autism or other developmental disabilities (Greer, Becker, Saxe, & Mirabella, 1985; Nuzzolo-Gomez, Leonard, Ortiz, Rivera, & Greer, 2002). Prior to conditioning toys or books as reinforcers, the researchers reported that these children engaged in disruptive stereotypic behaviors and did not show any interest in playing with toys or looking at books. After the pairing procedure that conditioned toys and/or books as reinforcers, the children showed preference in toy play or book observation during free play time and thus decreased the occurrences of stereotypic behaviors. Greer, Pistoljevic, Cahill, and Du (2011) implemented the stimulus–stimulus pairing procedure to condition adult voices as reinforcers for children with autism who exhibited disruptive behaviors and found that children chose to listen to stories rather than engaging in disruptive behaviors during free play time.

Conclusion

We present a selective number of studies that suggest that severe problem behaviors in people with intellectual disabilities can be prevented. Specific behavioral practices that we believe have contributed to an improved methodology for prevention include the following: (a) experimental functional analysis is increasingly used; (b) preference assessments provide vehicles for choice-making on a wide scale; (c) function-based treatment continues to be increasingly successful; (d) improved identification of young children at risk for severe problem behaviors are being taught behavioral methods of "inoculation" skills to prepare them for increased coping skills; and (e) increased focus on basic principles (e.g., conditioned reinforcement) may be the foundation that leads to better prevention.

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Community Support Needs

7

James R. Thompson and Stephanie DeSpain

Introduction

The purpose of this chapter is to summarize current research findings and describe best professional practices in relation to assessing the support needs of people with intellectual and developmental disabilities (IDD) in community settings. The chapter begins with a discussion of how changes in public policy, trends in service delivery systems over the past four decades, and new understandings of disability have contributed to a growing interest in support needs assessment, planning, and arranging individualized supports with people with IDD in community settings. Next, the logic underlying person-centered planning (PCP) processes is explained and several leading PCP processes are described. Also, research findings related to the efficacy of PCP are summarized. The final section focuses on support needs assessment tools that have been developed on which research findings have been reported in peer-reviewed, professional literature. A synthesis of findings related to the psychometric properties and factor structure of these tools are presented.

The Rise of the Community-Based Service System

From Deinstitutionalization to Community Living

The 1970s was a remarkable decade in terms of public policy affecting people with IDD due to the emphasis that was placed on deinstitutionalization and the expansion of community residential alternatives (Bruininks, Meyers, Sigford, & Lakin, 1981). The principle of normalization, a sociopolitical concept, called for making available to people with disabilities "patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society" (Nirje, 1969, p. 181). It provided advocates and policymakers a unifying philosophy on which to dramatically alter the landscape of human services offered to people with IDD. By the mid-1980s the future of institutions for people with IDD was in question. Scheerenberger (1987) summarized three schools of thought at the time: those who believed that institutions were no longer needed and should be disbanded; others who believed that the future of institutions rested in providing short-term care, such as respite care for families and intensive care for people in crisis (especially those with extreme problem behaviors); and still others who argued that there would always be a niche for institutions in a comprehensive service system.

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Almost 30 years later it is evident that those predicting the eventual elimination of institutions were correct. Although there are still people living in institutions today, data trends strongly suggest that institutions' days are numbered. The population of state operated institutions in the USA has decreased from 194,650 in 1967 to 29,574 in 2011. Moreover, 168 institutions have closed (or are in the process of closing) since 1969, and 13 states no longer operate any institutions (Braddock et al., 2013). A similar trend has been documented throughout Europe (Martinez-Leal et al., 2011) and Australia (Young, Sigafoos, Suttie, Ashman, & Grevell, 1998).

Life in the Community

Today, few people advocate for maintaining institutions as part of a jurisdiction's service delivery system. Moreover, there is little question that all people with IDD can enjoy life in community settings if they are provided with proper supports. One visible organization that supports the continuation of institutions is the VOR (formerly known as the Voice of the Retarded). Their primary argument is that people with IDD and their families should have the choice to live in an institution if they determine that this is the best option for them (VOR, 2014). Although it is self-evident that closing all institutions would restrict the range of choices that are available to people with IDD, the counterargument is that better options exist in the community. Taking away a bad option does not limit the array of suitable choices. An analogy would be to remove a defective car from sale at a car dealership. Yes, in one sense there would fewer automobiles to choose from, but it is safe to assume that nobody would want to purchase a car that is fundamentally flawed. Of course, the VOR does not consider an institutional setting to be necessarily a bad option, but years of data collected on people moving from institutions to community settings suggests otherwise.

Critics of institutions point to the decades of research showing that the vast majority of people with IDD experience a higher quality of life after moving from an institution to a community residence, including people who were initially reluctant to leave their institution. Factors that have been examined include degree of choice making, extent of community integration, employment outcomes, extent of family contact, level of personal and family satisfaction, involvement in social relationships, extent of problem behavior, and growth in adaptive behavior skills. Reviews of professional literature of deinstitutionalized populations published during the 1980s, 1990s, and 2000s have revealed a preponderance of evidence indicating a very high likelihood that people who leave institutions and move to community homes will experience considerable benefits across a wide array of indicators (Kim, Larson, & Lakin, 2001; Lemay, 2009).

The institutional option becomes even harder to defend when considering their financial costs. Stancliffe, Lakin, Shea, Prouty, and Coucouvanis (2005) examined a series of studies that revealed the cost of community services were from 5 to 27 % less than services offered at state operated institutions. Assuming that there will always be a finite amount of funding available to support people with IDD, continuing to spend extra money on people living in more expensive institutional settings has a net effect of restricting the amount of money available to fund services in local communities.

Although there still are public and privately operated institutions in the USA and elsewhere, the overwhelming majority of people with IDD live their lives in local communities (Braddock et al., 2013). The field of IDD has clearly moved beyond the question of "should people be supported in their local communities?" to "what is the best way to support people in local communities?"

The Diverse World of Community-Based Services

Despite the philosophical and public policy shifts in favor of supporting people with IDD in their home communities, the quality of support services and opportunities for people with IDD differ greatly from one local community to another, and even from person to person within the same community. People's daily lives and the supports to which they have access are quite diverse. Some people work on community jobs without extra supports, others work on community jobs with special supports, some work in sheltered workshops, and some are unemployed and unengaged (Boeltzig, Timmons, & Butterworth, 2008). There are people who live with a relatively large number of housemates, others with only a few housemates, and some people live in their own apartment or house. Some community homes are managed and staffed by service provider organizations, but most adults with IDD live in homes with family members (Braddock et al., 2013).

For the past 15 years there has been a growing commitment to establishing individual budgets, including situations where cash subsidies and/or vouchers are received by individuals and/or family members to hire support personnel (including family members) to provide support to persons with the disability (Braddock et al., 2013). Resource allocation methods and funding streams continue to evolve. Although the question of whether people with IDD should spend their lives in institutions or integrated community settings is settled, the challenge of finding the best ways to fund and support people with IDD in their local communities endures.

Understanding IDD Through a Social-Ecological Lens

Diagnosis and the Medical Model

Disabilities have traditionally been understood through examining people's deficits, and determining if the deficits are severe enough to warrant a diagnosis. In terms of IDD, the focus has been on understanding how much a person's general intelligence and adaptive skills deviate from that of the general population. Currently, all operational definitions for diagnosing intellectual disability are based on assessing deficits. For example, according to the DSM-5 (American Psychiatric Association [APA], 2013), intellectual disability "is a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains" (p. 33). Intellectual functioning is measured by an IQ test and adaptive behavior (AB) scales are used to assess AB skills. Both the DSM 5 and the American Association on Intellectual and Developmental Disabilities' (AAIDD) definition and classification manual (Schalock et al., 2010) set the same criteria for diagnosis. Namely, that standardized, norm-referenced intelligence assessments indicate a person is functioning two standard deviations below the mean of the general population (approximately the lowest 2 % of the population) along with evidence that concurrent limitations in adaptive behavior skills are present. Competent diagnosticians use psychometrically valid assessments and consider a host of factors when interpreting assessment results, such as the cultural background of the person being assessed and the standard error of measurement of the assessment tools used to inform the diagnosis (Schalock et al., 2010).

A deficit-based approach to assessing intellectual disability (as well as other disabilities) is consistent with a medical model of understanding disability. Identifying deficits within a person is helpful to the extent that deficits can be prevented or remediated. For instance, in terms of prevention, the discovery of phenylketonuria (PKU) and its association with intellectual disability led to newborn screening techniques (first by smell, then by urine test, and now by blood test) as well as a treatment (special diet). In developed countries where PKU screening has been in place for decades, there has been a dramatic reduction in cases of intellectual disability due to PKU (National Human Genome Research Institute, 2012). In regard to remediation, Nihira (1999) provided an overview of the history and evolution of work in the area of adaptive behavior (AB) in the field of IDD and reported that during the 1960s many considered the fact that AB scales assessed people's competencies in specific behavioral (i.e., observable and measurable) terms to be a significant advancement in the field of IDD. There was optimism that results from AB scales would be directly relevant to instructional goals. It was thought that if a person's AB skill deficits could be accurately identified, then educators could target specific AB skills for instruction and AB deficits could be ameliorated.

Preventing people from acquiring disabilities and teaching people with disabilities adaptive skills are certainly worthy endeavors. However, the problem with a medical model (i.e., deficit-based) understanding of IDD occurs when the disability cannot be prevented and a person's deficits cannot be fully remediated. In a medical context, a condition that cannot be fixed is understood as a chronic pathology within people that impairs their functioning and prevents them from participating in community life. An implication of such a conceptualization is to focus professional efforts on caring for people in specialized settings, which by default limits their opportunities to participate in society (Pledger, 2003). Creating institutions for the care of people with IDD is perhaps the most obvious example of medical model thinking. Just as people who experience serious health problems need care from professionals in a hospital setting, for many years it was assumed that people with IDD required care from specialized professionals in institutional settings in order for their needs to be met.

Another implication of medical model thinking can be observed in the "readiness approach" that has been adopted by so many schools and adult service provider organizations over the years. The readiness approach requires people to demonstrate prerequisite skills before being allowed to participate in activity in an integrated setting (Taylor, 2001). Opportunities to attend mainstream classrooms, work on jobs for community employers, and even participate in recreational activities and settings available to the general public were often withheld based on the rationale that a person with IDD did not possess sufficient skills for meaningful participation. This type of thinking resulted in people with IDD having to earn the privilege of participating in socially valued activities and settings that were freely accessible to other citizens in society.

The Social-Ecological Model

An alternative to medical model of IDD is a social-ecological understanding (see Pledger, 2003; Wehmeyer et al., 2008). Thompson (2013) concisely summarized the social-ecological conceptualization of IDD when he explained, "Intellectual disability is best understood in terms of the fit between personal competency and the demands of community environments. Understanding people this way focuses professional efforts on modifying the context by either changing the environment, such as is accomplished through universal design, or introducing personalized supports" (p. 516). It is important to understand that a social-ecological conceptualization does not deny that people with IDD demonstrate deficits in personal competency. Deficits, however, are not the most salient characteristic of people with IDD and therefore should not be the primary target of professional efforts. According to a social-ecological conceptualization, the most salient difference between people with IDD and the general population is that people with IDD need extra supports to successfully participate in daily life activities in community settings. The implication for professional work is to prioritize time and energy on modifying environments and activities so that a person can participate, as well as providing individualize supports that enable more successful participation.

Environmental modifications are undertaken to make settings and activities more accessible. For instance, an ATM requiring recall of a Personal Identification Number (PIN), entry of the PIN by keyboard, and navigation through a series of menus that require reading text might create a mismatch for many people with IDD who want to use the machine. If, however, the ATM allowed access through a thumb print instead of a PIN, icons were paired with text in its menu, and the bank provided the option of limiting choices for withdrawal when setting up the account (e.g., only allowed withdrawals $40 daily per a customer's request to address issues of vulnerability), then the ATM would be accessible to many more people with IDD.

Another way to address the mismatch is to provide individualized supports. Extending the ATM example further, even if it was impossible to modify the ATM as described above, it would still be possible for a person with IDD to use the machine if another person provided support. The intensity of support provided would be based on each person's unique support needs. For example, one person may require hand over hand assistance through each step of the process, which might take quite a bit of time to complete. Another person might only require monitoring with occasional verbal and gestural prompting, and the time necessary to provide the support might be minimal. If a person wanted to learn to use the ATM without extra assistance, instructional support may be intense at first because a task-analysis would need to be created and each step of process would need to be taught. If the instruction was successful, however, the intensity of support could be faded, perhaps even faded completely. Or it is possible that technological support could replace human support. For example, a step-by-step video model on a smart phone may provide sufficient support for some people.

Instruction as a Support

Notice that developing and delivering instruction on how to use the ATM was identified as support in the previous paragraph. The reader might ask "Isn't providing instruction to teach a new skill (and eliminate a skill deficit) consistent with the medical model?" The answer is "yes"—instruction to *eliminate a deficit* is consistent with medical model thinking. In the example above, however, the instructional support was not initiated to eliminate a deficit. Rather, its purpose was to *address the person–environment mismatch*. This distinction may seem superficial at first glance, but it is important in the context of determining how professionals should approach planning and service delivery with individuals and their families. Instructional goals that emerge from a social-ecological understanding of a person require a thoughtful analysis of a person's (a) desired activities and settings and (b) the competencies that the person brings to the activities and settings. Instructional goals based on these considerations are far more likely to be meaningful than instructional goals based on assessing a range of skill deficits.

An illustration of the usefulness of a social-ecological understanding of people with IDD in regard to setting instructional goals comes from the experience of the first author. Several years ago when employed as a special education teacher in a public school, he was charged with teaching beginning cooking skills to a classroom of adolescent aged students who were classified by the school district as students with moderate intellectual disability. Using a detailed task analysis and a most-to-least prompting strategy, each student eventually mastered cooking the breakfast dish known as "French toast." To assess generalization across settings, each student's parents were asked to allow their child to prepare the dish for their family at an upcoming meal. One by one the reports from the parents arrived, with all reporting that the dish was prepared expertly and that their child completed each phase of the process independently, from locating the ingredients to cleaning up afterwards. Just as the author was preparing to pat himself on the back for a job well done upon reading another glowing note from one of his student's parents, he asked the student who bought in the note a simple question: "So, how did it taste?" She replied that she chose to eat the meatloaf that was leftover from the night before because she really did not like French toast! The moral of the story is that a social-ecological consideration of the person–environment mismatch (i.e., what activities she wanted to do, the settings she wanted to do it in, current array of competencies) would have led to an instructional goal that was focused on learning to cook something that the student actually wanted to eat, not something that was simply a skill deficit.

In summary, the critical difference between the medical model and the social-ecological model is that the former calls for addressing deficits within the person and the latter calls for addressing the person's support needs arising from person–environment mismatch. Understanding people with

IDD through a social-ecological lens directs the attention of professionals toward identifying settings and life activities in which people want to participate as well as the personalized supports and environmental modifications they need to meaningfully participate.

Thompson et al. (2009) have defined support needs as "a psychological construct referring to the pattern and intensity of supports necessary for a person to participate in activities linked with normative human functioning" (p. 135). Like other psychological constructs, the intensity of a person's support needs (just as the intensity of someone's motivation, courage, or shyness) must be inferred because it is not directly observable. For approximately 15 years research groups from different parts of the world have embarked on efforts to develop psychometrically reliable and valid assessment scales that provide a means to measure people's support needs (e.g., Hennike, Myers, Realon, & Thompson, 2006; Jansson, Wennstrom, & Wiesel, 2005; Riches, Parmenter, Llewellyn, Hindmarsh, & Chan, 2009a, 2009b; Tadema, Vlaskamp, & Ruijssenaars, 2007; Tate, 2004; Thompson et al., 2004a, 2004b, 2014). Later in this chapter we describe the different support needs assessment scales that have been developed, review their psychometric properties, and summarize research findings from studies in which the scales have been used. But next, a review of the professional literature on person-centered planning (PCP) processes is presented along with summaries on how PCP processes are used to plan and deliver supports to people with IDD in community settings.

Person-Centered Planning Processes

Origins and Controversies

Some professional practices in the field of IDD result from systematic peer-reviewed research that has been disseminated through professional literature. It is not uncommon, however, for professional practices to emerge from the experiences of people working in the field. The disadvantage of such "bottom up" approaches is they lack scientific validation. Evidence for their effectiveness is usually limited to testimonials and anecdotal stories. Many a bad practice has persisted because nobody had the skill or the will to collect data to investigate its effectiveness. On the other hand, there are many bright, energetic people who are good problem solvers among the educators, psychologists, social workers, Qualified Intellectual Disabilities Professionals, and family members who have a wealth of direct experience in the field of IDD. These people are quite capable of coming up with innovative ways to address challenges faced by people with IDD on a daily basis. For instance, it is doubtful that the first teacher to create a homemade pencil grip with masking tape came up with the idea by searching through professional journals.

Person-centered planning (PCP) processes emerged in the 1980s largely from clinical practice according to O'Brien, O'Brien, and Mount (1997). They recounted how "person-centered planning grew as a voluntary commitment among interested people" (p. 482) and expressed skepticism about formalizing these processes or rigidly requiring specific procedures and outcomes. They argued that the loose structure (i.e., flexible guidelines, roles for people that are not clearly defined) and lack of formal requirements is liberating. It frees people to creatively problem solve and they contrast PCP planning to the constraints many people experience when engaged in more formalized planning processes such as developing an annual plan that is required by governmental regulations.

Not everyone agrees. The ambiguity associated with PCP processes is a serious concern for some, because it is impossible to scientifically evaluate what is in essence a moving target. Osborne (2005) charged that PCP processes have fuzzy goals and outcomes, and he characterizes them as a *faux fixe* in the field of IDD. Although he stopped short of calling PCP proponents charlatans, he concluded a highly critical chapter by acknowledging the widespread adoption of PCP processes, and stating "The Pied Piper appears to have successfully played his pipe again" (p. 325).

Holburn (2002) has been prominent among those who embrace the logic of PCP processes while calling for scientific rigor to be applied in evaluating PCP processes through means such as defining key variables, specifying procedures, requiring fidelity of implementation, and evaluating outcomes. As alluded to earlier, there are others (e.g., see Evans, 2002) who are hesitant to impose any evaluative structure on PCP processes. Despite objections that PCP processes cannot and/or should not be empirically investigated, several researchers have attempted to evaluate the effectiveness of PCP using research methods associated with the social sciences.

Empirical Evidence Supporting PCP

Robertson et al. (2006) followed 93 people in England over a 2-year period, collecting data before and after PCP implementation. Positive changes were found after PCP was introduced in the areas of social networks, contact with family, contact with friends, community-based activities, scheduled day activities, and choice; negative changes were noted in the areas of risk, physical health, and emotional and behavioral needs. Moreover, some people in their study clearly had improved life experiences and conditions following PCP while others experienced only slight changes or no meaningful benefits at all. Robertson et al. (2007) investigated the possible reasons for the varied results. They concluded that people with mental health issues and emotional or behavioral problems were less likely to benefit. Also, the skills and dedication of the person facilitating the PCP process influenced the likelihood of success.

Holburn, Jacobson, Schwartz, Flory, and Vietz (2004) completed a longitudinal study where they followed the 20 PCP participants with IDD and problem behavior who were moving from an institutional setting to a community home. When compared to a matched control group that received traditional planning services from the state, the PCP group experienced significantly better outcomes based on a variety of quantitative outcome measures of Quality of Life (autonomy, choice-making, daily activities, relationships with others, personal satisfaction). Moreover, these researchers concluded that PCP had a positive impact on planning team members. Specifically, "person-centered planning procedures enhanced team roles, commitment to a vision, and both identification and solution of barriers to community living" (p. 70).

Claes, Van Hove, Vandevelde, van Loon, and Schalock (2010) sought to evaluate the collective evidence supporting PCP processes by conducting an extensive literature search and systematically analyzing the results. They identified 108 potential articles purporting to investigate the efficacy of PCP processes. They set two criteria for inclusion in their review: (a) that person-centered planning was applied to people with IDD and (b) that researchers reported empirical findings other than purely descriptive findings (i.e., a story of what happened in a single, or a handful, of cases). The fact that PCP had been around for three decades and only 15 studies met their criteria for inclusion speaks to the dearth of scientific research on PCP processes. They concluded that the body of evidence from their review was weak in regard to conventional criteria (see Downs & Black, 1998) for evidence-based practice. Nevertheless, their findings revealed that PCP had a positive, but moderate, impact on personal outcomes.

In summary, PCP processes have been widely used in the field of IDD for approximately 30 years. Although there is a limited body of scientific research supporting the benefits of PCP, the research findings that are available have shown that the PCP processes yield mostly positive results (Claes et al., 2010). Critics such as Osborne (2005) have argued that practice should not be so widespread given the limited scientific evidence that support its efficacy. However, it is reasonable to ask such critics. "What is your alternative to PCP processes, other than to do nothing at all?"

PCP: Common Values and Popular Processes

There is no universally accepted definition of a PCP process. However, there are features common to all of the leading PCP processes. These include:

1. **The active involvement of the person with the disability**. The person with the disability should be engaged in every step of the process, and if possible should direct the process.
2. **A facilitator who leads the PCP team through the planning process**, **but does not direct it**. The only criterion for membership on the PCP team is that someone must care deeply about the person with the disability and be committed to assisting him or her in the future. Certainly professionals from schools and service provider organizations can meet these criteria. However, it is family members, family friends, and friends of the person with the disability who are the most critical team members.
3. **A focus on problem solving and long-term planning**. Those involved in a PCP process identify a future vision for the person and develop plans so that the future vision becomes a reality. People are encouraged to make commitments and/or assume responsibilities for carrying out the plans and achieving the vision (Butterworth, Steere, & Whitney-Thomas, 1997; Nicoll & Flood, 2005; O'Brien & O'Brien, 2002).

Four popular PCP processes are MAPS, ELP, PATH, and the PICTURE Method. Each is briefly described below.

MAPS

MAPS was originally developed at McGill University in Montreal. At first it was an acronym for the "McGill Action Planning Strategy," but currently people just refer to it as MAPS. The process is driven by eight questions and information is recorded on flip charts over the course of several meetings. In comparison to other PCP processes, Wells and Sheehey (2012) and Westling and Fox (2009) reported that MAPS is especially useful when planning with children. Although everyone on the planning team can contribute to each question, some questions are more directed to specific planning team members. Each question, as well as essential information about the question, is provided below:

1. What is MAPS? (the facilitator explains the process)
2. What is the individual's history? (Family members are asked to speak and include key milestones)
3. What is your dream for the individual? (All members share brief dreams—these are future oriented)
4. What is your nightmare? (This question is included so that team members can work to avoid the undesirable outcomes)
5. Who is the individual? (Team members are asked to think of words to describe the individual, and this phase concludes by selecting three key descriptors from the brainstormed list).
6. What are the individual's strengths, gifts, and abilities? (The intent is to come up with a comprehensive listing of things the person does well and enjoys doing).
7. What are the individual's needs? (What people need to do and what resources are needed in order for the dreams from question #3 to be achieved, and the nightmares from question #4 to be avoided).
8. What is the plan of action? (A specific plan of action is developed) (Employment and Disability Institute, 2014; Vandercook, York, & Forest, 1989; Wells & Sheehey, 2012).

Essential Lifestyle Planning (ELP)

ELP was developed by Michael Smull and Susan Burke-Harrison in the 1980s on a project that involved returning people with IDD who were living in institutions to their home communities. Compared to other PCP approaches, there appears to be relatively more emphasis placed on listening closely to people with IDD in order to get a complete understanding of what is important to them in life when using ELP. Also, there is relatively less emphasis placed on group discussion and decision-making. A key value underlying ELP is that planning for a person is ongoing and never-ending. In ELP it is stressed that the work of planning is never finished; plans are always going to need to be refined based on implementation issues, anticipated and unanticipated outcomes, and changing circumstances

(Employment and Disability Institute, 2014; Smull, 2000; Smull & Sanderson, 2009).

An ELP has an administrative section (information about the person with IDD who is the focus of the planning process, as well as others who were was involved), a person's section (a positive reputation profile that provides information on good things about the person, and a list of priorities identified by the person), a support section (what support the person needs, and what people who know and love the person believe are important for the person to be healthy and safe), and an action plan section (actions to be taken to address discrepancies between what is present in the person's life and what the person wants differently). Plans are developed through an iterative process of listening, learning, and acting (Employment and Disability Institute, 2014; Smull, 2000; Smull & Sanderson, 2009).

A key feature of the ELP process is information gathering. Interviews with people with IDD are conducted apart from a group meeting. ELP group processes are less prescriptive than other PCP approaches. In fact, information gathered through ELP interviews can be used in combination with other PCP approaches if users have a preference for a different group planning process. Sample questions from an ELP interview protocol include: (a) What are some things people like about you? (b) What are some things you must have in order to have a good day? These are things you cannot do without. (c) What are some things you do not want in your life? These are things that make you have a bad day (Employment and Disability Institute, 2014; Smull, 2000; Smull & Sanderson, 2009).

PATH

Planning Alternative Tomorrows with Hope (PATH) was developed in the 1990s by some of the same people who developed MAPS. The multistep process is unique among PCP approaches because it requires a team to work backwards from the desired end point (known as the "North Star"). The North Star is the long-term vision for the person. During this initial step of the process the person with IDD is encouraged to express their values, passions, hopes and dreams for the future, and eventually a thorough description of the vision is recorded. The group facilitator directs the planning team from the North Star all the way back to the current day where the first steps to reach the vision are acted upon. By the end of the planning process there are several interim goals (e.g., 3 months, 6 months) (Employment and Disability Institute, 2014; Pearpoint, O'Brien, & Forest, 1998).

Group problem solving is stressed in PATH and special efforts are made to identify people and/or organizations that will take responsibility for moving the plan forward, as well as identifying strategies and dates when work will be completed and milestones achieved. PATH places a priority on assuring that commitments made during)the planning process are not empty promises. Documenting decisions made by the planning team is an important aspect of PATH, and deliberate strategies are implemented to keep the planning team together over an extended period of time (Employment and Disability Institute, 2014; Pearpoint et al., 1998).

The PICTURE Method (PICTURE)

PICTURE was developed by Holburn, Gordon, and Vietze's (2007). Similar to ELP, PICTURE emphasizes identifying discrepancies between the person's life now and the person's desired life in the future, and addressing discrepancies is the focus of the planning process. Compared to other PCP approaches, PICTURE places relatively more emphasis on involving professionals whose jobs require them to provide some type of support or service to the person. Also, PICTURE encourages conducting structured observations and questionnaires to collect information before a group meeting, and for sharing information from these efforts during the group planning process (which they call the PICTURE meeting). The PICTURE Meeting is structured around a 10-step process, the last step of which involves setting a date and time to follow up and evaluate the progress made on the action plan that was established.

The manual on how to use PICTURE contains the catch phrase "person-centered planning made easy" on its front cover. Ironically, the authors state on the second page that "the actual process of carrying out person-centered planning as described by its founders is neither brief nor easy" (Holburn et al., 2007, p. 2). The manual provides detailed descriptions of the procedures involved in the PICTURE approach, and compared to other PCP methods there appears to be more explicit acknowledgement of hard work and significant investment of time that PCP processes require. It is made clear that a planning team should expect to face obstacles and barriers as they move forward with the PICTURE process. There is an entire section of the manual devoted to troubleshooting and a significant amount of guidance is provided in regard to facilitating planning efforts.

PCP as a Component of a Support Needs Assessment and Planning Process

There are valid concerns about PCP processes. PCP is an umbrella term that can include a wide array of approaches and criteria are unclear for what actually does and does not constitute a PCP process. Therefore, planning efforts that are claimed to fall under the PCP umbrella can certainly be misguided and the concept of a PCP process can be misapplied. Also, the value of PCP approaches can be overstated due to a lack of empirical evidence.

Despite these concerns, it would seem impossible to truly understand someone's support needs in the community without the type information that is gathered through a PCP process. At face value, the logic of PCP processes is sound. The focus of PCP processes is on "planning for and working toward a positive future of a single individual" (Holburn & Cea, 2007, p. 167). Is there any other way to accomplish this other than through bringing together the most important people in the life of a person to participate in a series of discussions and planning activities? All PCP processes require: (a) collectively envisioning a better life for the person, (b) engaging in thoughtful discussions about how to make the vision a reality, (c) developing plans to reach goals, (d) identifying who will take responsibility for carrying out the plans, and (e) following up with periodic meetings to assess progress in achieving the vision. If there is a more reasonable way to proceed, then those criticizing PCP processes should bring forth an alternative proposal.

PCP processes intuitively make sense, because typically developing people engage in the same types of activities, albeit on an informal basis through private discussions with family members and friends. Whereas most typically developing people have the wherewithal to take actions on their own, pursuing desired life options is a more challenging endeavor for people with IDD in the absence of extra support. For instance, if a typically developing adult wants to change jobs it is certainly a big decision, but for many people with IDD changing jobs requires a commitment of time and effort from many different people. It is logical to assume that people with IDD need a more explicit and structured process to envision and plan for desired future life experiences. Furthermore, in the absence of a vision and a plan that pushes the service system to meet a person's individual needs, the most likely result is for a person to simply take what the service system has traditionally offered (e.g., segregated employment, congregate living).

The social-ecological model of disability calls for understanding people by the extra support they need in order to navigate the demands of settings and activities in which they want to participate. Any information from the support needs assessment scales that are reviewed later in this chapter will be of limited usefulness unless the results are considered in the context of what constitutes a meaningful, fulfilling life for a person. Support needs assessment scales do not provide insight in regard to what people want to do with their lives, but PCP processes do. Therefore, we endorse PCP as a component of a comprehensive support needs assessment and planning activities for people with IDD.

PCP processes are not designed to explicitly assess the type or intensity support needed by people with IDD. There are, however, support needs assessment scales that have been developed for this very purpose. In the next section several scales will be described and research findings supporting their reliability and validity will be summarized.

Assessment Scales to Measure the Support Needs of People with IDD

The impetus for developing support needs assessment scales

If one were to ask people with IDD and their families what innovations in service delivery by professionals they would most welcome, it is doubtful that many would clamor for new assessment scales. For years there has been a marketplace full of assessment related products to aid professionals in decision-making (e.g., IQ tests, AB scales, academic achievement tests, vocabulary and language assessments, vocational evaluation kits, self-determination scales). Although innovations leading to expanded job opportunities, greater choice in terms of places to live, new friends, and more fun things to do during free time would be of great interest to people with IDD and their families, the publication of yet another assessment tool would surely cause little excitement.

So, why have eight new scales to measure the support needs of people with IDD been created and findings regarding their reliability and validity been published in the professional literature since 2000? Interest in this area came from the new way of understanding people with IDD associated with the social-ecological model that was discussed earlier in this chapter. The field of IDD needed tools that were aligned with this new conceptualization.

It is worth repeating that the most salient differences between individuals with IDD and the general population is the nature and extent of supports they require in order to fully participate in daily life activities in school and society. People with IDD require extra support that others do not need to live in community homes, learn in neighborhood schools, work on competitive jobs, and participate as full members of an interdependent, modern society. Understanding people with IDD by their support needs is essential when planning for and developing appropriate supports that bridge the gap between people's current life experiences and conditions, and the life they aspire to have.

AAIDD's publication of the 9th edition of their definition and classification manual (Luckasson et al., 1992) in the early 1990s moved the social-ecological conceptualization of IDD to forefront of the field's research and scholarship agenda. Although understanding IDD as a mismatch between a person's capacities and environmental demands had been discussed in prior years (see Mercer, 1979; Pope & Tarlov, 1991), it was not until the 1992 manual was published that serious efforts were undertaken to develop tools and processes that were aligned with social-ecological thinking.

The AAIDD's 1992 manual (Luckasson et al., 1992) was revolutionary because it changed the meaning of ID from a *deficit trait* that resides inside of a person to a *state of functioning* within the context of everyday life. The authors stated that ID "is not a *trait* … Rather, mental retardation is a *state* in which functioning is impaired … This distinction between *trait* and *state* is central to understanding how the present definition … shifts the emphasis from measurement of traits to understanding the individual's actual functioning in daily living" (Luckasson et al., 1992, p. 10). The relationship between people's support needs and their functioning was also addressed. "The needs for support reflect how the individual functions … the presence or absence of supports can reciprocally influence functioning" (p. 11).

The authors of AAIDD's manual proposed a process for evaluating support needs that was not well received by researchers or practitioners. The process centered on evaluating people using a 4-point metric pertaining to the intensity of support people required. It became known as the ILEP approach due to the four intensity descriptors used in the metric: Intermittent, Limited, Extensive, and Pervasive. The authors called for planning teams to evaluate people's support needs across ten adaptive skill areas, psychological/emotional, physical health, and environmental considerations using the 4-point ILEP metric. There was also intent to replace traditional classification categories with descriptions of needed support. “Terms such as mildly, moderately, severely, or profoundly retarded will no longer be used. Thus, a diagnosis might well be ‘a person with mental retardation who needs limited supports in communication and social skills’” (p. 34).

Not only was there considerable controversy about the eliminating traditional, deficit-based classification categories based on IQ scores [i.e., mild (55–70), moderate (40–54), severe (25–39), and profound (24 or lower)], but many were concerned with the subjectivity of the process for coming with up with either descriptions of support needed or support-based classification categories. The 4-points on the ILEP scale were not operationally defined, and distinctions were unclear between the ten adaptive behavior skill areas (as well as the other areas) on which the ratings were to be applied. More to the point, there were no data to indicate that this process to evaluate support needs was defensible from a scientific perspective (Jacobson & Mullick, 1992; MacMillan, Gresham, & Siperstein, 1993, 1995).

In response to the unsuccessful launching of the ILEP support needs assessment and classification approach, the AAIDD convened a *Support Needs Assessment Task Force*. The task force was charged with developing a uniform procedure to assess the pattern and intensity of needed extraordinary supports of people with IDD that yielded psychometrically defensible results (Wehmeyer et al., 2009). The work of this task force resulted in the creation and publication of the *Supports Intensity Scale* (SIS) in 2004 (Thompson et al., 2004a). The original SIS is now known as the SIS-A (Supports Intensity Scale—Adult Version) since a children’s version (i.e., the SIS-C; Thompson et al.; in press) has been recently introduced. Additionally, researchers outside of the AAIDD, both within and outside of the USA, began working on creating new support needs assessment scales. In the next section we describe and summarize research findings on eight different scales on which psychometric properties have been reported in peer-reviewed professional journals.

Search Methodology and Inclusion Criteria

To identify relevant professional literature on support needs assessment scales, a computerized database search of PsychINFO and ERIC was conducted for the years 1994–2014. We used keyword searches of “support needs measurement” and “support needs assessment” to identify relevant articles. We first screened the abstracts for relevance and if an article met criteria for inclusion we examined its reference section for other potentially useful studies. These efforts resulted in locating 28 articles from peer-reviewed journals where findings relevant to the reliability, validity, and/or factor structure of a scale purporting to measure the support needs of people with disabilities were reported.

We also located a considerable amount of grey literature regarding support needs assessment scales during the course of our literature search. These sources varied greatly in terms of the quality. For instance, the SIS-A and the NC-SNAP have user manuals that include information on the technical properties of the scales. Also, the Human Services Research Institute (HSRI) has published several reports that include findings from data analyses as well as thoughtful commentary regarding the use of support needs assessment tools for purposes of resource allocation and individual budgeting. However, there were numerous other sources that provided information about tools or methods to assess people’s needs for support that appeared to have very limited empirical support or theoretical justification. Therefore, despite the availability of some excellent resources outside of the peer-reviewed literature, we were unable to come up with criteria for deciding whether or not to include grey literature sources in our review. For the purpose of this chapter, we decided to limit our review to information on support needs scales that have been published in peer-reviewed journals.

Descriptions of each scale are provided below. The amount and quality of information available on the eight scales varied considerably. Some of the scales are proprietary and it would be quite difficult to get a thorough description without actually purchasing the materials. Others have extensive information online, including sample protocols.

Care and Needs Scale (CANS)

This scale was developed in Australia for use with the Traumatic Brain Injury population. An interviewer gathers information on 24 items and rates each item on a 1–8 scale (larger numbers indication greater levels of support need). Results provide a profile of support needed in relation to the 24 items (Tate, 2004).

Checklist of Child Characteristics (CCC)

This scale was developed in the Netherlands for use with children with profound and multiple learning difficulties. An individual who knows the child being assessed completes the checklist with respect to type of support needed. Results from the checklist can be transformed into support profiles that indicate the types of support necessary for education and care (Tadema et al., 2007).

I-CAN

This scale was developed and field-tested in Australia. It was designed for use primarily with people with IDD, but can be used with other disability populations. It is completed through a structured interview. According to Riches et al. (2009a), it "contains items in ten domain scales: four domains covering Health and Well Being (HWB) and six domains covering Activities and Participation (A&P). Each item is rated for support according to both frequency (from 0 = never through 5 = constant support throughout the day) and level of support (from 0 = none through 5 = total physical assistance from one or two people). Other quantitative data collected included disability and demographic data. Qualitative data included health conditions and behaviors requiring support, reasons for change in support needs, preferences and feedback about the instrument and the assessment process" (p. 329).

I-CAN results provide a profile of support needed across multiple support domains, but no standard scores are provided (Riches et al., 2009b).

Need of Support and Service Questionnaire (NSSQ)

The NSSQ was developed and field-tested in Sweden. It was originally designed for use with people with mental health disorders requiring psychiatric services. The authors indicate, however, that the NSSQ could be used with any population needing community social services. It is completed through a structured interview and includes 33 items that are divided across three domains: (1) Socio-demographic information and present living situation: (2) Need of support in activities of daily living: and (3) Need of service provided by the public health and social service sector. Results generate a profile of support needed in relation to the 24 items (Jansson et al., 2005).

North Carolina-Support Needs Assessment Profile (NC-SNAP)

This instrument was originally developed and field-tested in US state of North Carolina, and was designed for use by the state's developmental disabilities agency. Examiners score 11 items on a 5-level scale in three support domains (daily living, health care, and behavioral) through interviewer or observation. Results are used to assign people into one of five support intensity levels (Hennike et al., 2006).

Service Need Assessment Profile (SNAP)

The SNAP was developed and field-tested in Australia, and was intended for use with "different disability types and levels of severity" (Harries, Guscia, Kirby, Nettelbeck, & Taplin, 2005, p. 25). It is completed through interview, and includes 29 items that are divided across five domains. Results provide a profile of support needed in relation to the 29 items (Harries et al., 2005).

Supports Intensity Scale: Adult Version

The SIS-A was developed in the USA and field tested throughout North America. Completing the scale requires interviewing at least two people who know the person being assessed, either in separate or group interviews. It was designed for use with people with IDD. Although it has been used with other disability populations, the standardization sample on which the standard scores are based is a population of people with IDD and includes three sections. Section 1 is comprised of 6 subscales (49 items) that produce norm-referenced, standard scores for each subscale (a support needs profile) as well as a standardized composite score (SNI score). The standard scores indicate the relative intensity of people's support needs in relation to a representative sample of adults with IDD. Each item describes a life activity and is rated against three support dimensions (frequency, type, and time). Each dimension is rated on a 5-point scale. Section 2 (8 items) and Section 3 (29 items) do not produce standard scores, but these sections provide measures of support needs associated with protection and advocacy activities, exceptional medical needs, and exceptional behavioral needs (Thompson et al., 2004a). The SIS-A has been translated into 13 languages (AAIDD, 2013).

Supports Intensity Scale: Children's Version

The SIS-C (Thompson et al., in press) was recently developed in the USA and field tested throughout North America (Thompson et al., 2014). Completing the scale requires interviewing at least two people who know the person being assessed, either in separate or group interviews. It was designed for use with children with IDD, ages 5–16. It includes two sections. Section 1 does not produce standard scores, but provides measures of support needs associated with exceptional medical (19 items) and behavioral (14 items) needs. Section 2 is comprised of 7 subscales (61 items) that produce norm-referenced, standard scores for each subscale (support needs profile) as well as a composite score (SNI score). The standard scores indicate the relative intensity of a child's support needs in relation to a representative sample of children with IDD (ages 5–16). Each item describes a life activity and is rated against three support dimensions (frequency, type, and time). Each dimension is rated on a 5-point scale (Thompson et al., in press).

The Reliability and Validity of Support Needs Assessment Scales

Measuring Psychological Constructs

As mentioned previously, support needs are considered to be a psychological construct referring to the pattern and intensity of supports necessary to participate in culturally valued/normative activities of daily life. If someone has extraordinary support needs it means there is a degree of mismatch between the person's "personal competency" and the "demands of everyday environments" that most others in society do not experience. According to a social-ecological conceptualization of IDD, by definition people with IDD have extraordinary needs for support.

Within the population of people with IDD, there are significant differences in regard to the types and intensities of support people require. Because a useful measurement tool brings individual differences to light, a support needs assessment scale for people with IDD must reflect relevant differences. There can be quantitative (i.e., number of supports needed) as well as qualitative (type or nature of support needed) differences. Individual differences can be communicated through a profile of support needs that reveals the pattern of extra supports that are required in different domains of life. Also, individual differences can be communicated by indicators of relative intensity of support required by different people. Although there are many different ways to communicate individual differences, a support needs assessment scale that yielded the same information on everyone (i.e., provided no indication of individual differences) would be of no value.

Assessment scales must be reliable and valid in order to have merit. In the next two sections we summarize research findings from the published literature that have been reported regarding the reliability and validity of eight support needs scales.

Reliability

Reliability refers to the consistency of an assessment. There are multiple indices available to researchers to investigate a scale's reliability. The nature of the scale (e.g., what it purports to measure, types of the items) and data characteristics (e.g., sample size) must be taken into consideration when deciding which indices to use (Salvia & Ysseldyke, 2007). Like other psychological constructs, a person's support needs are assumed to be relatively stable over time and its measurement should not be influenced by extraneous factors such as who is administering the assessment. Therefore, a support needs scale that accurately measures the construct must yield consistent (i.e., reliable) results. However, although reliability is a necessary condition for judging the validity of a scale, it is also insufficient (Salvia & Ysseldyke, 2007). In other words, just because a scale provides a reliable measure of support needs does not mean it provides a valid measure of support needs.

To assess scale reliability, researchers have investigated the extent to which the same results occur when different assessors are involved in administering the scale (interrater reliability) and when scales are administered at different times (test–retest reliability). Also, findings pertaining to the internal consistency of items on a scale (i.e., if items are truly measuring the same construct they should highly correlate with one another) as well as the split-half reliability (if a scale is divided into two parts, the two sections should have a strong correlation) have been reported. The reliability findings for support needs assessment scales that have been reported in peer-reviewed, professional journals are summarized in Table 7.1.

Of the 19 articles published in peer-reviewed journals where reliability data on support needs scales were reported, 12 provided findings relevant to the SIS-A, including the original English language version and 4 translated versions. Information on reliability was found in two articles relevant to the SNAP, and the CCC, SIS-C, I-CAN, NSSQ, and NC-SNAP, each had one article where findings were reported. No reliability findings were found for the CANS. Collectively, the support needs scales in Table 7.1 have strong reliability properties (with the possible exception of the CCC, discussed below). A degree of publication bias may be at play, as it would likely be difficult to justify publishing an article using data from a scale that did have reasonably strong reliability.

Internal Consistency

The most easily comparable findings between studies are those pertaining to the internal consistency of items. This analysis does not require a separate administration of a scale. Cronbach's coefficient alpha was used by researchers to determine the degree of homogeneity among items on the SIS-A, SIS-C, and CCC. Findings reveal that data from the SIS-A and SIS-C generated high correlation coefficients, providing strong evidence of internal consistency based on the guidelines provided by Landis and Koch (1977). These findings suggest that users of the SIS-A and SIS-C can have confidence in the internal consistency of these scales. It is noteworthy that Thompson et al. (2014) were the only researchers to examine internal consistency using coefficient omega. They reported that coefficient omega is appropriate to use in conjunction with coefficient alpha when factor loadings are not identical for all items, which was the case for the SIS-C.

The alpha coefficients reported by Tadema et al.'s (2007) for the CCC were extremely low, but it is probable that the manuscript simply contained a misprint. The only sentence in Tadema et al.'s manuscript in regard to reliability is, "The results indicate that it is a reliable instrument (in all three categories alpha ranges from 0.091 to 0.097)" (p. 151). If the coefficients actually are near 0.09 then the conclusion in the text is wrong because the items in this scale are most certainly not homogeneous (and the scale is not reliable). However, based on the accompanying text, it seems more likely that the alphas are actually in the 0.91 to 0.97 range and the additional "0" was simply a typographical error.

Test–Retest

Test–retest findings were reported for the SIS-A, NC-SNAP, NSSQ, and I-CAN. Reliability coefficients for the SIS-A, NC-SNAP, and NSSQ were quite strong under test–retest conditions, based on guidelines for evaluating the reliability of adaptive behaviors scales provided by Cicchetti and Sparrow (1981). In contrast, the test–retest coefficients for the I-CAN were mixed, with some subscales being quite weak to the point of being meaningless (e.g., an *r* as low as >01 was

Table 7.1 Reliability findings reported in peer-reviewed journals for support needs assessment scales

Scale	Source	Population	Findings
CCC	Tadema et al. (2007)	Mixed disability child population	*Internal consistency:* alphas ranged from 0.091 to 0.097
I-CAN	Riches et al. (2009b)	Mixed disability adult population	*Interrater:* r was 0.99 (all domains very high rs) based on observer scoring of interviews; *Test–retest:* rs on 19 sections ranged from 0.05 to 0.93 at 1-year and 0.01 to 0.94 at 2-year intervals
NSSQ	Jansson et al. (2005)	Individuals with a variety of psychiatric disabilities	*Test–retest:* mean percentage agreement was 92.2 % with the corresponding mean kappa of 0.80; *interrater:* mean percentage agreement was 87.2 % with the corresponding mean kappa of 0.68
NC-SNAP	Hennike et al. (2006)	IDD	*Interrater:* $r=0.73$
SNAP	Guscia, Harries, Kirby, Nettelbeck, and Taplin (2005)	IDD; TBI; psychiatric disabilities	*Test–retest:* rs ranged from 0.86 to 0.97; *interrater:* rs ranged from 61 to 0.91; disaggregating for 3 subgroups, the range of rs for test–retest and interrater were 0.65–0.93 for people with ID, 0.49–0.90 people with TBI, and 0.25 to 0.71 for people with psychiatric disabilities
SNAP	Guscia, Harries, Kirby, and Nettelbeck (2006b)	IDD	Descriptive data show that 22 people who were assessed in order to establish funding levels were scored as having markedly more intense support needs than when they were assessed previously for research purposes
SIS-A (Dutch translation)	Bossaert et al. (2009)	Mixed disability population, but no ID	*Internal consistency:* alphas ranged from 0.58 to 0.94
SIS-A (Chinese translation)	Chou, Lee, and Chang (2013)	IDD	*Internal consistency:* alphas ranged from 0.87 to 0.93
SIS-A (Dutch translation)	Claes, Van Hove, Vandelvelde, van Loon, and Schalock (2012)	IDD	*Interrater:* interrespondent (consumer v staff) rs ranged from 0.31 to 0.80; staff consistently rated support needs as “more intense” compared to consumers
SIS-A (Spanish translation)	Jenaro, Cruz, Perez, Flores, and Vega (2011)	Psychiatric disabilities	*Internal consistency:* alphas ranged 0.83 to 0.94; interrater rs 0.67 to 0.98

SIS-A (French translation)	Lamoureux-Hebert and Morin (2009)	IDD	*Internal consistency:* alphas ranged 0.89–0.98
SIS-A (French translation)	Morin and Cobigo (2009)	IDD	*Interrater:* interinterviewer and interrespondent reliability *r*s ranged from 0.79 to 0.92 and 0.87 to 0.92 for the two conditions respectively
SIS-A (Spanish translation)	Ortiz, Rio, Rodriguez, and Robaina (2010)	Psychiatric disabilities	*Internal consistency:* alphas ranged from 0.95 to 0.99
SIS-A (Dutch translation)	Smit, Sabbe, and Prinzie (2011)	Physical disabilities (48 % also ID)	*Internal consistency:* alphas ranged from 0.71 to 0.98
SIS-A (English version)	Thompson et al. (2002)	IDD	*Internal consistency:* alphas ranged from 0.97 to 0.99
SIS-A (English version)	Thompson, Tassé, and McLaughlin (2008)	IDD	*Interrater:* interrespondent, interinterviewer, and mixed interrater *r*s ranged from 0.73 to 0.93, 0.74 to 0.96, and 0.66 to 0.90 for the three conditions respectively
SIS-A (English version)	Shogren et al. (2014)	IDD	*Interrater reliability of P&A section:* interrespondent, interinterviewer, and mixed interrater *r*s were 0.83, 0.71, and 0.70 for the three conditions respectively; *internal consistency of P&A section:* alpha was 0.87; *split half for P&A section:* $r = 0.81$; *internal consistence of SIS-A with P&A included*: alphas ranged from 0.92 to 0.99
SIS-A (Spanish translation)	Verdugo, Arias, Ibanez, and Schalock (2010)	IDD	*Internal consistency:* alphas ranged from 0.90 to 0.99. *Test–retest: rs* ranged from 0.84 to 0.93 (corrected *rs* ranged from 0.90 to 0.98); *interrater: rs* ranged from 0.60 to 0.84 (corrected *rs* ranged from 0.62 to 0.86); *split half:* coefficients ranged from 0.86 to 0.98.
SIS-C	Thompson et al. (2014)	IDD	*Internal consistency:* alphas ranged from 0.93 to 0.95 and omegas ranged from 0.97 to 0.99

reported). Whereas time between test administrations ranged from 1 day to 1 month with test–retest studies concerning the SIS-A, NC-SNAP, and NSSQ, Riches et al. (2009b) collected I-CAN test–retest data at 1 and 2 year intervals. It is logical to assume that, in general, the shorter the interval the higher will be the estimated reliability due to the fact that there would be fewer confounding events (e.g., changing health status) occurring between administrations. Therefore, the low test–retest reliability on some of the I-CAN subscales may be attributable to the much longer length of interval between administrations in comparison to procedures used by researchers investigating the other scales.

Considering the different intervals used in assessing test–retest reliability begs a broader research question concerning the extent of time that one would expect people's intensity of support needs to change and therefore prompt a reassessment. How long do support needs assessment results remain valid in the absence of a clear intervening event such as a major trauma that significantly alters physical-motor functioning? At this time there is no empirical basis to suggest when a reevaluation is warranted, although it is undoubtedly true that over time people's support needs do change in important ways.

Interrater Reliability

Although researchers investigating the I-CAN's test–retest reliability might have used an overly stringent process for assessing test–retest reliability of this scale due to the length of their test administration intervals, their process for assessing interrater reliability was considerably less stringent than procedures used by the other researchers. The I-CAN's interrater reliability did not involve two separate administrations of the scale. Rather, their data were collected during a single administration involving two observers: one who conducted the interview and scored the scale and one who observed the interview and scored the scale as it took place (Riches et al., 2009b). The near perfect coefficients of 0.99 were not surprising when considering that both recorders were observing the exact same event. It could be argued that these researchers investigated interobserver reliability instead of interrater reliability.

For the SIS-A, SNAP, NC-SNAP, and NSSQ, researchers used separate administrations. Other than the fact that there were two administrations, an "apples to apples" comparison of the studies is a challenge to the different procedures used. Some investigations involved combinations of different interviewers (e.g., Thompson et al., 2008) while others used the same pair of interviewers for all cases (e.g., Verdugo et al., 2010). Some investigations involved different respondents for each interview (e.g., Hennike et al., 2006), while others used the same respondents and only the interviewers were different (e.g., Guscia et al., 2005). There were some investigations where both different interviewers and different respondents were involved in the two separate administrations of their scale (Thompson et al., 2008). Morin and Cobigo (2009), Shogren et al. (2014), and Thompson et al. (2008) attempted to parcel out differences in reliability due to having different interviewers or different respondents. Their data revealed consistently strong reliability indicators under both conditions.

Despite differences in procedures, based on Cicchetti and Sparrow (1981) guidelines, interrater reliability was good to excellent for SIS-A, NC-SNAP, and NSSQ. Thompson et al.'s (2008) finding that interviewer training significantly increased interrater reliability has particular relevance for jurisdictions that are considering using support needs scales to inform high-stakes decisions, such as resource allocation. Also, Claes, Van Hove, van Loon, Vandevelde, and Schalock's (2009) interrespondent study was particularly interesting. They compared the responses on SIS-A items for separate interviews with support staff and people with IDD. Their data revealed that ratings from the two groups were reliable in the sense that people whom the staff rated as having comparatively higher or lower support needs relative to others in the study were the same people who rated themselves as having higher or lower support needs relative to others. However, people with IDD also consistently rated themselves as having less intense support needs in comparison to ratings by paid support staff.

There could be several plausible hypotheses for the parallel, but unequivalent, staff and self-advocate ratings. Prior research has suggested that many people with IDD attempt to cloak their disability because of the stigma associated with being labeled (e.g., Edgerton, 1967). Also, people with IDD may not be fully aware of, and therefore may not fully consider, their vulnerabilities (Greenspan, Loughlin, & Black, 2001). On the other hand, it could be that paid staff has a tendency to overprotect people with IDD and therefore overestimate the support they need. There is an abundance of historical precedence for people without disabilities "over supporting" people with disabilities, sometimes to the point of stripping away people's dignity (Wehmeyer, 2013). The Claes et al. (2009) study highlights the importance of obtaining perspectives on support needs from multiple respondents, including people with disabilities, as well as the importance of probing respondents when conflicting information surfaces.

Validity

The concept of test validity refers to the extent to which an assessment tool truly measures the construct (in this case, support needs) that it is suppose to measure. Although this description may seem straightforward, assessing the validity of any assessment instrument requires multiple evaluative judgments that are based on empirical evidence as well as theoretical justification (Salvia & Ysseldyke, 2007). Moreover, judgments about validity require multiple investigations that through converging evidence enable one to have increasing (or decreasing) confidence in the validity of an assessment scale.

Historically, there have been three general classes of evidence related to the validity of an assessment tool: content validity, criterion-related validity, and construct validity. While acknowledging that the boundaries between different types of validity can be blurry, Salvia and Ysseldyke (2007) succinctly describe each type of validity in the following way: "evidence related to test content as content validity; evidence of the relationship between the test and other performances as criterion-related validity; and evidence related to the internal structure, evidence of convergent and discriminant power, and evidence of the consequences of testing as construct validity" (p. 145). Evidence supporting each type of validity for eight supports needs assessment tools are summarized in the following sections.

Content Validity

Content validity refers to evidence showing a scale's content has been carefully examined. For example, have the developers of a scale provided evidence that assessment items were based on a theoretical model and/or a review of professional literature? Were experts, other than the scale developers, involved in making judgments regarding the appropriateness of items included in the scale or the comprehensiveness of item content?

Thompson et al. (2002) provided content validity evidence for the SIS-A by explaining the scale's connection with the conceptual work of AAIDD's 9th edition of its definition and classification manual (Luckasson et al., 1992) and describing how a literature review involving 33 descriptors and approximately 1500 sources were used to generate an initial item pool of 130 indicators of support needs. Their next step in the development of this scale was to use Q-Sort methodology with 50 experts in the field of IDD to group the indicators into 12 initial support domains that served as the structure for the pilot version of the scale. Translated versions of the SIS-A have also employed additional methods to promote content validity. For example, Verdugo et al. (2010) used as expert judges and a systematic agreement analysis process to assess the adequacy of the Spanish translation.

In regard to the SIS-C, the first step of the research team was to pull items from the SIS-A that at face value appeared to be as applicable for children as they were for adults (e.g., extra support needed for toileting). After that, the same process to develop the SIS-A (i.e., literature review, Q-Sort by team of experts) was used to develop a pilot-test version of the SIS-C (Thompson et al., 2014).

Content validity evidence for other support needs scales has been less thoroughly described. Riches et al. (2009b) made reference to a precursor of the I-CAN that was developed in the late

1990s and early 2000s. Upon review of the references cited by the authors, it appears that an instrument called the SCAN (Supports: Classification and Assessment of Needs) provided the basis for the I-CAN. The SCAN was developed based on a review of the professional literature and was intended to theoretically align with the World Health Organization's (2001) International Classification of Functioning, Disability and Health (ICF) model of disability (Riches, 2003).

As for the NSSQ, Jansson et al. (2005) reported that initial item development was based on needs most frequently reported in prior studies of people with psychiatric disabilities. Also, a questionnaire designed by the Swedish National Board of Health and Welfare was used to guide item creation. Once an initial item pool was created, the NSSQ was further developed "in close cooperation with psychiatric care and social service providers as well as with the clients" (p. 466). The final step for the NSSQ before field-testing was to collect comments from "staff in psychiatric care and social services, clients and relatives of the clients" and "based on these opinions, adjustments were made and the final format was compiled" (p. 466).

The CANS and CCC, like the I-CAN, were also intended to be scales that were theoretically aligned with the World Health Organization's (2001) International Classification of Functioning, Disability and Health (ICF) model of disability. For the CANS, the authors examined 10 scales relating to rehabilitation with people TBI with a critical eye toward modifying items to more adequately measure "the variety and extent of support needs" (p. 446) in relation to typical environments encountered after leaving a more specialized rehabilitation or hospital setting. For the CCC, researchers solicited expert feedback from 22 "carers and teachers" who were employed at special education centers in the Netherlands (Tadema et al., 2007).

No information specific to content validity evidence for the NC-SNAP or SNAP was located. This does not mean that evidence for content validity was not collected for these scales. Rather, no information was reported in the peer-reviewed journals on which this review is based.

Criterion-Related Validity

An assessment has criterion-related validity when data suggest it is effective in predicting criterion associated with a construct (Salvia & Ysseldyke, 2007). It can be established when criterion measures are obtained at the same time as the assessment scores and data reveal that assessment scores accurately estimate scores from the related criterion measure. For example, in terms of a support needs assessment scale, researchers could demonstrate criterion validity of a scale if scores were positively correlated with respondent reports of the intensity of support needed by the person being assessed. Evidence for criterion-related validity can also be gathered when assessment scores are related to a measure that is logically associated with the construct. For example, it is logical to assume that a measure of the intensity of supports a person needs would have a reciprocal relationship with a measure of personal competence, such as an IQ score or AB scale score.

Table 7.2 summarizes evidence for criterion-related validity that has been reported on the support needs scales included this review.

As mentioned earlier, there can be ambiguity when determining what types of evidence supports different aspects of validity (i.e., content, criterion, or construct). This was the case in this review when deciding whether correlations between scores on support needs scales and single measures of personal competence pertained to criterion-related or to construct validity. For instance, Verdugo et al. (2010) discussed the correlation between SIS-A scores and AB scores in the construct validity section of their article, whereas Guscia et al. (2006a) reported SNAP and AB correlational findings in their criterion-related validity section. The matter comes down to how criterion-related and construct validity are defined and interpreted.

In one sense, support needs and personal competences are related constructs because of their reciprocal relationship (as personal competence decreases it is logical to assume that support needs increase), and therefore investigating the relationships between the two types of measures pertains to criterion-related validity. In another

Table 7.2 Criterion-related validity findings reported in peer-reviewed journals for support needs assessment scales

Scale	Source	Research Method	Findings
CANS	Tate (2004)	CANS scores were correlated with two measures of functional outcome (the CHART and SPRS)	Coefficient*s* ranged from 0.46 to 0.85 for the sections of the CANS with sections of these two instruments
I-CAN	Riches et al. (2009b)	I-CAN domain scores were correlated with adaptive behavior measures (the ICAP)	Coefficients ranged from 0.45 to 0.62 with the I-CAN and ICAP
NSSQ	Jansson et al. (2005)	NSSQ scores were correlated with scores from the Global Assessment of Functioning (GAF) scale and Social and Occupational Functioning Assessment Scale (SOFAS)	Coefficient*s* ranged from 0.26 to 0.49 for the sections of the NSSQ with sections of these other two instruments
SNAP	Guscia, Harries, Kirby, Nettelbeck, and Taplin (2006a)	The SNAP was correlated with scores from the SIS-A & ICAP, as well as staff estimates of support needs. For comparison, SIS-A and ICAP scores were also correlated with staff estimates.	The "SNAP/ SIS-A" coefficient was 0.79, the "SNAP/ICAP coefficient was 0.78. The coefficients of the SNAP, SIS-A, and ICAP scores with "staff estimate" were 0.60, 0.79, and 0.78 respectively.
SIS-A (Dutch translation)	Bossaert et al., (2009)	A subset of SIS-A scores shared factor loadings with items measured on two adaptive behavior scales	The shared factor loadings provides evidence of the relationships between the 3 scales
SIS-A (English version)	Brown, Ouellette-Kuntz, Bielska, and Elliott (2009)	SIS-A scores were correlated with three subscale scores on the SIB-R	Coefficients between SIS-A and SIB-R ranged from 0.15 to 0.93
SIS-A (Dutch translation)	Claes et al. (2009)	SIS-A scores were correlated with subscale scores on the Vineland Z	Coefficients between SIS-A and Vineland-Z ranged from 0.37 to 0.89
SIS-A (English version)	Harries et al. (2005)	SIS-A scores were correlated with two AB measures: the ICAP and the ABS	Coefficients between SIS-A and ICAP section scores ranged from 0.64 to 0.94; coefficients between SIS-A and ABS section scores ranged from 0.58 to 0.94
SIS-A (Spanish translation)	Jenaro et al. (2011)	SIS-A scores were correlated with Global Assessment of Functioning (GAF) scores	Coefficients between SIS-A scores and GAF scores ranged from 0.49 to 0.62
SIS-A (French translation)	Lamoureux-Hebert and Morin (2009)	SIS-A scores were correlated with two measures level of intellectual severity (mild, moderate, severe, profound)	Coefficients between SIS-A scores and severity of intellectual disability classification ranged from 0.56 to 0.69
SIS-A (French translation)	Lamoureux-Herbert, Morin, and Crocker (2010)	SIS-A scores correlated with SIB-R measures of challenging behavior (internalized, asocial, externalized, general)	Coefficients ranged from 0.18 to 0.36 between SIS-A scores the SIB-R subscales measuring challenging behavior; correlations were of similar magnitude for a sample with mild ID and a sample with moderate ID

(continued)

Table 7.2 (continued)

Scale	Source	Research Method	Findings
SIS-A (Spanish translation)	Ortiz et al. (2010)	SIS-A scores were correlated with Global Assessment of Functioning (GAF) scores	Coefficients ranged from 0.57 to 0.67 between SIS-A scores and GAF scores
SIS-A (English version)	Thompson et al. (2002)	SIS-A scores were correlated with rater estimates of support needs corresponding to each subscale domain as well as overall needs; SIS-A scores were correlated with ICAP scores	Coefficients for "SIS-A/Rater Estimates" scores ranged from 0.28 to 0.65.; coefficients for "SIS-A/ICAP" scores ranged from 0.11 to 0.67
SIS-A (Spanish translation)	Verdugo et al. (2010)	SIS-A scores were correlated with rater estimates of support needs corresponding to each subscale domain as well as overall needs; SIS-A scores were correlated with ICAP scores	Coefficients for "SIS-A/Rater Estimates" scores ranged from 0.64 to 0.93; coefficients for "SIS-A/ICAP" scores ranged from 0.49 to 0.59

Note: All coefficients in table are reported as absolute values

sense, the relationship between the two types of measures provides evidence of whether or not separate constructs are being measured, and therefore findings pertain to construct validity. A near perfect negative correlation (e.g., $r=-1.0$) would provide evidence against the construct validity of a support needs scale because it would suggest that instead of developing a new scale measuring a new construct, what was developed was actually an alternative assessment for the other measure (i.e., a −1.0 correlation with an AB scale would suggest that the "new" support needs scale was in reality just another way to measure of adaptive behavior). For purposes of this chapter, we decided to include findings of correlations between support needs scales and scores from assessments of personal competence (e.g., IQ or AB scores) in the criterion-related validity section. In the construct validity section, however, we have included findings related to the relationship between support needs scores and broader indicators associated with personal competence (e.g., multivariate measures of personal independence).

In all of the studies where the relationship between personal competence measures (i.e., AB scores and IQ scores) and measures of support needs were examined, it was noteworthy that all of the correlations were in the expected direction (note that absolute values were reported in Table 7.2 for clarity). That is, as personal competence scores decreased the intensity of support needs scores increased. However, the magnitude of the correlations were never too high to suggest that a support needs scale was measuring the same construct as a personal competency scale. The highest r values reported were by Harries et al. (2005) who indicated that the "community self-sufficiency" score on the ABS had a 0.94 correlation with the SNI (composite) score on the SIS-A and the "personal living skills" score on the ICAP had a 0.94 correlation with the "home living activities" subscale score on the SIS-A. It is, however, important to acknowledge that only 5 of the 56 correlations produced in Harries et al.'s (2005) investigation of SIS-A, ICAP, and ABS scores (<9 %) yielded coefficients equal to 0.90 or higher. Guscia et al. (2006a) reported the largest correlation between an adaptive behavior scale score and a score on a support needs scale other than the SIS-A, indicating that the SNAP's correlation with the ICAP was 0.78.

Table 7.2 shows that coefficients between support needs measures and personal competency measures were generally in the 0.40–0.70 range. The exceptions outside of this range were often reasonable upon closer examination of findings. For example, the "Motor Skills" section of the

ICAP and the "Social Activities" subscale of the SIS-A had a very low *r* value of 0.11 (Thompson et al., 2002). A low correlation between these two measures is logical given that motor limitations would not be expected significantly impact on supports a person needed to engage socially with others. In contrast, the "Motor Skills" section of the ICAP and the "Home Living Activities" subscale of the SIS-A generated a relatively high *r* valued of 0.67. It makes sense that people with limitations in motor skills would require additional support to complete everyday activities in the home such as preparing meals and housekeeping.

Guscia et al. (2006a), Thompson et al. (2002), Verdugo et al. (2010), and Arnold, Riches, and Stancliffe (2014) all asked people who knew the person with the disability who was being assessed to provide global ratings regarding the intensity of the individual's support needs using a "Likert type" scale (e.g., from most intense to least intense). They compared these ratings with scores on their respective support needs scales (i.e., SNAP, SIS-A English, SIS-A Spanish, I-CAN). Collectively, these correlations were strong and positive.

Criterion-related validity findings were reported for every scale except the CCC. Overall, there is ample evidence that the support needs scales developed over the past 15 years have good criterion-related validity.

Construct Validity

A test can be determined to have construct validity if there is converging evidence that it truly measures the theoretical construct its developers intended it to measure. According to Salvia and Ysseldyke (2007), assessment scale developers must "rely on indirect evidence or inference" (p. 152) to establish construct validity. "In a real sense we don't validate inferences from tests or other assessment procedures; rather, we conduct experiments to demonstrate that the inferences are not valid. The continued inability to disconfirm the inferences in effect validates the inferences" (p. 152).

Table 7.3 provides summaries of findings related to the construct validity of the scales.

As with content and criterion validity, the findings across the 17 investigations of construct validity suggest that there is considerable evidence supporting the construct validity of the support needs assessment scales during the past 15 years. Converging evidence is apparent in the findings related to correlations with related measures, group differentiation, intercorrelations of subscale scores, and factor structure.

Relationship to Related Measures

Table 7.3 shows that there were multiple investigations focusing on the extent to which scores from a support needs scales corresponded to measures logically related to support needs. As mentioned earlier, the boundary where criterion-related validity ends and construct validity begins is unclear, but for this review evidence for construct validity was considered when the criterion measure was something other than a single test score on a personal competence scale (i.e., either an AB or IQ score) or single measure of support needs (e.g., a respondent's estimate of support needs)

Many of the criterion measures in Table 7.3 are amalgamations of data from multiple assessment tools and/or clinical judgment. Some of these measures are more logically related to support needs than others. For instance, Riches et al. (2009b) provided findings showing low to moderate correlations between I-CAN scores and measures of Quality of Life (QOL). It could be argued that the two constructs should not be related and, if they are, it is because there is a failure of the service system. The reasoning is that a person's quality of life should not be a function of their intensity of support needs, but QOL could be related to the intensity of *unmet* support needs. Put another way, a person with very intense support needs whose support needs were largely met should have a higher quality of life than someone with relative less intense support needs, but whose needs are not being met. QOL is best considered an outcome measure that is a function of the extent to which support needs are met, but is not necessarily related to individual differences in support needs.

The connection between support needs, services received and funding received would seem to be more defensible. Based on an assumption

Table 7.3 Construct validity findings reported in peer-reviewed journals for support needs assessment scales

Scale	Source	Research method	Findings
CANS	Tate (2004)	Logistic regression analyses were used to investigate the extent to which the CANS distinguished people who are "independent" from people requiring some level of support	Statistically significant differences on the CANS scores were found among subgroups with different levels of support needs.
I-CAN	Riches et al. (2009b)	Correlations between I-CAN scores and Quality of Life (QOL) measures were investigated stepwise multiple regression analyses, with support hours as the dependent variables, were used to investigate variance explained by I-CAN	Correlations ranged from 0.15 to 0.57 with ICAN scores and the QOL measures 40 % of daytime support hours and 27 % of paid 24-h support was predicted by I-CAN scores
I-CAN	Arnold et al. (2014)	Correlations between a classification algorithm developed based on I-CAN scores with clinical judgment regarding level of support need	For the 2 measures, *K* values of 0.65, 0.66, 0.75, and 0.94 were generated for the 4 samples
NC-SNAP	Hennike et al. (2006)	NC-SNAP, ICAP, and DDP (questionnaire addressing of needs for services) data were correlated with a "level of support need" determined by the jurisdictional agency.	The NC-SNAP had higher correlations with support levels compared to the ICAP and DDP.
SNAP	Guscia et al. (2006a)	SNAP, SIS-A, and ICAP scores were analyzed in regarding to discriminating between subgroups	Using multiple indices, the SNAP and SIS-A were superior to the ICAP in predicting categorization based on number of disabilities and severity of disability.
SIS-A (Dutch translation)	Bossaert et al. (2009)	SIS-A scores were correlated with a measure of "quantity of services" being received Confirmatory factor analysis (CFA) was used to test a six-factor model (based on the SIS-A subscale structure). Exploratory factor analysis was used to generate an alternative factor structure.	Coefficients ranged from 0.71 to 0.74 between SIS-A scores and the services measure CFA failed to support the six-factor model. EFA resulted in a shortened version of the SIS-A, including four factors and 22 items.
SIS-A (Chinese translation)	Chou et al. (2013)	SIS-A scores and scores generated from medical diagnostic information were correlated with a measure of "independent activities of daily living" (IADL)	Coefficients ranged from ranged from 0.64 to 0.79. between SIS-A scores and IADL measures, and the SIS-A had much higher correlations than medical diagnostic information
SIS-A (English version)	Harries et al. (2005)	Exploratory factor analysis was used to identify a factor structure emerging from a combination of SIS-A, ABVS, and ICAP data	Combined data from the 3 scales supported a unidimensional factor structure.
SIS-A (Spanish translation)	Jenaro et al. (2011)	SIS-A scores were correlated with length of disease (i.e., time since onset of mental illness)	Coefficients ranged from 0.17 and 0.23 for the SIS-A and length of disease

(continued)

Table 7.3 (continued)

Scale	Source	Research method	Findings
SIS-A (French translation)	Lamoureux-Hebert and Morin (2009)	SIS-A scores were correlated with two measures level of intellectual severity	Correlations between level of severity of ID and SIS scores ranged from 0.56 to 0.69
SIS-A (Dutch translation)	Kuppens et al. (2010)	Confirmatory Factor Analysis (CFA) was used to evaluate a six-factor model (based on the SIS-A subscale structure). Invariance analysis was used to test the factor structure across a variety of subgroups.	Goodness-of-fit tests associated with CFA provided evidence for a 6-factor model based on the subscale structure of the SIS-A. Invariance analysis revealed the 6-factor model was robust across subgroups
SIS-A (Dutch translation)	Smit et al. (2011)	ANOVA procedures were used to analyze SIS-A SNI scores in regard to discriminating between subgroups with different numbers of disabilities	SIS-A SNI scores predicted membership in one of three groups: a group with only one motor disability, a motor disability plus one other disability, a motor disability plus two or more other disabilities
SIS-A (English version)	Shogren et al. (2014)	Intercorrelations of SIS-A P&A scale with SIS-A subscale scores with 2 samples SIS-A P&A scale scores were correlated with DDP	Coefficients ranged from 0.79 to 0.90 in sample 1 and 0.69 to 0.85 in sample 2 Coefficients ranged from 0.18 to 0.74
SIS-A (English version)	Thompson et al. (2002)	Intercorrelations of subscales examined	Coefficients ranged from 0.47 to 0.88
SIS-A (Spanish translation)	Verdugo et al. (2010)	SIS-A scores were correlated with level of intellectual disability (ID) Intercorrelations of subscales examined	Coefficients between subscale scores and level of ID ranged from 0.42 to 0.52. Coefficients among subscales ranged from 0.78 to 0.88, with subscale total scores ranging from 0.90 to 0.95.
SIS-A (English version)	Wehmeyer et al. (2009)	Logistic regression analysis was used to investigate the application of SIS-A scores to predict membership in a jurisdiction's "extraordinary funding group" that was based on a variety of factors, including clinical judgment and data from the Developmental Disabilities Profile (DDP).	SIS-A was more effective in predicting an existing extraordinary funding group membership than the DDP, even though the existing extraordinary funding group was configured, in part, using DDP data.
SIS-C	Thompson et al. (2014)	Intercorrelations of subscales examined	Coefficients ranged from 0.67 to 0.85.

Note: All coefficients in table are reported as absolute values

that current service systems are at least somewhat responsive to individual differences in need, one would suspect that scores on a support needs scale would be positively correlated with measures of services and funding received. Hennike et al. (2006) provided this type of evidence for the NC-SNAP, Riches et al. (2009) provided it for the I-CAN, and both Wehmeyer et al. (2009) and Bossaert et al. (2009) provided it for the SIS-A.

Finally, there should be a strong association between measures of limitations in daily functioning and support needs. Chou et al. (2013), Lamoureux-Hebert and Morin (2009) and Verdugo et al. (2010) each examined SIS-A scores in relation to multidimensional measures of human functioning. Consistent with the single instrument personal competency findings presented in the criteria-evidence validity section, people with more functional limitations had more intense needs for support.

Group Differentiation

Table 7.3 presents findings from multiple studies that have shown that support needs assessment scales were useful in predicting group membership: (a) The CANS distinguished people reporting that they were "independent" from people reporting that they needed "some level of support"(Tate, 2004); (b) the I-CAN predicted support hours people received (Riches et al., 2009b); (c) the NC-SNAP predicted service need level (Hennike et al., 2006); (d) the SNAP predicted categorization based on number of disabilities and severity of disability (Guscia et al., 2006a), and (e) SIS-A predicted length of disease of mental health patients (Jenaro et al., 2011), quantity of disability conditions (Smit et al., 2011) and funding level (Wehmeyer et al., 2009).

Intercorrelation of Subscale Scores

Several research teams investigated the extent of intercorrelations of the SIS-A subscales. The logic underlying these investigations is that evidence of subscale intercorrelations (0.40 to 0.90 according to MacEachron, 1982) indicates the subscales are measuring the same overall construct. As can be seen Table 7.2, several translations of the SIS-A were investigated by multiple research teams and, in each instance, data were collected that showed strong intercorrelations among the subscales. Thompson et al. (2014) reported a similar finding for the SIS-C.

Factor Structure

Findings pertaining to a subscale intercorrelation must be balanced by evidence that subscales also provide unique information. Therefore, a key indicator of construct validity is factorial validity. Not only should items on an entire scale share variance in a manner that suggests a common construct is being measured, but because subscales suggest there are multiple dimensions of a construct, there should also be evidence for a multidimensional latent-factor structure. Investigations of factor structure have been limited to the SIS-A. Harries et al. (2005) combined data from SIS-A scores and two AB scales, and proceeded to conduct an Exploratory Factor Analysis (EFA) to investigate the factor structure of the combined data. They concluded that their data supported a unidimensional factor structure. Their findings raised the prospect of whether or not the SIS-A and AB scales were truly measuring different constructs.

Although Harries et al.'s (2005) conclusions were not unreasonable based on their findings, combining data from three scales could actually mask a factor structure that might have emerged if data from only one scale had been entered. Long (1983) and Norris and Lecavalier (2010) cautioned that because EFA does not place any constraints on data, EFA can be an arbitrary approach to obtaining an understanding of a construct. With EFA, there is a chance (due to lack of constraints) that a misleading factor structure may emerge due to random data.

A more meaningful test of the factor structure of a scale (and of a construct) is through confirmatory factor analysis (CFA) where factor structures are tested that are based on prior research or theory. Structural models are evaluated in terms of how well they fit or explain a data set. Goodness-of-fit (GOF) indices associated with CFA show how well data support (or do not support) a specific factor structure.

Bossaert et al. (2009) and Kuppens et al. (2010) used CFA to investigate the factor structure of the SIS-A. Bossaert et al. (2009) tested the 6-factor model suggested by the subscale structure of the SIS–A. Based on a variety of GOF indices, they concluded the 6-factor structure did not fit data collected on half of a large sample of people with wide array of primary disability conditions. They then used EFA to investigate an alternative factor structure on the other half of their data set. They found support for a 4-factor solution (Community Living, Personal and Social, Daily Living, Work).

In contrast, Kuppens et al. (2010) tested both the 6-factor subscale structure of the SIS-A and Harries et al.'s (2005) 1-factor solution on a very large sample ($n = 14, 862$) of persons with intellectual disability. Using a variety of GOF indices, the 6-factor solution had strong empirical support based on a subsample of their data set (the 1-factor did not and was rejected). The 6-factor solution was cross-validated on another subsample of their data set where GOF indices once again indicated strong empirical support. Further analyses were completed to investigate factorial invariance. The authors reported that the "… six-factor structure yielded strict factorial invariance across gender, age, and disability complexity, whereas invariance of factor configuration was merely established across disability severity groups" (p. 327).

The SIS-A is the only support needs scale whose factor structure has been investigated and there is a need for future researchers to investigate data collected on other scales to see if similar domains of support needs emerge. As for the SIS-A, additional CFA studies comparing factor structures are needed. In light of Shogren et al. (2014) findings that the P&A supplemental scale has strong psychometric properties, future studies should include data from this P and A in their analyses scale and investigate how its items affect the factor structure (Could a 7-factor structure emerge?). Also, the prospect of a hierarchical factor structure with first order factors (e.g., the subscales) sharing a common underlying, second order factor (as is implied by a composite SNI score), should be investigated.

Limitations

An important limitation of this review was the omission of findings from the grey literature. There could very well be evidence to support the reliability and validity of the scales beyond what has been reported in peer-reviewed journal articles. Anyone considering using any of the scales included in this review should investigate other information that could be available in regarding a scale's psychometric properties.

Planning with People with IDD

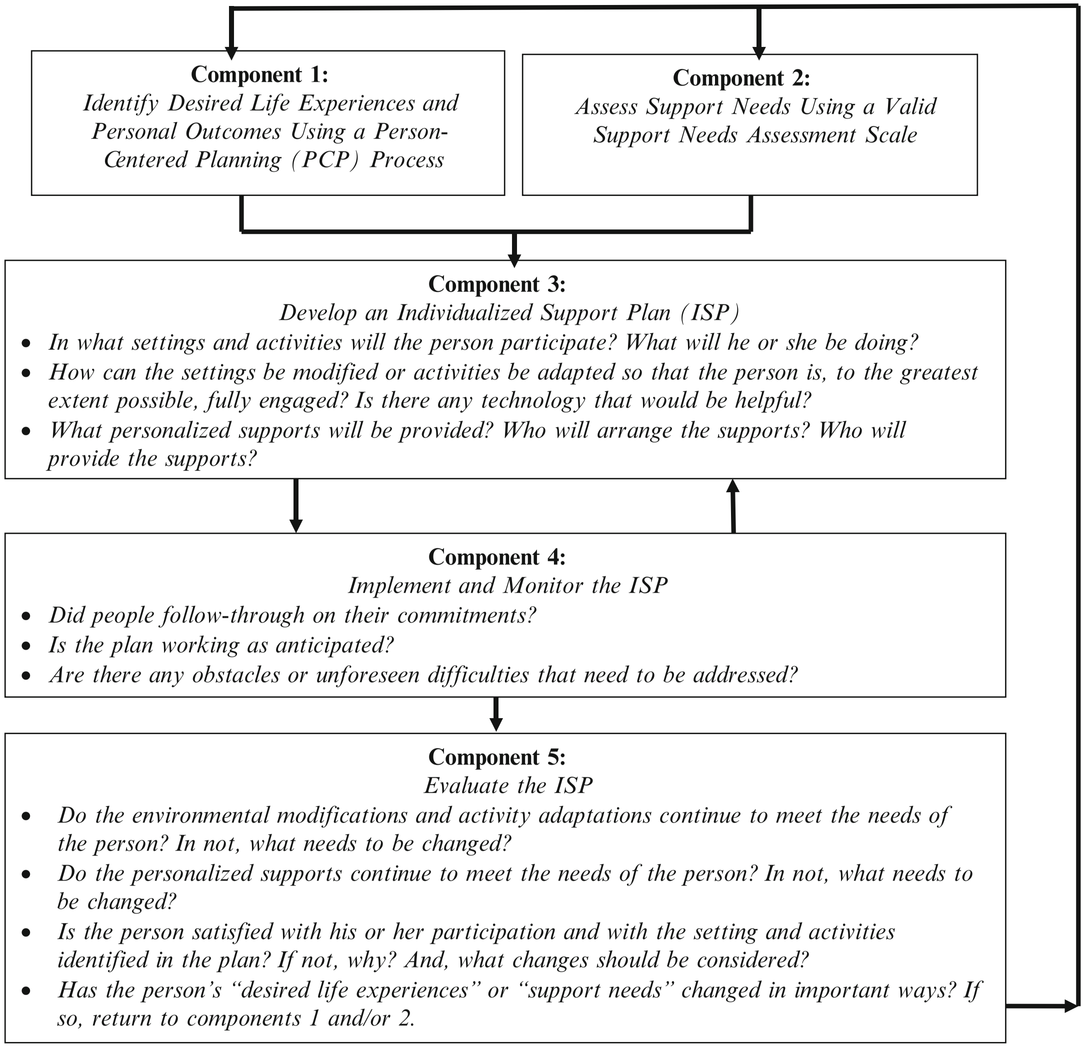
We began this chapter by discussing the trends in the field of IDD over the past several decades and how these led to an interest in PCP processes and developing new assessment tools that enable professionals to better understand the support needs of people with IDD. The Support Needs Assessment and Planning Process shown in Fig. 7.1 illustrate how information from PCP processes and supports needs assessments can be used to inform planning at the individual level. The initial version of this process was presented in the first article reporting data on the SIS-A (i.e., Thompson et al., 2002).

Component 1 requires completing a PCP process and the goal is to get a unified vision among key stakeholders as to what would constitute desired life conditions, experiences, and opportunities. Information from Component 1 includes identifying discrepancies between "what is" and "what could be," as well as identifying aspects of the person's life that are very important to maintain. Also, Component 1 requires prioritization. There must be consensus on what is most important to maintain and change, as well as what is relatively less important.

Component 2 involves an assessment of support needs such as is completed through using one of the supports needs assessments reviewed in this chapter. A structured support needs assessment not only provides useful information to the planning team when developing an actionable, annual plan (Component 3), but also assures that a person's support needs are comprehensively considered. Informal assessment of support needs, such as is completed through direct observations and anecdotal logs, can supplement information from an assessment scale.

Component 3 is the actionable plan. This should be an "optimistically realistic" plan where settings and activities in which the person will be involved during a typical week are specified, environmental modifications and activity adaptations are carefully thought through, and personalized supports are unambiguously identified. Additionally, identifying who is responsible for following through on specific actions is necessary..

It is important to note that the arrows go back and forth between Components 3 and 4. This is an acknowledgement that support plans hardly ever proceed without a hitch. Component 4,



Component 1:
Identify Desired Life Experiences and Personal Outcomes Using a Person-Centered Planning (PCP) Process

Component 2:
Assess Support Needs Using a Valid Support Needs Assessment Scale

Component 3:
Develop an Individualized Support Plan (ISP)

- *In what settings and activities will the person participate? What will he or she be doing?*
- *How can the settings be modified or activities be adapted so that the person is, to the greatest extent possible, fully engaged? Is there any technology that would be helpful?*
- *What personalized supports will be provided? Who will arrange the supports? Who will provide the supports?*

Component 4:
Implement and Monitor the ISP

- *Did people follow-through on their commitments?*
- *Is the plan working as anticipated?*
- *Are there any obstacles or unforeseen difficulties that need to be addressed?*

Component 5:
Evaluate the ISP

- *Do the environmental modifications and activity adaptations continue to meet the needs of the person? In not, what needs to be changed?*
- *Do the personalized supports continue to meet the needs of the person? In not, what needs to be changed?*
- *Is the person satisfied with his or her participation and with the setting and activities identified in the plan? If not, why? And, what changes should be considered?*
- *Has the person's "desired life experiences" or "support needs" changed in important ways? If so, return to components 1 and/or 2.*

Fig. 7.1 Support needs assessment and planning process

Monitoring the Support Plan, is critically important because there will likely be unforeseen difficulties that need to be addressed. Without a true commitment to monitoring, there is a very real danger that planning team members will come up with grand plans that never get put into action due to a lack of follow-through. A responsive process calls for people to be accountable for the commitments they make.

The final component is evaluation. It is important to acknowledge that personal preferences and support needs change over time. Supporting people with IDD in community settings and activities is hard, ongoing work. It is work that is never finished. Plans must be revised when they no longer meet a person's needs, and this may require returning to Components 1 and 2 (i.e., initiating a new person-centered planning process and reassessing support needs).

Conclusion

In this chapter, we describe leading PCP processes and support needs assessment scales, and summarize research evidence supporting their use. The PCP approach to planning is logically appealing, but there is a limited research base in regard to its effectiveness. Several new scales to assess the support needs of people with disabilities have been introduced over the past 15 years, but it is evident that the work of developing valid tools to measure support needs is still in its infancy. Although much progress has been made in developing new tools and improving professional practices related to effectively supporting people with IDD in community settings, it is clear that much work remains to be done.

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Quality of Life

8

Robert A. Cummins

Introduction

The adoption of quality of life (QOL) measurement within the field of intellectual disability was catalyzed by deinstitutionalization, which began within Anglophone countries during the 1970s. This massive relocation of people, with all levels of disability, moving back into open society, caused intense media interest. The resulting publicity included exposure of living conditions in the institutions of that time. The view that was portrayed shocked the sensibilities of many ordinary citizens, including the parents of the people being relocated. One reason these parents had made the difficult decision to institutionalize their child was the promise of a safe and secure environment for their vulnerable offspring. Now, they were being confronted by the reality of institutional care.

Early QOL researchers operating within this milieu saw the potential of their measures to make service delivery more accountable and so to mold policy. Their initial measures were objective indices of QOL, such as the conditions of accommodation, freedom of movement, etc. But the generic QOL field at this time was starting to develop an alternative arm of research which concerned subjective measures and the development of a central construct called subjective wellbeing (SWB) (Andrews & Withey, 1976; Campbell, Converse, & Rodgers, 1976). These measures tapped SWB through questions of satisfaction.

Measuring SWB proved a very difficult conceptual and operational task within the generic field of QOL research. Moreover, these difficulties were much exaggerated when applied within the field of intellectual disability. Since measurement of SWB depends on the self-report of a subjective state, it is essential to establish that each respondent is capable of performing the task required. And this added not only a new level of measurement complexity but also the realization that such measures are beyond the capacity of people with severe forms of ID. These problems remain to the present day, even as the constructs of life satisfaction and subjective QOL are increasingly understood at a theoretically useful level, and some issues of measurement are yielding to some simple solutions.

Despite these difficulties, the early pioneers in measuring SWB for people with an intellectual disability could see the potential for this form of measurement. For example, Schalock (1997) advocated the use of satisfaction measurement because it can provide “a common language that can be shared by consumers, policy makers,

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regulators, and researchers; assessing consumer needs; and evaluating consumer satisfaction" (p. 6). In a similar vein, Brown (1999) suggested that service delivery should "reframe to quality of life" by using measures of satisfaction in order to meet the principles "that every person with intellectual disabilities has the right to lead a life of quality, and that this presents us with three service goals, namely, to maintain or improve (1) good conditions of life, (2) each person's happiness, and (3) the ways people have of becoming enabled to lead fulfilling lives of their own choosing" (p. 299). So, these ideas led to many important issues. Foremost was the extent to which people with an intellectual disability could answer the questions necessary to measure their SWB. Then, if this barrier could be overcome, to determine whether their responses could be used to understand the most important factors allowing these people to lead a life of high quality.

The primary purpose of this chapter is to introduce QOL as a generic science. The application of this science to intellectual disability will be a simple extension because the generic understanding of QOL applies equally to all people. The only real limitation of this application to intellectual disability is the current inability to make such measurement for the most severely disabled people. Other special features will be noted as the description unfolds and issues concerning the scales of measurement will be addressed at the end of the chapter. The overall aim, therefore, is to provide an overview of contemporary thinking in the application of QOL measurement to people with intellectual disability. This form of measurement has application both within the context of service delivery and also within the context of these people as citizens within our communities.

In order to start this journey with common understanding, it is necessary to present the generic literature. That is, QOL measurement for people with an intellectual disability does not stand alone. It is just part of a large literature concerning the topic, and upon which there is now substantial levels of understanding with direct relevance to the QOL for people with an intellectual disability. The first problem to be addressed is the vexed issue of nomenclature. This issue remains unresolved, despite numerous authors decrying the confusion caused by a lack of agreement concerning the meaning of commonly used terms.

Issues of Terminology

Almost 20 years ago, Cummins (1997a) noted the wide diversity of definitions and meanings attributed to the term QOL and the need for precise definition. Sadly, the contemporary literature offers no more precision. The term QOL has recently been used as a synonym for subjective well-being (SWB: Cini, Kruger, & Ellis, 2013), a global rating of life quality (Forrest et al., 2014), as a synonym for health-related quality of life (Griva et al., 2014), while other authors use the term QOL with no definition at all (Wu, 2013).

Within the realm of subjective QOL, the wildly different meanings that have been given to the terms "well-being" (Cummins, 2014a) and "happiness" (Cummins, 2013a, 2013b) have been documented in some detail. From these reviews and from scanning the contemporary literature, it is apparent that there are no naming rules for the variables in this area either. Authors use any term that takes their fancy and then use the term to mean whatever they like. Worse, they rarely offer a definition of the term(s) they use.

All this is so despite many excellent reviews of SWB composition and nomenclature (Diener, 2006; George, 1979; Stones & Kozma, 1980). However, authors rarely refer to these authorities in making their personal choice of terminology, and the result is a catastrophic situation of nomenclature anarchy. It means that researchers are commonly using the same term as their colleagues to refer to a quite different construct. In other words, researchers frequently misunderstand the results that other researchers are describing.

In summary, the only way an author, or a reader, can be certain about what variable is under discussion is to take personal control. This can be achieved by the application of three linked strategies as:

1. To decide on a personally satisfying set of terms and to define each term according to a specified rationale based on the literature. This may be informed by previous scholarly opinion and the known content of specific measurement scales.
2. To phrase (as author) or rephrase (as reader) the terminology in question, using the rules established under (1).
3. In circumstances where a metric cannot be clearly specified, to use some generic term such as "subjective life quality" if the metric is derived from subjective variables or "well-being" if it is a mixture of objective and subjective.

While this places a significant burden on both the author and reader, it is the only sure way of avoiding nomenclature confusion. For the current discussion, subjective well-being will refer to a construct measured through semiabstract questions of satisfaction or happiness, such as are represented by either the Satisfaction With Life Scale (Diener, Emmons, Larsen, & Griffin, 1985) or the Personal Wellbeing Index (International Wellbeing Group, 2013).

Objective Versus Subjective

Ever since theorists in the 1970s first pondered the nature of life quality, it has been accepted as comprising two parts, one objective and the other subjective. The traditional measures of life quality are objective and focus on the circumstances of living, sometimes called the "quality of living." These objective variables are tangible in that they can be simultaneously observed by a number of people, usually as estimates of frequencies or quantities. Examples may be the number of friends a person has or the extent of their disability. Certainly, such measures involve degrees of subjective judgment, but when the measures are carefully performed, they yield a high degree of interrater agreement.

The other part of life quality is subjective, and the variables here are quite different. Each individual person can directly experience them, such as by their degree of felt happiness or satisfaction. Consequently, they can only be measured by asking the individual concerned how they feel about their life. It is not valid to infer SWB from proxy ratings made by other people. It is also not valid to infer SWB levels from objective measures, due to the influence of homeostasis (see later).

These subjective variables are far more complex in terms of their conceptualization and measurement than are the objective measures. This complexity will become evident as the chapter progresses. However, despite this, measures of SWB are gaining prominence by providing a crucial insight into the human condition, which is not otherwise available. Indeed, it is quite reasonable to consider that SWB is the most important measure of the human condition. People must feel that their lives are worth living.

In the specific context of intellectual disability, Schalock (1997) has been a staunch advocate for the usefulness of QOL, and SWB in particular, to provide a fundamentally positive and growth-oriented principle that can form the basis for developing policy. He wrote "The concept of quality of life steers us in the right direction: towards person-centered planning, supporting people's needs and desires, and asking people what they think and how they feel" (p. 2).

So, what is the relationship between objective and subjective life quality? Our common sense tells us they must be related. Surely someone who is physically healthy and materially rich must be happier than someone who is ill and in poverty? The answer, as a population average, is in agreement with common sense. But the actual nature of the relationship at the level of individual people is far more complex and far more interesting.

The Relationship Between Objective and Subjective

Early Ideas

The earliest indications of a complex relationship between objective "quality of living" measures and SWB involved data from population surveys conducted during the 1950s and 1960s. Studying the trends across time revealed that, while GDP was rising, the average levels of happiness were not. In January, the US Department of Health, Education, and Welfare (1969) submitted to President Johnson *Toward a Social Report*, which stated “Money income, of course, cannot buy happiness, and it is by no means obvious that satisfaction rises along with income” (p. 41).

This was a touchy subject for the discipline of economics. About 300 years previously, Scottish philosopher Smith (1776) had published *The Wealth of Nations* (for a synopsis, see Coase, 1977), which is credited as the origin of economics as a discipline. Since Smith was a philosopher, he was concerned far more with the logic of ideas than of evidence. Indeed, in 1776 there was precious little evidential knowledge to work with. So he, and others of that time such as English philosopher Bentham (1780), made all sorts of philosophical assumptions upon which to base their arguments and the budding discipline. Most crucially for the current discussion, they believed that the benefits of economic activity could not be directly measured. Such positive outcomes for the individual could only be inferred from their rational choice behavior, and this benefit became known as utility. Thus, it came about that, within economics, income became a proxy for happiness, and, *ceteris paribus*, the more money individuals or nations have, the happier they are.

This way of avoiding the issue of direct measurement was a clever philosophical device. However, now that we are better informed by psychological science, it is understood that this philosophical assumption is simply wrong. Happiness can be directly measured, and it does not have a linear relationship with wealth. An excellent summary critique has been published by Gittins (2010).

At the time *Toward a Social Report* was published, very little of this was understood. However, researchers in psychology and sociology were becoming increasingly suspicious that the relationship between objective and subjective variables was complex and not linear as had been supposed. For example, Robinson and Converse (1972) noted that people’s reports of their own subjective states can be quite different from what might be predicted on the basis of an objective description of their situation. As a consequence of this new literature, some influential economists became intrigued by this apparent incursion into the province of their discipline. And so it came about that just 3 years later, in 1972, the Organisation for Economic Co-operation and Development held a high-level, invitation-only symposium to discuss the issue.

Many of the leading authorities on social indicators gave papers, and these have been collectively published (Strumpel, 1974a, 1974b). In his review of the situation, Strumpel (1974a) recognized the objective–subjective divide and concluded: “For evaluating and using indicators of subjective well-being, information is needed about both the objective condition and future prospects and how both are experienced” (p. 90). In this same volume, Campbell (1974) went one step further, while also placating the economists, stating “There is no suggestion that objective data should be set aside in favor of subjective measures. The value of subjective measures of the kind proposed here is to give additional information to the repertoire of the scholar and decision-maker, to provide an array of psychological data parallel to the more familiar kinds of indices. It is to be hoped that integration of the two kinds of data will make possible a fuller and truer representation of the state of society than we command at present.” (p. 19)

One can only surmise that the economists were neither placated nor amused at the idea that utility (happiness) could be directly measured. The idea certainly did not impact Wilson’s (1972) claim that “the quality of life of any individual or community can in a direct and simple way be related to income” (p. 131). In fact, Wilson’s view continued to dominate within economics for several decades. It was to be almost another 40 years before the organization published guidelines advising their member nations how to measure SWB (OECD, 2013).

Contemporary Ideas

As has been described, the discipline of economics has traditionally used money as a proxy for happiness. Thus, it is assumed from within economics, rich nations are happy nations and the rationale for increasing GDP is to make citizens ever happier. Within the social sciences of psychology and sociology, however, this assumption has been empirically demonstrated to be false since the early 1970s. In their insightful review of the evidence, two of the leading researchers at that time, Campbell and Converse (1972), concluded "We have become deeply impressed at the degree to which subjective states can 'pull apart' from what might be deduced on the basis of our current ways of understanding objective situations" (p. 8).

Over the intervening decades, a galaxy of papers have demonstrated the uncertain relationship between money and SWB, and the fact that objective measures of wealth cannot be used as proxy measures of SWB has emerged as a fundamental truth (for a review, see Cummins, 2000b). The same lack of simple relationship has been emphatically demonstrated between physical health or disability and SWB (e.g., Cummins, 2012; Cummins, Woerner, Tomyn, Gibson, & Knapp, 2006; Fabian, 1991). Such findings have deep implications for the way QOL data are treated.

Most crucially, since there are two separate dimensions to life quality and since both are important measures in their own right, each dimension needs to be measured to give a balanced overview of life quality. While this is quite commonly accepted by researchers in the area today, many still fail to comprehend that objective and subjective indicators are not only completely different from one another but cannot be validly combined into a single metric. Thus, each form of measurement must be considered separately (Andrews & Withey, 1976; Lehman, 1983). There are at least two reasons for this (Cummins, 2000a). First, objective items do not form scales; they form lists. Objective items normally do not have a built-in source of common variance that causes them to intercorrelate. Thus, objective variables cannot even be combined with one another to form a single valid metric. Second, changes in subjective well-being are normally opposed by a homeostatic system designed to hold SWB within a positive range for each person. One consequence of this is that changes in an objective variable, such as physical health, will not normally cause a matching change in SWB.

This understanding has very far-reaching implications for quality of life measurement and for the interpretation of results. Since objective measures cannot be used as a proxy for happiness, it also means in relation to physical health that the whole notion of a "healthy mind in a healthy body" (Juvenal, 55AD–127AD) is a prejudicial nonsense that has been damaging our view about the life quality of people who are disabled for two millennia, at least.

In summary, the fact of having a serious medical condition or a disability does not necessarily cause low SWB. Indeed, people who are being successfully treated for high blood pressure have a mean level of SWB that actually lies slightly (but not significantly) above the normal range (Cummins, 2012). There are two reasons for this. The first is that most people, who are appropriately treated for high blood pressure, are not directly aware of their life-threatening medical condition. They only have indirect awareness through the measurement that has been made by their physician. So, the extent to which they will find their condition stressful will depend on how much anxiety they experience recalling the fact of their high blood pressure and whether their condition is severe enough to cause awareness due to functional limitations, such as shortness of breath. Similar considerations apply to people who have asthma and many heart conditions.

Other medical conditions, however, are associated with below-normal SWB. In such situations, the medical condition, either directly or indirectly, is an ongoing source of psychological distress. Direct causes of distress may be linked to the experience of pain (e.g., arthritis), daily injections (diabetes), or anxiety/depression. Indirect causes may be, for example, the stigma of living with an HIV infection (Hutton, Misajon,

& Collins, 2013). So, what is it that allows a coherent description of the relationship between objective and subjective indicators? One such mechanism is SWB homeostasis.

Subjective Well-Being Homeostasis

Subjective well-being (SWB) has several intriguing properties. Perhaps, the most basic is that it is normally positive. That is, it is normal for people to feel good about themselves. As demonstration of this, using the data from over 60,000 people gathered over 13 years by the Australian Unity Wellbeing Index project (Cummins et al., 2013), only around 4 % of scores are <50 on the standard 0–100 point scale. The second intriguing feature of SWB is its stability over time. This can be demonstrated by two kinds of data. One uses the mean scores from population surveys, and the other are data obtained from individuals.

Stability in Subjective Well-Being

The first requirement for scientific measurement is that empirical estimates of the phenomenon under examination can be made reliably. This was first achieved in relation to SWB over 80 years ago when Watson (1930) found that self-ratings on a printed rating scale correlated 0.81 with a composite score comprising a number of indices. He concluded that the general level of happiness could be measured reliably.

Other researchers then started to make such measurements, and it was soon discovered that measures of mood happiness were surprisingly stable over time. For example, Hartmann (1934) obtained a test–retest reliability of 0.70 with two testings a month apart, while Wessman and Ricks (1966, p. 103) reported that happiness-related measures taken 2 years apart correlated 0.67.

By the 1970s, it was clear that there was considerable long-term stability in SWB, with significant retest correlations being reported over many years (Andrews & Withey, 1976; Palmore & Kivett, 1977). So researchers started to ask what might be the cause of this stability and looked to personality for their answer. After all, there was a conventional view that personality was largely genetically determined (for reviews, see Block, 1981; Brim & Kagan, 1980; Jackson & Paunonen, 1980), and because of this it was stable. Thus, if personality were strongly linked to SWB, it would be the likely cause of SWB stability.

The true extent of this stability, and therefore the predictability of population mean scores, was first reported by Cummins (1995). This paper combined data from population surveys performed in various Western countries. This review included highly diverse studies, each one having been conducted by different researchers, using different scales of measurement, at different times over the decades 1970–1990. The key to combining these disparate results was to convert all scores to the standardized 0–100 range called "percentage of scale maximum" (%SM). The formula for this conversion is presented in the manual for the Personal Wellbeing Index (International Wellbeing Group, 2013).

When the mean scores from the 16 population surveys were recorded to lie in the 0–100 point range, it was found that they averaged 75 points and their standard deviation was 2.5. These 16 survey mean scores were then used as data to create a normative range. Two standard deviations on either side of the mean of the means create a range within which there is a 95 % probability of including any particular survey mean. This procedure yielded a normal range of 70–80 points and represents the first estimation of a normal range for SWB population mean scores.

This, however, is a very approximate estimation, heavily contaminated with error variance resulting from the many methodological differences between the studies. Much greater stability has been revealed by the 30 surveys conducted by December 2013 through the Australian Unity Wellbeing Index (Cummins et al., 2013). This project samples 2000 fresh respondents several times each year. People are recruited by telephone, from the Australian adult population, by random dialing within 50 specified geographic regions that together cover the continent. Sampling within each region is proportional to population density.

Using the mean scores of these 30 surveys as data, the grand mean is 75.3 points and the standard deviation 0.72. This yields a normative range of 73.8–76.7 points. In other words, the mean score of a random survey of people in Australia can be predicted, with 95 % certainty, to lie within a 2.9 percentage point range. There is no precedent in the literature for such extraordinary stability in measures of SWB. In a global context, however, there is much greater variation.

Set Points for Subjective Well-Being

Animal breeders have known that personality has a strong genetic basis since time immemorial. As Smith (1961, Chapter 6) pointed out, domestic animals have been bred for differing levels of emotionality. So with the idea of SWB stability in mind, it did not take long for researchers to study the relative influence of genetics and environment on the SWB of twins. Early studies, reported mixed results, in part because researchers had only sampled twins reared together. Clarification came from Tellegen et al. (1988) who studied both monozygotic (MZ) and dizygotic (DZ) pairs of middle-aged twins, who had been either reared together or separated in infancy and reared apart. Using the 23-item well-being scale of the Multidimensional Personality Questionnaire (Tellegen & Waller, 1982), which is stated to measure "positive emotionality" (Patrick, Curtin, & Tellegen, 2002), their best estimate of well-being heritability was 0.48 (SD 0.08). Moreover, the contribution of a common family environment was negligible.

This result was reinforced by Lykken and Tellegen (1996), who also used the well-being scale on DZ and MZ twins, first tested at about 20 years of age and retested 10 years later. The retest correlation for DZ was 0.07 and for the MZ 0.40. They stated this latter figure represents "80 % of the retest correlation of 0.50" which they argued "suggests that the stable component of well-being (i.e., trait happiness) is largely determined genetically" (p. 188). They also reported combined results on 1380 pairs of twins, drawn from various US sources, which essentially replicate the above results. They ended with the memorable observation: "it may be that trying to be happier is as futile as trying to be taller and therefore is counterproductive" (p. 189).

While the above studies laid a solid foundation for the idea that SWB has a strong genetic influence, none of the cited authors combined this information with the evidence of SWB stability, mentioned earlier. Headey and Wearing (1989, 1992) provided this important step and gave a name to the phenomenon of SWB stability as an individual's "equilibrium level." This raises the issue of terminology, particularly the distinction between baseline, equilibrium level, and set point.

In science, the term baseline refers to an initial reliable measurement against which subsequent measurements may be compared. It carries no connotations of normality. Baseline measures are commonly employed to assess treatment effectiveness where the variable in question (e.g., anxiety) is pathological. Confusingly, however, some researchers, such as Clark, Diener, Georgellis, and Lucas (2008), use the term as though baseline represents normality, which is importantly misleading. For example, their Table 8.1 shows that 18.3 % of the general life satisfaction (GLS) scores comprising their sample had a value of 50 points or less, which is pathologically low (see Cummins, 2010). Clearly, the interpretation of change will differ depending on whether the baseline measure represents normal or pathological levels of SWB.

The term equilibrium level, as introduced by Headey and Wearing (1989, 1992), does imply normality. It denotes a level of SWB stability for each person, which they attributed to their personality. However, they say, equilibrium levels can change due to "slowly changing personal characteristics" which may be induced due to chronic changes in wealth (1992, p. 104), social connections (p. 127), or age (p. 130). They regarded these as examples "of environment molding personality" (Headey & Wearing, 1992, p. 104).

In sharp contrast to both of the above terms, set points are both normal and genetically set at a

Table 8.1 Levels of general satisfaction and happiness

Study	Country	Scale	Level of disability mean (SD)	Place of residence	N	Data check Y/N	%SM mean	(SD)
Parmenter et al. (1991)	AU	H1	Moderate/severe	SH	32	N	53.13	
Rosen, Simon, and McKinsey (1995)	US	PALS	IQ = 49 (15)	CH	100	N	84.36	(18.91)
Schwartz and Ben-Menachen (1999)	IL	LSS	Mild/moderate	SH PA IN	20 18 20	Y1	60.18 57.74 57.32	(2.96) (3.72) (5.49)
Heller, Factor, and Hsieh (1998)	US	LSS	Mild/moderate	NH0 NH0 NH + 2 NH-SH + 2	37 14 37 14	Y1	53.5 59.2 57.9 70.2	(20.7) (12.7) (15.5) (10.6)
Verri et al. (1999)	IT and AU	COM-ID4-S	Mild/moderate Mild/moderate	PA SH	44 110	Y2	83.0 75.3	(23.4) (22.3)
		COM-A4-S	Non-ID Non-ID	CON GP	92 100	Y2	73.82 72.67	(10.05) (8.85)
Simon et al. (1995)	US	PALS	Mild/moderate	SH	46	N	87.0	(20.3)
Yu, Jupp, and Taylor (1996)	AU	LSS	Mild/moderate	IN + CH + SH	49	Y3	68.68	(15.20)

Country: *AU* Australia, *IL* Israel, *IT* Italy, *US* United States of America

Scales and %SM calculation: H1: "Do you feel very happy, happy, just OK, or unhappy?" %SM: The number of respondents at each level of the response scale are 19, 10, 1, and 0. The conversion process considers these to represent a scale as 3, 2, 1, and 0. Then, the calculation becomes [19 × 3] + [10 × 2] + [1 × 1] + [0 × 0] = 34. The scale maximum is [32 × 2] = 64. Thus, using the formula:

$$\%\mathbf{SM} = \left[X - k_{\min}\right] / \left[k_{\max} - k_{\min}\right] \times \mathbf{100}$$
$$= \left[\mathbf{34 - 0}\right] / \left[\mathbf{64 - 0}\right] \times \mathbf{100} = \mathbf{53.13\%SM}$$

[X = the mean score to be converted, $k_{\min}$ = the minimum possible scale score, $k_{\max}$ = the maximum possible scale score]

PALS: Rosen et al. (1995) satisfaction scale, comprising 11 items. 3-point response scale of satisfied (1), neutral (0), or not satisfied (0) [binary scoring]. The raw score mean and standard deviation are 9.28 (2.08). %SM: $k_{\max} = 11$, $k_{\min} = 0$. %SM = 84.36 %SM

%SD conversion: This is simply an arithmetic proportional adjustment to the change in the magnitude of the mean. So, 2.08 × [84.36/9.28] = 18.91 %SD Notes: Simon et al. (1995) assume they used the same scoring as the original. Raw scores 9.57(2.23)

LSS: Lifestyle Satisfaction Scale (Heal & Chadsey-Rusch, 1985) Schwartz and Ben-Menachen (1999) scores range from −56 to +56. The raw score mean and SD are (for PA) 8.67 (4.17). %SM: Because the score range lies on either side of zero, the raw score must be adjusted such that it lies on a range from 0 to 112. Thus, 8.67 + 56 = 64.67. In order to convert this to the 0–100 range, a proportional adjustment is required: 64.67 × [100/112] = 57.74%SM. %SD conversion: The proportional adjustment is to the range 4.17 × [100/112] = 3.72 %SD

Notes: (1) A description of the LSS (Lifestyle Satisfaction Scale) (Heal & Chadsey-Rusch, 1985) concludes that the scale does not measure SWB as defined for this chapter, (2) Heller et al. (1998) use 31 items and a score range of −61 to +62, and (3) Yu et al. (1996) used an unpublished earlier version of the LSS (Heal et al., 1981). There is confusion in their Table 1 where the mean value for the subscale GENSAT (22.05) is out of the possible range of values (−20 to +20). However, the authors provide values for the whole scale of 29.88 (24.32) and give a possible range of scores as −80 to +80

COM-ID4-S: Satisfaction subscale of the Comprehensive Quality of Life Scale (4th Edition)—Intellectual Disability (Cummins, 1993)

COM-A4-S: Satisfaction subscale of the Comprehensive Quality of Life Scale (4th Edition)—Adult (Cummins, 1993)

Place of residence: *SH* share-home, *CH* cluster housing, *PA* with their parents, *IN* institution, *NH* nursing home/shared house, *NH0* nursing home at baseline measurement, *NH + 2* follow-up at nursing home 2 years later, *NH-SH + 2* follow-up of people who moved to a shared house in the community 2 years later, *CON* non-disabled convenience sample, *GP* non-disabled general population sample

(continued)

Table 8.1 (continued)

Codes for "Y": Y1, the scale has an acquiescence scale but the authors do not report the result; Y2, in accordance with instruction in the ComQol scale manual, individual data sets were removed if these evidenced a response set through the endorsement, by the respondent, of a maximum score for all domains either on importance or satisfaction. This resulted in the removal of 26 out of 70 respondents from the Italian-ID group (37.1 %) and 41 out of 151 from the Australian-ID group (27.2 %). No respondents needed to be removed from either of the general population samples. Y3, the LSS also provides an acquiescence assessment, where a score of six or more invalidates assessments based on a participant's other responses (see Heal & Chadsey-Rusch, 1985). Of the initial sample of 69 people, the responses from 20 (29.0 %) were eliminated on this basis

constant level. Examples from biology are body temperature and blood calcium levels. They are, therefore, unmodifiable by environmental experience. However, these biological examples also have a complex management system designed to counter variations and return the variable in question to its set point. In order for SWB to have a set point, it would also need such a management system.

The Theory of Subjective Well-Being Homeostasis

Building on the information that SWB is generally quite stable and that each person has a set point for their resting level of SWB, the idea that SWB is managed by a process called "homeostasis" was first mooted by Cummins (1998). The use of this term implies an analogy between the physiological management of internal body states, such as body temperature, and the management of SWB. However, while the homeostatic management of body temperature lies within the province of the autonomic system, SWB is managed by dispositional, genetically pre-wired, neurological systems.

The theory describes the relationship between experience and levels of SWB. The model depicting this relationship is shown in Fig. 8.1.

This figure is described as follows:

1. The vertical axis shows the 0–100 scale of SWB and includes the average set-point range of 90–70 points. It also shows an illustrative set point at 80 points.
2. The lower horizontal axis shows the two opposing forces as:
    (a) The strength of the combined negative challenges to homeostatic control, such as might be caused by poverty or anxiety
    (b) The strength of the combined resources aiding homeostatic control, such as might come from money and supportive relationships
3. The upper horizontal axis shows the dominant source of control over SWB. The source of this control changes depending on whether SWB is under homeostatic control or whether the level of SWB is being determined by the challenging conditions, be they either positive or negative.
4. The curving "response line" depicts the changing level of SWB as it moves from:
    (a) Homeostatic defeat due to a positive challenge
    (b) The upper margin of the set-point range at 90 points
    (c) Homeostatic control
    (d) The lower margin of the set-point range at 70 points
    (e) Homeostatic defeat due to a powerful negative challenge
5. An important limitation in this depiction is that the position of the response line depicts someone with a set point at 80 points. The vertical positioning of markers b–e will vary between people, determined by the position of their set point. Thus, for people who have set point below 80 points, the response line will also be lower.
6. A second limitation in this depiction is that it shows the theoretical outcome of the combined influences of supportive and challenging agents acting on the homeostatic system at any one time. Due to such multiple influences,

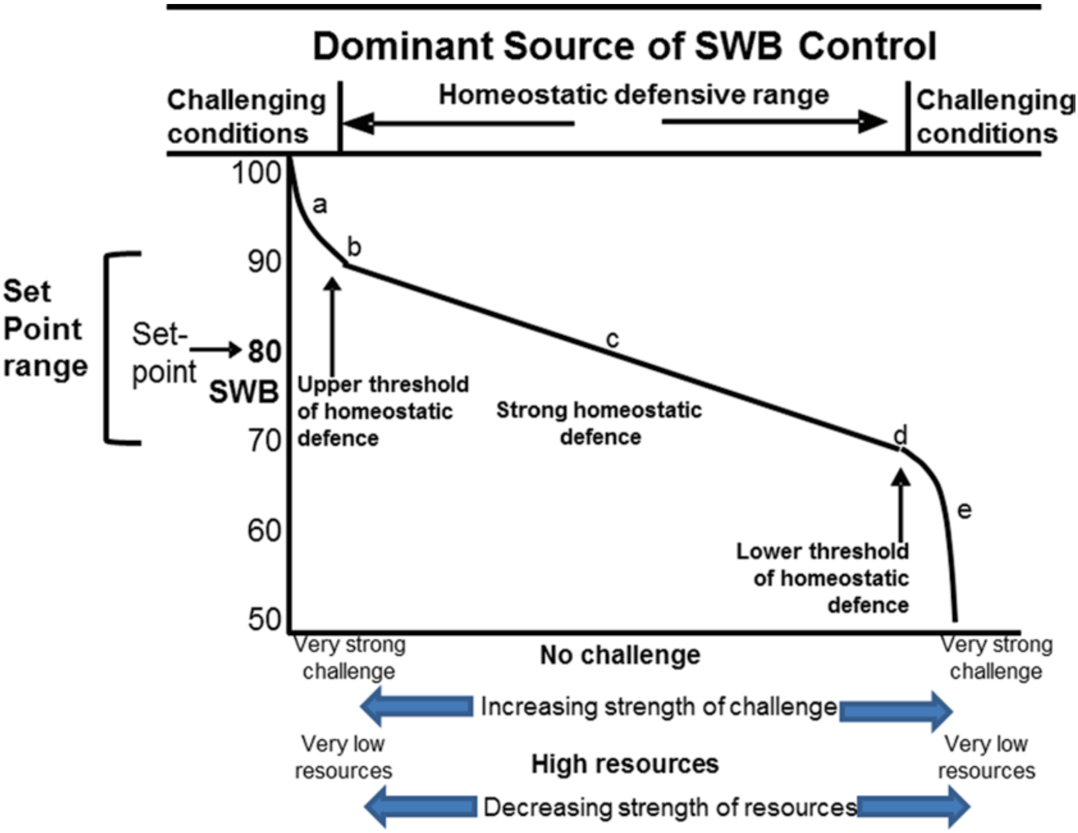

Fig. 8.1 Changing levels of SWB as homeostasis are challenged

any empirical investigation of the relationship between SWB and its sources of influence can only be expected to approximate the pattern that is shown.

Using Fig. 8.1 as a reference, the relationship between levels of SWB, resources, and challenges can be elaborated further. If nothing much is happening, the person is not feeling anxious, depressed, or distressed, and they are in a resting state, then their SWB will be at a level that approximates their set point (level c).

As mild sources of threat are experienced, the level of SWB will vary within its set-point range (b–d). Moreover, its position within the range will be a probability statement determined by the balance of good and bad momentary experience and the resilience of the homeostatic system. Thus, a sustained environment where good experience dominates will cause SWB to average higher than the set point, while the reverse chronic experience will cause SWB to average lower than the set point. However, the extent of such fluctuations is predicted to be quite modest. Since the magnitude of the set-point range is calculated to be around 10 percentage points on either side of the set point (Cummins, Li, Wooden, & Stokes, 2014) and since this represents just one response point unit on a 0–10 response scale, the overall impression from a measurement perspective will be one of stability.

As the strength of emotional threat to homeostasis intensifies, the strength of the homeostatic defense also increases in an attempt to maintain stable levels of SWB. This is depicted by the threshold lines at (b) and (d). Here, homeostasis manages to hold the line and prevents SWB from moving either above or below its set-point-range. Importantly, during phase (c) the value of SWB is relatively insensitive to changing levels of the challenging agent. That is, although the strength of the challenge is increasing, SWB will be held steady at a value between the upper or lower threshold. This phase will continue as long as the homeostatic system is effective.

At some higher strength of challenge, homeostasis will be overwhelmed. This signals that the strength of the challenging agent has become too strong for homeostatic management. Now, the value of SWB enters either phase (a) or (e). In these phases, the dominant source of control over the level of SWB has shifted from homeostatic processes to the challenging agent. Now, the value of SWB is sensitive to the strength of the challenging agent, and as the strength of the challenge increases, the value of SWB will sharply rise or fall. Moreover, the higher or lower level of SWB will persist until homeostasis regains control.

What Is Homeostasis Defending?

Most contemporary theorists regard the measurement of SWB, obtained through a verbal or written response, to involve both affective and cognitive processes. This was first recognized by Campbell et al. (1976) who suggested that this amalgam should be measured through questions of "satisfaction." This suggestion has struck a chord in researchers ever since, with satisfaction questions becoming standard for SWB measurement. However, relatively little research has been directed to examining the relative contribution of affect and cognition. Certainly, the two components are separable (Lucas, Diener, & Suh, 1996), but whether, as claimed by Diener, Napa Scollon, and Lucas (2004), SWB represents a dominantly cognitive evaluation is moot. To the contrary, research by Davern, Cummins, and Stokes (2007) points to the essence of SWB being a construct these authors call "Core Affect."

The term Core Affect was coined by Russell (2003) to describe a neurophysiological state that is experienced as a feeling, which may be conceptualized as a deep form of trait affect or mood. He describes it as analogous to felt body temperature in that it is always there, it can be accessed when attention is drawn to it, extremes are most obvious, and it exists without words to describe it. Naturally enough, Russell regarded Core Affect in conformity with his circumplex model of affect, comprising a blend of hedonic (pleasant–unpleasant) and arousal values (activation–deactivation).

The reason Davern et al. (2007) were attracted to adopt this term was Russell's description of Core Affect as a biologically influenced mood, rather than an emotion. Specifically, he made it clear that while the feeling of Core Affect can be consciously accessed, it is not tied to any specific object in the manner of an emotional response. Instead, it is a mood state, which refers to how the individuals sense themselves in an abstract, but personal, way. If the perception of the Core Affect feeling becomes linked to a cause, then the feeling state makes the transition from mood to emotion.

Russell's (2009) later description of Core Affect, however, muddied this distinction. In this publication, he made it clear that Core Affect may be involved in either moods or emotions. He proposed that Core Affect may become directed at something and, indeed, that Core Affect may itself be changed by a variety of other influences. Thus, a new term was required to describe the mood affect associated with homeostasis. We proposed the term homeostatically protected mood (HPMood) to describe a feeling state with the following characteristics:

1. It is a biologically determined positive/activated mood that comprises the most basic experienced feeling. It is hardwired for each individual, representing the tonic state of affect that provides the activation energy, or motivation, for behavior.
2. HPMood is not only the dominant affective constituent of SWB, as determined by Davern et al. (2007), but also the basic steady-state set point that homeostasis seeks to defend.
3. HPMood perfuses all higher processes, including personality (for a review of the neurobiology of personality, see Depue & Collins, 1999), memory, and momentary experience. It perfuses all cognitive processes to some degree

> but most strongly the rather abstract notions of self (e.g., I am a good person). These self-perceptions are held at strength of positivity that approximates the set-point HPMood.

Consistent with this fundamental role, we hypothesized that the process of evolution has advantaged the survival of individuals who experience a level of HPMood corresponding to 80 points pleasant or positive. Notably, SWB values above and below this value are associated with different forms of cognitive functioning, each of which having its own advantages and disadvantages. For example, higher SWB is associated with enhanced friendliness and problem solving (Lyubomirsky, Sheldon, & Schkade, 2005) but has the downside of poor information processing, an exaggerated sense of control, and therefore enhanced risk taking.

Lower SWB, on the other hand, leads to more careful information processing (for a review, see Forgas, 2008) and greater preparedness for threat (Sweeny, Carroll, & Sheppard, 2006) but carries the risk of low motivation and even depression if it becomes chronic (Cummins, 2010). Thus, we proposed, 80 points is a trade-off between the advantages and disadvantages of higher and lower values. This level then, on average, provides the optimum set-point range for SWB, corresponding to the most adaptive range of mood affect.

Homeostatic Processes

The affect produced by HPMood provides a steady background to consciousness, which influences general feeling about the self. This background normally approximates the set point and so provides the target level for homeostatic management. When average levels of felt affect deviate from this background, homeostatic processes are activated for the purpose of restoring the level of felt affect to set point.

The first line of homeostatic defense is to establish conditions for the self, which minimizes the probability of homeostatic failure. The second line of defense is to use resources that will facilitate rapid recovery after homeostatic failure. These resources are referred to as "buffers," meaning that while their primary function is to defend homeostasis, they also assist the repair process after homeostatic failure. These resources can be either external or internal to the person.

External Buffers: Money

There are serious misconceptions as to what money can and cannot do in relation to personal well-being. People who are rich experience rapid adaptation to high living standards, so living in a mansion with servants may feel luxurious in the short term, but with the passage of time it will just feel "normal." Moreover, high wealth cannot shift the set point to create a perpetually happier person. So, in this sense, money cannot buy happiness. No matter how rich someone becomes, once their level of income saturates the wealth-dependent buffering capacity of the homeostatic system, additional wealth will not raise SWB further.

The real power of wealth is to protect well-being through its capacity to be used as a flexible resource assisting homeostasis (Cummins, 2000b). It does this by allowing people to minimize the unwanted challenges they experience in their daily life. Wealthy people pay others to perform tasks they do not wish to do themselves. Poor people, who lack such financial resources, must fend for themselves to a much greater extent. As a consequence, their level of SWB is far more at the mercy of their environment. Because of this influence, SWB rises with income in an asymptotic curve.

External Buffers: Relationships

A second major external resource is a relationship with another adult that involves mutual sharing of intimacies and support. Almost universally, the research literature attests to the power of such relationships to moderate the influence of potential stressors on SWB (for reviews, see Henderson, 1977; Sarason, Sarason, & Pierce, 1990).

Internal Buffers: Automatic

When the external buffers are not strong enough to prevent the occurrence of a negative experience, the internal buffers are activated.

These comprise a set of genetically programmed protective devices that involve the way we process information as it pertains to our self.

At the simplest level, these involve the automatic processes of adaptation and habituation. These act over time to make us less aware of challenging experiences. An example of this phenomenon can be observed in relation to the gradual loss of motor functioning with age. Because people adapt their behavior and expectations to fit the reality of their diminishing motor capacity, the loss of functioning only weakly engages awareness and so fails to threaten SWB. The extent to which this can happen is amazing. Many people with multiple sclerosis, which induces a gradual loss of motor functioning, report normal levels of SWB even when they lose the capacity to independently breathe and require mechanical ventilation (Bach, Campagnolo, & Hoeman, 1991).

Domain Compensation

When a threat is chronic, a process is activated called domain compensation (Best, Cummins, & Lo, 2000; Heidemeier & Göritz, 2013). This involves an adjustment of the relative extent to which a particular life domain contributes to GLS. Domains that provide a chronic negative experience, such as a poor work experience, are de-emphasized, while domains that provide a positive experience are emphasized. This focus on life domains that are positive assists the maintenance of normal homeostasis.

In summary, these three homeostatic devices of habituation, adaptation, and domain compensation act below our level of consciousness to return the experience of affect back to set point. Homeostasis is also assisted by a set of cognitive buffers. These use cognition to restructure reality, thereby helping to restore a normal positive sense of self after a negative experience.

Internal Buffers: Cognitive

The cognitive buffers use various short-term cognitive devices to put a positive spin onto failure. The ways they do this are quite varied, but they can be classified according to the aspect of self that is central to the defense. These aspects are the sense of perceived control, self-esteem, and optimism.

Our sense of control comes in two forms, primary and secondary control (Rothbaum, Weisz, & Snyder, 1982). Primary control is achieved when the person's actions are effective in changing their environment, such as seeking assistance when something goes wrong. Secondary control is control of the self, such as being behaviorally passive when something goes wrong and internally dealing with the negative thoughts in a way that converts the event from a negative into a positive. For example, one can find meaning in the event ("God is testing me"), regard the failure (dropping a vase) as useful ("I did not like that old vase anyway and now I can buy another"), or see themselves as having gained from the experience ("I have learned something important from that").

People can also refuse to acknowledge the event as having relevance for themselves. They may do this by refusing to take responsibility for the failure ("it was not my fault") or by a process called splintering. For example, when dropping the vase, one may think "So I am a bit clumsy, but it doesn't matter because I am so good at other things (making friends, cooking, writing)." Here, the cause of the bad event has been relegated to some aspect of performance that the person regards as unimportant to their sense of identity. Finally, people can use imaginary potential scenarios to make it seem as if they have actually been very lucky ("It could have been much worse") or use their optimism to see a brighter future ("This has been a bad day, but tomorrow will be better").

However, all of these defenses against loss of positivity are limited in two important respects. First, as with any homeostatic system, the buffers have a limited capacity to counteract reality. Second, overuse of these cognitive buffers carries its own danger. Because these buffers create perceptions that are not consistent with reality, these positive biases must be held in check and not allowed to lose touch with reality all together. The thought "I do not need either my income or my friends" is rarely likely to be adaptive.

Despite this potential danger, the effect of these cognitive devices, when effectively employed, is to restore peace of mind. Some explanation or rationalization for the experience has been found that allows the person to feel that their sense of self and ability to understand the world is intact. Therefore, the homeostatic threat has been dissipated, and, ceteris paribus, SWB returns to its set-point range. A more detailed discussion of these internal buffering systems is provided in Cummins and Nistico (2002) and Cummins, Gullone, and Lau (2002).

In summary, the homeostatic system has the role of maintaining a positive sense of well-being, which is both nonspecific and highly personalized. It is concerned only with the abstract core feelings that the individual has about himself or herself and only in the most general sense. One consequence of this is to imbue people with a "positivity bias" in relation to themselves. So, people normally feel they are "superior" to others or better than average (Diener, Suh, Lucas, & Smith, 1999; Headey & Wearing, 1988, 1989). They believe they are luckier, happier, and more moral (Andrews & Withey, 1976). This is all part of the general positive bias that is "value added" by the brain to such thought processes and which leads, under the normal circumstances of living, to a generalized positive self-view (Taylor & Brown, 1988; Weinstein, 1989).

It is these characteristics that allow the personal sense of well-being to be so defendable against the slings and arrows of misfortune. Because these self-beliefs are held at such an abstract level, specific instances of personal bad luck or incompetence that might otherwise damage the sense of personal well-being can be dismissed by using the internal buffers to maintain the abstract belief. This general idea has been around for 25 years at least. For example, Tesser, Pilkington, and McIntosh (1989) provide empirical support for a model of self-evaluation maintenance, in which the self recognizes good performance on a variety of dimensions yet aspires to be good at (or personally values) only a few such dimensions.

Thus, one's own performance is not threatening to self-evaluation provided that failures are confined to non-valued dimensions in life. Such processes assist people who are deaf, for example, to maintain a positive self-view (Bat-Chava, 1994).

A Summary of Predictions Arising from SWB Homeostasis

The term homeostasis is theoretically interesting because its adoption requires that the relationships between SWB and other variables conform to homeostatic principles. Thus, describing SWB management in these terms makes very clear predictions concerning the relationship between SWB and other variables. These predictions apply equally to people who have an intellectual disability and include the following:

1. The level of SWB is quite stable for each individual. Under conditions of zero threat, SWB will average to its set point, which lies between 70 and 90 points (Cummins et al., 2014). Under such conditions, homeostasis will maintain SWB within a set-point range of about 10 points on either side of the set point. However, it can move outside this range due to the influence of a strong emotion. Such movements are usually acute, as the homeostatic forces return SWB to set point. However, if the emotion is negative, sustained, and strong, SWB may remain below its set-point range on a chronic basis.
2. The level of SWB is normally restricted to the positive sector of the dissatisfied–satisfied continuum. This is a corollary of (1) above.
3. The level of SWB shows a normal distribution within general population samples that is consistent with what psychologists refer to as an individual difference. That is, it appears to have a strong genetic determination, with a distribution consistent with SWB being an innate characteristic. This conclusion of a strong genetic component has been made by a number of authors on the basis of twin studies (Lykken & Tellegen, 1996). In addition, Cummins et al. (2014) reported a normal distribution of set points between 70 and 90 points in a normal population sample.

4. The relationship between SWB and objective variables, such as physical health and wealth, is not linear. Instead, it shows a curvilinear, asymptotic relationship. This is a typical output from a management system that can be saturated. That is, supplying more of some relevant resource (money) may or may not cause an increase in output. The effect of the resource on levels of SWB is dependent on the level of deprivation. For people who are poor, all other things being equal, increased wealth will increase SWB. But this will continue only up to some ceiling value, which reflects full and unrestricted functioning of the system in relation to that resource. This ceiling value averages about 80 points for group mean scores.
5. There is a threshold value that is being defended by the homeostatic processes. This prediction is based on homeostasis theory. It is predicted that, as this value is approached, the system works harder than normal to retain control. Then, as the threshold value is exceeded by an overwhelming challenge, homeostasis will fail and no longer has control over the level of SWB.
6. Following homeostatic defeat, with the passage of time, the system will act to regain homeostatic control over SWB. If homeostatic control is reestablished, the level of SWB will return to a stable approximation of its set point. If homeostatic control is not reestablished, due to the dominance of challenge over resources, then the level of SWB will remain below its set-point range.
7. To the extent that homeostasis reflects the potential of the operating system to recover from an emotional experience, the strength of homeostatic control is equivalent to the concept of psychological resilience, and the strength of such control will differ between people. Such variation is a function of two forms of resource. First, since the level of the set point is an individual difference, it is possible that high set points signal greater resilience than low set points. This will be due to the influence of HPMood on the buffers, holding then naturally at higher or lower levels.

   The second resource is the external factors, such as money and relationships, which can be employed as agents to assist recovery.
8. The sensitivity of SWB to variables that either enhance or challenge the operation of the homeostatic system will depend on baseline levels of SWB. If the operating system is already saturated with a particular resource, such as money, then increasing the levels of that resource will have little if any long-term impact on the level of SWB. However, if the operating system is deficient in money and SWB is below its normal operating range, then the addition of more money will increase resilience, and levels of SWB would be expected to rise.

As a last word on SWB homeostasis, all of the descriptions and predictions contained in this section apply to all people. Thus, they certainly apply to people who have an intellectual disability.

Institutions and Deinstitutionalization

Historical Perspectives

There are many excellent accounts of the living circumstances and life quality of people with an intellectual disability throughout recorded history (e.g., Deutsch, 1949; Frohboese & Sales, 1980; Wolfensberger, 1972). These works do not make pleasant reading. Low life quality was almost guaranteed, not just for people with an intellectual disability but anyone who was recognizably outside the normal range of appearance or ability within society.

In the early days of civilization, when family groups coalesced to form towns, the struggle for survival meant there were few spare resources. Each person had to contribute positively to his or her family and to the community. Persons perceived to be socially deviant or handicapped were considered to be a liability and were ostracized. If they were manageable, not dangerous, and had caring parents with adequate resources, they may have lived at home away from public view, perhaps in a back room, cellar, or attic. If they were unmanageable or dangerous, they may have lived their lives at home under restraint. However, if they were forced to exist in public view, they were likely to be considered the "town fool" and treated as an "object of merriment and ridicule" (Wolfensberger, 1976, p. 45) at best and at worst subjected to exorcism or torture.

With the establishment of more populated and stable towns, with improved economic conditions and public resources, attitudes changed. Public attitudes became characterized by the belief that deviant persons should be segregated from the rest of society. As a result, public resources were used to establish facilities for this purpose such as hospitals, institutions, and almshouses for "deviant" persons. The majority of such institutions were custodial in nature and served as crowded, communal dumping grounds, where intellectually disabled people were congregated with indigent and mentally ill persons. So, for example, when in 1722 the first US house of corrections was built in Connecticut, people with all forms of "degeneracy" were housed together.

At this time, the term degenerates served as a collective noun for all people who did not fit the mold of regular society membership, including criminals, prostitutes, paupers, and all mental afflictions, including intellectual disability. Thus, through this inclusion, people with intellectual disability were just a normal part of society's fringe, especially since illiteracy and poverty were so common.

As such institutions multiplied and the drain on the public purse intensified, increasing interest was directed to what might be the cause of degeneracy. Practically every conceivable cause was championed throughout the 1700s and 1800s, but the one that had the greatest impact was linked to the new science of genetics. This gave rise to the idea of eugenics, at its most formidable from 1890 to 1930. Essentially, so the belief ran, degenerate parents produced degenerate children. Not only that, but such parents were more fecund, thereby causing degenerate people to form an increasing proportion of the population. The solution to this problem, argued the eugenicists, was to break the cycle. Degenerates needed to be prevented from becoming parents through sterilization or institutionalization.

The most authoritative voice promoting eugenics was Goddard (1912), and his account provides a harrowing description of poverty and intellectual disability for people living in the society of that time. His view of the situation includes the following passage:

> The father himself, though strong and vigorous, showed by his face that he had only a child's mentality. The mother in her filth and rags was also a child. In this house of abject poverty, only one sure prospect was ahead, that it would produce more feebleminded children with which to clog the wheels of human progress. The laws of the country will not permit children ten years old to marry. Why should they permit it when the mentality is only ten! (p. 78)

And so it came about that the public was persuaded by the eugenicists, certain directors of institutions, and public officials that "the feebleminded" were helpless, hopeless, and too dangerous to be at large (Packard & Laveck, 1976). New legislation in the USA was passed to promote widespread compulsory sterilization. This was made possible through the infamous Supreme Court decision by Justice Holmes, in which he analogized sterilization to compulsory vaccination and declared that "Three generations of imbeciles are enough" (Buck v. Bell, 274 U.S. 200, 1927).

The consequence of this new societal view was that people with an intellectual disability became not only removed from general society and incarcerated in institutions but also systematically sterilized. Some legislators went further. Packard and Laveck (1976) reported the consequences of this mind-set "Carried to their extreme, these expressions turn into proposals for Hitlerian legislation, such as the so-called "death with dignity" bill introduced in the Florida State Senate. This bill would permit the withholding of medical services and medicine from retarded persons in State institutions, so that those with Down's syndrome, for example, would succumb to pneumonia, to which they are especially vulnerable" (p. 111). As a result, treatment in isolated, custodial institutions, away from the public gaze, became regarded as the norm.

Life Quality in Institutions

Many authors have detailed the various characteristics of institutional life that make it so different from life in general society (e.g., Griffiths & Curtis, 1984; Hayes, 1984; Wolfensberger, 1971). These include an environment that caters for a low common denominator among its residents; regimentation, particularly with meal times and staff rosters; residents having few, if any, personal possessions; low-level opportunities to develop appropriate daily living and self-care skills; inadequate teaching programs; superficial relationships between the sexes; and poor provision of functional knowledge concerning the society outside the institution. Nirje (1969) described life in an institution thus:

> In the large wards, the rhythm of the day reduces the retarded to an object in an empty, machinelike atmosphere. The normal rhythm of daily routines of occupation, leisure, and personal life is emasculated to surrogate activities, not integrated with a meaningful personal existence. The normal rhythm of the year is mostly dwarfed through the experience of monotonous confinement. The development of individuality is helplessly mutilated and crushed in a life in herds. (p. 187)

A more detailed description, compiled from several reports, is found in Griffiths and Curtis (1984). It included the following passage:

> …many may have never owned anything that they could have called their own. Their clothing likely was institutional issue and they would have exchanged articles of clothing daily, with items of clean clothing given out by staff from piles as the residents lined up in the halls to receive them. Thus, a shirt a resident wore one day would be worn by another the next day. Even gifts from the outside likely were managed by staff, and in some institutions residents may not have been allowed to keep their gifts in their rooms or on their wards. This deprivation of personal possessions may have resulted in hoarding…. (p. 261)

A common justification given to parents, encouraging them to institutionalize their child with intellectual disability, was that the child needed specialist medical care. The reality, however, was that the standard of medical care was usually inadequate and less than the child may have received if living at home. To emphasize this misinformation, Wolfensberger (1972) cites a report by the Governor's Citizens' Committee on Mental Retardation (1968) concerning the status of 1908 residents at Nebraska's only "and rather typical state institution for the retarded." Despite the fact that 77 % of the residents were classified as above the profound level of disability, almost half were entirely unable to bath/shower unassisted, 4 % could not even sit up, and 48 % never left the ward. He reports:

> . . . rows of beds with helpless persons, grotesquely enlarged heads [due to untreated hydrocephalus], grievous bed sores, and progressive deterioration; all this leading to the creation of major and expensive nursing problems, lack of learning in he child, and deprivation of social acceptance, potential mobility, and often, even of life itself. (p. 127)

Supporting this dismal view of inadequate professional care, a separate review of US institutions by Kurtz and Wolfensberger (1969) reported that children's mortality in the first year of their residence was sometimes near 50 %. In the behavioral sphere, Zigler (1977) reviewed his own work spanning 20 years and detailed the delayed and aberrant behavioral characteristics associated with institutional living.

In sharp contrast to the USA, by the late 1960s, Scandinavian institutions for people with an intellectual disability were showing a very different profile. This was due to the application of normalization principles, described in more detailed in the next section. Wolfensberger (1972) brought this experience to the USA. He reported his experience of visiting the unit of an institution containing "the most retarded and impaired persons to be found." Even though 60 of the 68 adult residents he encountered were not toilet trained, only one was chronically bedfast, about 12 were wheelchair-bound, while the rest of the residents were ambulatory. Wolfensberger's report heralded a new era. Normalization was to transform institutions in Anglophone countries.

In summary, the appalling conditions of life in institutions were largely invisible to the general public. Would the conditions for these incarcerated people have been better had they remained within their family? This question is very difficult to answer in the absence of any methodologically rigorous data. There is little doubt that, at the time the parents made their fateful decision to institutionalize their child, their family would have been in crisis. So whether the continued presence of the child would have exacerbated the dire family circumstances, or whether the family would have adapted, cannot be answered with any degree of authority.

Deinstitutionalization

During the latter half of the twentieth century, in Western countries at least, there was a general closure of institutions for people with an intellectual disability, with their relocation to share-homes. In the text to follow, "share-home" will be used as a generic descriptor for accommodation in society, which involves people with an intellectual disability living outside an institution. This form of accommodation is most commonly in the company of other people who are also intellectually disabled. But it may also be with non-disabled people and sometimes with staff. The share-home commonly has the appearance of a regular house but may also be a small unit or a hostel with up to 20 or so other people. The distinction between these various forms of residence will only be made if it is important in the context of understanding. Share-homes will be distinguished from foster care homes and living with the person's own family.

Deinstitutionalization legislation was passed at different times in different countries. For example, it was passed in Britain in 1971 (UK Department of Health, 2001); in British Columbia, Canada, in 1981 (Griffiths & Curtis, 1984); and in Victoria, Australia, in 1986 (Victorian Government, 1986). Of course, the rate of deinstitutionalization also varied markedly with location. Effectively, however, by about 1990 throughout the Western world, the great majority of people had been relocated out of institutions and into share-homes of some description.

As has been stated, the motivation for these closures came from the ideology of normalization (Wolfensberger, 1972; Wolfensberger & Glenn, 1973, 1975), first conceived by Bank-Mikkelsen, head of the Danish Mental Retardation Service. According to Wolfensberger (1972), Bank-Mikkelsen had described normalization as "letting the mentally retarded obtain an existence as close to the normal as possible" and was instrumental in having this principle written into the 1959 Danish law governing services to people with an intellectual disability. As described by Nirje (1969), Swedish law followed suite in 1968.

The transition of Bank-Mikkelsen's initiatives beyond Scandinavia was slow. A decade was to pass, from promulgation of the Danish law in 1959, before the principle of normalization was systematically presented in the literature by Nirje (1969), who was then executive director of the Swedish Association for Retarded Children. He described normalization as "making available to the mentally retarded patterns and conditions of everyday life that are as close as possible to the norms and patterns of the mainstream of society" (p. 181). The first description of the normalization principle in the British literature was 1970 (Gunzburg, 1970; Nirje, 1970; Zarfas, 1970).

Then, Wolfensberger's (1972) manifesto was published in the USA, and normalization took the world of intellectual disability by storm. His publication contained much detail as to how normalization should be conceived and applied. A few of the aspects that apply directly to life quality are as follows:

1. Normalization is a judgment of the extent to which the life circumstances of people are equivalent to the circumstances experienced by the majority of the population. Consequently, measures of life quality must be referenced to such norms.
2. Normalization is culture specific, because cultures vary in their norms.
3. The description of normalization is entirely concerned with objective criteria. This is

consistent with the expectation of the era, which preceded a concern with subjective well-being.

4. A major focus is on normalizing the "deviant" person's behavior. One of the major ways to do this is to engineer social systems so that the person is brought into contact with non-disabled people. This leads to some interesting corollaries as follows:
    (a) It denies individuality, in that people are expected to normalize their social behavior whether they like it or not.
    (b) It puts an emphasis on the person to take an active role in this process. For example, "in order to accomplish the greatest amount of normalization, deviant persons should be encouraged to imitate non-deviant ones" (p. 35).
    (c) It dictates that people should not be allowed to congregate in large groups because "a person in a large group may find too many of his social needs met too conveniently to motivate him to reach out for normalizing socialization" (p. 37).
5. The ideology also covers the normalization of sexual opportunities and behavior. A complete chapter deals with this topic, which was then, and remains, an awkward issue for many staff. The advice, however, is straightforward, and Wolfensberger is clearly empowered by his exposure to the matter-of-fact way his Scandinavian colleagues view sexual relationships, "where a Canadian or American housemother might admonish one of her date-bound retarded girls to 'be good', the Scandinavian housemother is more apt to remind her to 'be safe', to know her own mind, and to make her decisions strong ones" (p. 166).
6. Of course, relationships may lead to marriage, and into the minefield of procreation, so bitterly opposed by the eugenicists. Wolfensberger remains steadfast on this topic and notes that appropriate support services need to be instituted for parents who are intellectually disabled while also recommending voluntary sterilization or other form of effective contraception.
7. The issue of self-determination, which is championed by normalization, raises many issues. One is that, while self-determination is likely to be facilitated by groups formed of people who have disability in common, this then constitutes a form of segregation, so strongly opposed in point 4.3 above. Here, however, Wolfensberger falters in his opposition to non-integrated groups. He notes that while such segregation is a danger, he also recognizes that this must be balanced against the important functions such groups may perform, such as providing "an opportunity for social interaction and self-expression which otherwise may not be available in the same quantity or quality" (p. 186). While this appraisal is certainly true and evidenced by the rise and rise of such groups since 1972, it does present a very mixed message to normalization devotees.

Over the intervening years, the principle of normalization has been developed and interpreted from several different perspectives. A "rights" interpretation has been provided by Griffiths and Curtis (1984), founded in the belief that people who are disabled have "a legitimate right to participate in the mainstream of society and that as closely as possible the conditions of their everyday life should reflect the normal rhythm of daily existence" (p. 259). In these terms, life quality for the resident would be measured by the extent to which such rights have been recognized.

An age-appropriate perspective for a measure of share-home success has been provided by Jones (1986), as requiring that the lifestyle of the residents approximates very closely the lifestyle expected of non-disabled people of the same age. This, then, would form a criterion for objective life quality.

In his later work, however, Wolfensberger (1983) has transcended such simple, functional statements of normalization principles, through his conception of "social role valorization." Here, it is proposed that the ultimate aim of normalization must be the creation and support of valued social roles for people who are at risk of societal devaluation. He also claims normalization and valorization as having the status of a scientific theory, which clearly they are not. It would be impossible to falsify this ideology through empirical means.

Public Attitudes

In 1976, the US President's Committee on Mental Retardation stated that deinstitutionalization "… is not simply an emptying out of the institutional population. It is a total reorientation of society to the care and treatment of mentally retarded persons. The issues surrounding this transition are massive and manifold, but they constitute the principal challenge of the next quarter century" (p. 23).

During the period when people with an intellectual disability were housed in institutions, the attitude of the general public to these people was generally dismissive or hostile. The residents were generally feared because their behavior appeared less predictable than normal, but this did not matter much because they were removed from general society. Such public attitudes mattered much more, however, when normalization caused the placement of share-homes into the extant communities of neighbors. Clearly, the success of the planned integration was going to be dependent on neighborhood attitudes.

When people were relocated from institutions, their replacement accommodation was usually located in the suburbs of cities and towns. These share-homes generally appeared little different from the surrounding dwellings, thus blending in with their location. However, the new presence of people with an obvious intellectual disability in a neighborhood was, of course, quite noticeable to neighbors, and this raised the ante in relation to attitude. Neighbors were now much more likely to encounter the residents as they used neighborhood amenities. Thus, the neighbor's response style (welcoming, indifferent, or hostile) became an issue for the share-home staff to manage.

It seems rather obvious in retrospect that a priority for share-home staff should have been to understand the psychology of relationship formation as it applied to integration. After all, the staff had responsibility for managing the interaction between residents and neighbors. Unfortunately, however, there is scant evidence that they either had or implemented such understanding. The prevailing attitude, conveyed by the literature of that time, is that passive exposure would be a sufficient impetus for positive attitudes to form. That is, the mere fact of neighborly contiguity, and passive exposure of share-home residents to the neighborhood, would be sufficient to cause a positive change in public attitudes. Several decades earlier, however, Allport (1954) had already explained why this strategy would fail: "The nub of the matter seems to be that contact [between people] must reach below the surface in order to be effective in altering prejudice. Only the type of contact that leads people to do things together is likely to result in changed attitudes. It is the cooperative striving for a goal that engenders solidarity" (Allport, 1954, p. 264).

Allport's (1954) conclusion was reached after broadly reviewing evidence from social psychology. It has certainly stood the test of time in respect to attitudes of people with an intellectual disability. For example, Strauch (1970) studied the attitudes of non-disabled adolescents to intellectual disability. Two groups were compared. One had been passively exposed to fellow pupils who had an intellectual disability, while the other had not. There was no reliable difference between them. There is also, however, evidence of stereotypic attitude change over long periods in which people with an intellectual disability have retained a public presence. In a US study conducted in the decade following wholesale deinstitutionalization, Williams (1986) found that undergraduates considered people with an intellectual disability to be more amiable than average in the general population. However, they also regarded them as having less self-restraint.

Public Attitudes to Share-Homes

The best prediction of how neighbors will respond to the news, that a new share-home is to open in their neighborhood, comes from their preconceived notions about the residents. These notions come from two main sources of information. One is the average stereotypic view of people with an intellectual disability in the relevant society. The other is specific information available to neighbors concerning the nature of the share-home and its residents.

In relation to the stereotypic views, surveys over many decades have revealed a reasonable level of informed opinion about intellectual disability within general society, at least in North America (Kastner, Reppucci, & Pezzoli, 1979; Locker, Rao, & Weddell, 1979). More specific information concerning a particular share-home, available to neighbors, is commonly acquired from informal sources. Less commonly, such information can also be provided by the government agency responsible for establishing the share-home. Researchers collecting data on attitudes can also supply such information inadvertently.

As the legislation empowering deinstitutionalization became actualized, a large literature started to appear concerning the attitudes of neighbors to a share-home in their area. This literature reveals various levels of competence on the part of the researchers. Leading questions are common, such as "Should homes for retarded adults be allowed in residential districts?" (Sigelman, 1976). This form of question is leading an otherwise un-opinionated respondent to an expected and acceptable answer of "no." So it is no surprise to find a majority of respondents to such questions answering in the negative.

Other studies used an even more biased approach. For example, "Suppose mildly or moderately retarded persons have been educated to live in the general community. Would you object to six of them occupying a home on your block, or not?"(Kastner et al., 1979). Or, "Do you feel that retarded people tend to frighten vulnerable populations, such as pregnant women and elderly people?" (Cnaan, Adler, & Ramot, 1986). Such negatively loaded questions are not just leading; they actively invite opposition. The responses people make to such questions can only be fairly evaluated against comparative data collected in reference to alternative groups, such as to moderately committed atheists. This, however, is rarely if ever done, so the record of neighborhood opposition gathered from such surveys is actually a methodological artifact, and so is unreliable.

Transcending simple opinion, some authors (e.g., Cnaan et al., 1986; Sigelman, 1976) reported substantial levels of neighborhood opposition, to the extent of preventing group homes being established. However, the sources they cite are a mix of unverifiable personal communications, unpublished conference papers, or non-refereed reports. This type of information cannot be accepted as scientific evidence.

Other reports of serious neighborhood opposition may lack reliability for other reasons. For example, using information derived from the program directors of agencies responsible for the establishment of share-homes in Pennsylvania, Dudley (1988) recorded considerable opposition. He reported that a majority (63 %) of the agencies had experienced opposition to one or more of their residential units "when they were being opened" and 17 % of the proposed share-homes never opened because of community opposition. However, Dudley did not report whether the respondents were employed by their agency at the time of this opposition. If they were not, then they were responding on the basis of hearsay. And, even if they were actually present at the time in question, their memory of the level of negativity may have become exaggerated over time. Retrospective data such as these are unreliable. They are most unlikely to represent a veridical recollection of the prior hedonic state (for a review, see Ross, 1989). Moreover, retrospective reports of affect intensity tend to be exaggerated compared to the actual intensities experienced at the time of the event (Thomas & Diener, 1990).

In summary, much of this literature claiming strong neighborhood opposition to the opening of a share-home is clearly unreliable. Nevertheless, government agencies should give consideration to what preemptive strategy may best be employed to facilitate an accepting attitude by neighbors. Should they be prepared with information prior to the move, should they be provided with information after the move, or should they be given no special information at all (as recommended by Seltzer, 1984)? In his review of this issue, Leyin (1988) came to no firm conclusions, which is hardly surprising given the complexity of the issues and demographic diversity. However, he did raise some relevant fundamental considerations derived from various rights declarations of the United Nations. These include:

> Everyone has the right to freedom of movement and residence within the border of each state. (United Nations General Assembly, 1948)
>
> The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings. (United Nations, 1971)
>
> No disabled person shall be subjected, as far as his or her residence is concerned, to differential treatment other than that required by his or her condition …. (United Nations General Assembly, 1975)

These are obviously noble sentiments, but their real-life application needs to be tempered by the balance between the rights of people to be unrestricted in their choice of living circumstances and the rights of other citizens to live in the general society free from threat and harassment. Curiously, the process of deinstitutionalization and relocation of the residents into share-homes is commonly violated by both of these rights.

First, normalization is aimed to reduce the public's recognition of retardation as a deviance, by making these people a normal part of society. The method used to achieve this aim was an administrative fiat. Share-homes, and their residents, were imposed on selected neighborhoods. Justification for this action came from the principles of normalization (Wolfensberger, 1972). Integration was the goal, and the central strategy to achieve this end had two parts. One was to actively discourage the congregation of persons with an intellectual disability (see Rhoades & Browning, 1977). The other was to distribute such people through the general population.

In this process, the people being relocated had no choice but to be relocated. This seems in violation of the resolution of the United Nations General Assembly (1975) cited above. Secondly, the neighbors to the share-home had no real choice as to the changed purpose of the dwelling, since so few were ever consulted. Moreover, neighbors' rights were further violated, when, prior to their relocation, a resident was known to have seriously maladaptive social behavior. This is not a hypothetical issue. The exhibition of such behavior was indeed the major reason for people who have been deinstitutionalized to be moved back into an institution (see, e.g., Pagel & Whitling, 1978).

All in all, it is quite surprising that neighborhoods were generally so accommodating to the establishment of share-homes in their midst. Some opposition was reliably recorded, but this was generally of a low level. Notably, however, no positive reports of neighborhood welcome seem to have been recorded.

After Share-Home Opening

Strong media coverage of deinstitutionalization had drawn public attention to the dreadful living circumstances within institutions and to the more positive living conditions of residents in the share-homes. This almost certainly had some influence on public opinion, most particularly among those members of the public who experienced the presence of a share-home in their area. Thus, for example, Pittock and Potts (1988) found less negative attitude among neighbors to people in share-homes than to people living in a large institution. Indeed, both the media coverage and the scientific literature conveyed such strong negative opinion of institutions that the term "institutional living" quickly acquired negative connotations. In contrast, the new forms of accommodation for the residents were commonly referred to, in positive terms, as community housing.

This is an interesting choice of words, with both positive and negative consequences. On the positive side, during the period of deinstitutionalization, it made the transition easier to accept by the parents of relocated daughters and sons. The term community living carries implied positive affect through the assumption that it will involve increased levels of human affiliation with non-disabled people in the neighborhood. Moreover, the smaller size of dwelling units was anticipated to bring more humane administrative procedures.

Also on the positive side, this terminology held appeal to the public servants charged with implementing the policy of normalization. It allowed them to be seen as implementing a moral mandate to improve the life quality of institutionalized people, grounded in the ideas of integration. However, there is also a negative side to the term community housing. This became evident when the measured levels of integration and neighbors' reactions to the share-home started to receive research attention. The subtle positivity inferred by this term community has the potential to bias evaluations of the relative advantages, and disadvantages, of such housing compared to institutions.

There are, thus, some very positive reports of neighborly attitudes following the share-home establishment. Unfortunately, however, they tend to come from data with questionable reliability. For example, Lubin, Schwartz, Zigman, and Janicki (1982) [also reported in Zigman, Lubin, and Janicki (1984)] sent a single questionnaire to 459 share-homes in New York. They report that about 30 % of the respondents indicated their facilities had been opposed by neighbors prior to opening, compared to less than 2 % at the time of completing the current survey. However, the following problems are evident as: (a) No information is provided as to who completed the questionnaire, what data they used to make their assessments, or on any of the circumstances surrounding the share-home opening; (b) Assuming that the respondents made their assessments on the basis of hearsay or personal anecdotal information, it is well established that not only is memory for emotional events notoriously inaccurate (for a review, see Frederick & Loewenstein, 1999) but also that retrospective reports of affect intensity tend to be exaggerated (Thomas & Diener, 1990).

More commonly, neighborhood surveys taken after the establishment of a share-home record either no overt hostility to the home (Cummins & Dunt, 1990) or hostility confined to a small minority of neighbors (Locker et al., 1979; Lord & Hearn, 1987; Zigman et al., 1984). The great majority of surveyed neighbors evidenced either mild acceptance or cautious indifference (Conroy & Bradley, 1985; Kastner et al., 1979). Thus, the burden of facilitating neighborly interactions became largely dependent upon the willingness of share-home staff to seek such contact (Dudley, 1988). Newcomers to any neighborhood share such a process of reaching out to neighbors, especially if they are from a minority group in the general population.

In summary, the picture of integration and neighborly reactions that emerged from the research literature was not the positive neighborly welcome anticipated by the normalization rhetoric. Rather, it was a picture of stoic acceptance by neighbors of a situation that they could not change.

Attitudes of Families to Deinstitutionalization

At the most general and theoretical level of understanding, it is obvious that families will have difficulty in coming to terms with institutional closure and the physical relocation of their relative. As observed by Taylor, Racino, Knoll, and Lutfiyya (1986), the arguments for and against institutions were conducted by professionals and bureaucrats, not by parents. The decisions that led to deinstitutionalization were purely bureaucratic based on changing ideology. So in a perfect world, it might be expected that when the professionals and the bureaucrats changed their collective minds to advocate deinstitutionalization, significant energy would be directed toward the consultation, education, and counseling of parents. Bureaucracies, however, do not usually operate in this fashion. They operate in an environment where information is power and are consequently loath engaging in anything more than token acts of consultation and information sharing. As a consequence, the negative experience of deinstitutionalization for families is compounded by bureaucratic and professional insensitivity. Parents find that this major life decision has been made for their institutionalized relative with little or no consultation with that person or their family (Lord & Hearn, 1987) and certainly without the involvement of the family in the earliest planning stages. So, families are faced with a fait accompli.

Seemingly forgotten in this deinstitutionalization process is that parents have already gone through an agonizing period of decision making, which resulted in the institutionalization of their child in the first place. This difficult decision likely engendered feelings of inadequacy and guilt, given societal attitudes of parental responsibility. However, over the intervening years, most parents would have adapted to the reality of their situation. The great majority of parents came to regard institutional accommodation as most appropriate for their child (Elks & West, 1982; Spreat, Telles, Conroy, Feinstein, & Colombatto, 1987). Moreover, subsequent reflection would have reminded them that they had made a necessary decision, in order for their family to survive as a functioning unit. Thus, over a protracted period, they adapted to the consequences of decision, and this would involve the consolidation of various supportive beliefs about themselves and their child. Part of this would be the production of a coherent set of strongly held views confirming the adequacy of professional and specialist care provided by their child's institution.

When parents initially decided on institutionalization, they also believed their decision to be permanent and final. Now they are being told, we are going to remove your relative from the institution because the reasons that convinced you to institutionalize your relative are no longer believed to be valid. Your relative does not need 24-h medical care; in fact, your child may need no different medical care than any other person in the community. Moreover, your child should not be protected from society, as you were initially advised, but should be free to interact with the general community, to be able to take risks and be challenged by their environment.

In summary, after living through a very demanding, long period of decision making, rationalization, and adaptation, parents are now required to accept a new reality. In doing this, they must overturn many of their hard-won positive beliefs that sustained them following their decision to institutionalize their child. So it is hardly surprising that news of their child's impending relocation generates a fresh crisis for the families concerned (Frohboese & Sales, 1980; Lord & Hearn, 1987). They must now, once again, readjust their thoughts as to where their child should best reside, and for many of them this readjustment will be very difficult. It may well engender strong negative feelings toward the responsible administrators, which likely involves activated negative affect, at least initially. So they will become angry. But over time, this anger will normally dissipate, to become deactivated negative affect, and if this is internalized and parents start to blame themselves, it may become depression. Thus, the parents of the deinstitutionalized residents are at risk of strong threats to their subjective life quality.

The data on changing parental attitudes confirm the above theoretical description. The initial attitude of parents to the news of impending deinstitutionalization is most commonly oppositional (e.g., Conroy & Bradley, 1985; Lord & Hearn, 1987; Spreat et al., 1987). The reasons have been stated and are both obvious and avoidable. Foremost is the common absence of parental consultation prior to the announcement of institutional closure. Indeed, in the USA this almost had the status of formal policy. Bradley (1978), for example, in detailing the bureaucratic steps to achieve deinstitutionalization, fails to even mention parental consultation in the early planning stages.

This lack of attention to parents by bureaucrats was paralleled by a lack of interest from researchers. The whole concentration of research attention had been on the people being relocated and their living conditions. For example, McCarver and Craig (1974) identified 175 such studies, yet not one of these concerned parents. Nevertheless, most families are surprisingly resilient. Despite the negative pressures placed upon them, by the time of the actual relocation of their child, most parents have become confident that the process will be a success and that their relative will adapt to their new environment. Moreover, these views are generally reinforced after the event (Cummins & Dunt, 1990).

After Share-Home Opening

High levels of family satisfaction with medical services and relationships with staff in share-homes have been reported both before and after the move, first in the USA (Conroy and Bradley (1985) and then in Australia (Cummins & Dunt, 1990). There are, however, other aspects of the new accommodation that tend to be regarded with less enthusiasm.

One of these is the implication of the "least restrictive alternative." This is the rhetoric of ideology and not necessarily shared by parents who are concerned that their child may not be properly protected in their new share-home (Frohboese & Sales, 1980). The second major implication of the move, which concerns many parents, is uncertainty regarding the implications for their own involvement and future responsibility in respect to their child.

A number of other parental sources of worry following deinstitutionalization have also been empirically identified. These are as follows:

(a) Concern that the share-home system is unstable and impermanent (Conroy & Bradley, 1985; Frohboese & Sales, 1980; Lord & Hearn, 1987). At least in the USA, this concern proved quite valid, especially for small community-based units. Hill, Bruininks, Lakin, Hauber, and McGuire (1985) reported the following rates of stability over the 5-year period 1977–1982: foster homes with one to four residents = 46 %; group residences with staff who provide care, supervision, and training of one to six residents = 59 %; semi-independent units or apartments housing one to seven residents = 26 %; boarding homes for one to five residents = 62 %; and total care homes for one to four residents = 68 %. These figures may be contrasted with the stability rate of 98 % for institutions housing 500 or more residents. These figures, however, are not transferable to Australia. In Victoria, for example, all community residential units opened since the deinstitutionalization program commenced in August 1984 have remained in operation.

(b) Concern that the quality of service in the share-home system will diminish over time (Frohboese & Sales, 1980; Meyer, 1980; Spreat et al., 1987). Such concerns are often centered on the quality of medical service, and it is interesting to note that some families may hold a distorted view of their relative's requirement for intensive medical attention. For example, Conroy and Bradley (1985) identified 57 residents (14 % of their sample) about whom the family reported that the person would not survive without 24-h medical care. The facility staff, on the other hand, reported that each of these 57 had no serious medical needs at all.

(c) Concern that inadequate supervision may lead to their relative being exploited or at least fail to protect their relative's safety and health (Landesman-Dwyer, Sackett, & Kleinman, 1980; Lord & Hearn, 1987; Spreat et al., 1987).

(d) Concern that community living may increase the probability of the home being subjected to idiosyncratic administrative practices with decreased accountability (Frohboese & Sales, 1980).

(e) Doubts as to their ability to cope with their relative in the community or at home (Frohboese & Sales, 1980; Landesman-Dwyer et al., 1980).

(f) Doubts that their relative has the potential for further educational or psychological development. It was reported by Conroy and Bradley (1985) that 75 % of their sample families held this view. Moreover, this attitude was not related to their relative's level of adaptive behavior or IQ and was even maintained after behavioral development had been demonstrated following their move to the share-home.

In summary, it seems clear that the parents have a far more complex set of concerns regarding the share-home than they did about the institution. These concerns are occasioned by the smaller nature of the share-home operation, more variability between share-homes, and increased visibility as to the actual nature of life in the share-home. While such visibility may engender anxiety among parents, it also has a positive side in increasing accountability. Maintained external scrutiny is an important feature with the potential to prevent the share-homes from becoming small institutions. This has positive connotations for the life quality of residents.

Relationship Formation with Neighbors

At the beginning of the deinstitutionalization journey in the 1970s, the whole concentration of energies was to get people with an intellectual disability into general society. A major implicit expectation was that the mere fact of the sharing of neighborhood space and facilities would be sufficient to cause the new residents to be welcomed, accepted, and integrated into their new neighborhood. Not only was this expectation unrealistic, it should have been anticipated. The idea that integration would take place through passive exposure was counter to the social psychological theory at that time. The disappointing reality, therefore, was that such people remained physically within, but unintegrated with, the general society in which they lived (for a review, see Cummins & Lau, 2003).

As research revealed the reality of non-integration, it also demonstrated the friendship networks of people living in share-homes to be dominated by coresidents and members of staff. But this was not the intention of normalization, and as the reality of this situation became apparent, the issue of integration took on increasing importance as an unresolved consequence of deinstitutionalization. As noted by the UK Department of Health (2001), “helping people sustain friendships is consistently shown as being one of the greatest challenges faced by learning disability services” (paragraph 7.39).

Also during this period, a new kind of thinking evolved, which changed the focus from a poorly defined integration to the more clearly specified target of social inclusion. While this has been defined in various ways, an excellent contemporary definition is provided by the Family and Community Development Committee (2014) who stated:

> Social inclusion extends beyond simply being present or passively participating in activities in the community. For people with disability, like everyone, social inclusion means experiencing respect for difference and for individual aspirations. It means having control over their own lives and having opportunities to contribute and participate in society in meaningful ways. It means feeling valued and experiencing a sense of belonging. It involves having significant and reciprocal relationships. It can also mean having the appropriate support to be socially included. (p. vi)

Thus stated, social inclusion is clearly a worthy goal. Disappointingly, however, the committee also noted that there is currently no effective tool for measuring social inclusion and therefore no way to reliably determine whether interventions are effective in this respect or not. Moreover, achieving inclusion encounters the same problems that have beset integration. It is hampered by the obvious differences that exist between the new residents and the neighbors. Quite apart from the fact of the disability, the new residents are relatively compromised on each of the three objective cornerstones to the normal maintenance of subjective well-being as income, achieving in life, and relationships. Their earning capacity is usually limited to their pension, and their sense of achieving is limited to activities around the home and, perhaps, menial employment, while their relationships, certainly in the form of intimate friendships, tend to be very limited. All of these deficits will mitigate against the new residents and existing neighbors finding common ground for a relationship.

Clearly, good intentions are not enough. What seems to be largely missing from the integration and social inclusion literature for people with an intellectual disability is a clear statement of theoretical understanding, which can be used to operationalize effective strategies to attain the desired goals. Before this theoretical background can be presented, it is necessary to develop a sound basis of agreed nomenclature.

The Meaning of Community

Within the literature concerning deinstitutionalization, and even the literature concerning intellectual disability more generally, the term “community” is almost always used inappropriately. A community refers to a proximal and small collective, while a society is a distal and large collective (Zambianchi & Bitti, 2014). What most writers intend to say is that the share-home was located in a neighborhood or within society at large. But their use of the term community connotes a characteristic of the dwelling and its occupants that does not actually exist. This gives rise to important misperceptions concerning the relationship between the share-home residents and their neighbors.

According to Merriam-Webster (2014), a community is described as a unified body of individuals linked by a common interest, a shared characteristic, or a shared policy. So, for example, it is appropriate to use the local university community (Christodoulou, Schneider, & Stone, 2014). In such use, community can be considered an objective ecological domain, lying between the domain of the individual and society at large. For example, authors make the distinction between individual, partner, family, community, and societal levels (Fite, Johnson-Motoyama, Rubens, & Peaches, 2014). This sequence represents social distance from the self, evidenced by a progressively decreasing correlation between positive view of self (SWB) and the target domain (Andrews & Withey, 1974; Antonovsky, 1974). That is, the correlation between SWB and satisfaction with partner (a proximal influence) is normally far stronger than between SWB and satisfaction with community (a distal influence) (Cummins, Eckersley, Pallant, Van Vugt, & Misajon, 2003).

In subjective terms, community can also be defined through two strongly overlapping constructs. Within sociology, social capital is commonly used to define the essence of community (for a review, see Schuller, Barton, & Field, 2000). Its associated elements are social and community participation, obligations and expectations, information channels, ties between members, sense of cohesiveness, social norms, and social exclusion (Bourdieu, 1986; Coleman, 1989).

An expansion of this sociological definition, pertinent to integration and inclusion, is Putnam's (2000) "bonding" and "bridging" social capital. Bonding social capital connects people who are similar and sustains in-group reciprocity. This is likely an automatic process, with a strong genetic basis, and has high survival value due to in-group cooperation.

Bridging social capital, on the other hand, connects diverse individuals through sustained reciprocity (for an extended discussion, see Wilson, 2006). This is a far more cautious process. Creating social capital with out-group members carries a higher risk of exploitation. In-group members are controlled by their need for group approval. Bridging, however, may allow outsiders to exploit developed trust for their own exclusive advantage. So there has to be a good reason to develop bridging capital with neighbors who are overtly different and so clearly out-group, and such an association will be naturally resisted. Thus, social exclusion is the natural response by neighbors to a household of people who are intellectually disabled.

In a different sphere of interpretation, within psychology the term community is commonly defined as "sense of community," which refers to the feeling of being part of a community (see, e.g., Cicognani et al., 2008). A sense of community has been defined by Sarason (1977) as "the feeling that one is part of a readily available, supportive and dependable structure" (p. 14). This definition incorporates social capital and emphasizes a sense of community connectedness, personal interdependency, and belonging. In a similar vein, a four-dimension model of sense of community has been proposed by McMillan and Chavis (1986) to include the following components: membership, influence, integration and fulfillment of needs, and shared emotional connection. A fifth dimension has been proposed by Obst, Smith, and Zinkiewicz (2002), as the extent to which individuals identify with their community.

Given this overlapping understanding within sociology and psychology, the term community clearly has a definite meaning as an ecological domain. Moreover, this meaning is inconsistent with its use within the context of deinstitutionalization, first initiated by the President's Committee on Mental Retardation (Packard & Laveck, 1976). Their report includes the statement that "the Committee can state its goal for public attitudes quite simply: To achieve a firm and deep public acceptance of mentally retarded persons as members in common of the social community and as citizens in their own right" (p. 108).

Misuse of community is now endemic within the literature describing accommodation for people with an intellectual disability. As observed earlier, these people are very commonly described as living in the community instead of among the general public or within general society (see, e.g., Braddock & Hemp, 1997; Chen & Lin, 2014; Felce, 1998).

While the above distinction between community and the general population may seem pedantic within the context of some research literature, the distinction is crucial within the area of intellectual disability. Here, a community home is considered the antithesis of congregate care (see, e.g., de Kock, Saxby, Thomas, & Felce, 1988) or institutional care (Felce, 1998; Young, Sigafoos, Suttie, Ashman, & Revell, 1998). Moreover, within this literature, associations are commonly made between community and inclusion. Both of these are feel-good terms, engendering thoughts of pleasant human linkages creating some imagined collective, wherein the members are meaningfully and positively involved with one another. This assumption is false.

The Meaning of Neighborhood

A closely related term to community is "neighborhood." While the term neighbor means next to or near, its precise meaning when used by authors is often very vague. This imprecision is exemplified by Merriam-Webster (2014), where neighborhood can mean either a section of a town or city or as referring to the people who live near each other. These are very different meanings.

Consider, for example, the description that researchers "interviewed neighbors … regarding the amount of contact they had with service users" (Emerson & Hatton, 1996, p. 26). It obviously makes a huge difference to understanding their results whether the neighbors lived in adjacent housing or on the other side of the city. Even when neighborhood is defined as the whole street (Bates & Davis, 2004), clearly the probability of contact will differ if the two parties live either in adjacent houses or at opposite ends of the street.

There is a simple principle. It is intuitive that, *ceteris paribus*, any measure of contact or involvement with a neighbor will show an inverse probability with distance from the target residence. Therefore, a lack of precision regarding the level of geographical contiguity makes findings impossible to compare between studies. A reasonable distance by which to define a neighbor, suggested by Pittock and Potts (1988), is a radius of about 100 m from the target residence.

In terms of its conceptual positioning relative to the self, neighborhood occupies an ecological domain that is similar to community, lying between family and society. Thus, "from family, close friends or neighbors" (Gokdemir & Tahsin, 2014) and "individuals, neighborhoods, and societies" (Helliwell & Wang, 2014). It is therefore appropriate to use the term as in neighborhood committee (Cheng, 2014). However, using the term neighborhood residential estates (Griva et al., 2014) gives rise to the difficult issue of high-rise accommodation. These places have a very different social structure, and therefore a different meaning for neighborhood, from those involving detached houses in the suburbs or villages. As described by Ager (2002), within the Malawian culture, teaching children to greet neighbors politely is seen as a social imperative. Within high-rise apartments, where even people sharing a common wall are likely not to know one another, such behavior may be seen as a threat to the child's welfare.

In summary, both of the terms community and neighborhood have a clearly specified meaning, yet both terms are frequently incorrectly applied. This misuse leads to misunderstandings regarding the implications of research results. Moreover, since community carries such strong positive associations, there is a danger, most particularly within the disability literature, of regarding "community homes" in a more positive light than a non-biased view might reveal.

The Meaning of Communities

In an early review of communities as collectives, Rossi (1972) considered a core aspect of community to be that the members link their own well-being to the fate of the collective. This recognizes the power of community to enhance the resilience of its members. The following derivative principles can be identified:

1. Within the group, the stronger the sense of difference from the general population, the stronger will be the interpersonal ties, social capital, and social support. Thus, Savassi, Bogutchi, Lima, and Modena (2014) found unusually strong friendship ties within a Brazilian leprosarium using the social subscale of the WHOQOL-BREF (WHOQOL Group, 1998). Note that this predicts a sense of community within the share-home, not between the share-home residents and their neighbors.
2. In low-income, isolated communities in developing countries, residents are very highly dependent on one another. They are connected to the people who live around them as a social imperative (see, e.g., Davey, Chen, & Lau, 2009; Tsai & Dzorgbo, 2012). A similar situation, in diluted form, exists in towns and cities among the low-income people who live in socially homogeneous neighborhoods, comprising people of the same class or ethnic background (Stack, 1975). These people are commonly unwilling to connect socially with people from outside their immediate neighborhood and so are interdependent with one another. Again, the comment under (1) would apply. However, this tendency is counteracted in many large cities by the high turnover of residents in poor neighborhoods, with consequential low social capital (Campbell & MacLean, 2002; Chang & Tipple, 2009; Putnam, 2007). The equivalent influence in a share-home would be high levels of staff turnover.
3. A robust finding is that a general sense of threat causes the community to bond more closely with one another (see Henderson, 1977). Thus, at such times, SWB might be expected to be more influenced by a sense of community connection than during non-threat times. This has been demonstrated in relation to Hong Kong neighborhoods during the period of threat from the contagious severe acute respiratory syndrome in 2003 (Lau et al., 2008). Other studies have reported social cohesion as an important buffer to SWB following threats experienced by a community (Cummins, Eckersley, Pallant, & Davern, 2002; Liem & Liem, 1978). Again, such a sense of threat, as may be experienced by share-home residents and staff in the face of neighborly hostility, or even neighborly indifference, may cause them to turn inward, to seek bonding rather than bridging social capital.
4. These factors may help to understand the formation of enduring relationships between people with an intellectual disability and their friend who are intellectually normal. These relationships are particularly interesting due to the substantial intellectual imbalance, power differential, and logistic problems. However, much the same factors underpin such relationships as other relationships in society. That is, they often form out of initial contiguity, at the time the friend was a staff member (Lutfiyya, 1991), and their friendship is sustained by a sense of reciprocal social support (Newton, Olson, & Horner, 1995), obligation, and mutual pleasure.
5. Finally in this list, as has been stated, communities are formed of people with a shared characteristic or interest. Thus, people who do not share a characteristic or interest with community members will tend to be excluded. This rather obvious fact has been understood and described for about 70 years (Kardiner & Ovesey, 1951; Lewin, 1948; Rosenberg, 1965). Consequently, people with an intellectual disability are likely to experience prejudice from members of the general population in situations where they encounter an already formed community of neighbors, work employees, and so on (Dewees, Pulice, & McCormick, 1996). This calls into question

the assumption within much of the disability literature that placing people with an intellectual disability within a suburban neighborhood will reduce prejudice. In sympathy with the above discussion, this is most unlikely (for a review, see Wessel, 2009).

From the theoretical perspectives offered above, there is little reason for people in a share-home to have any dependence or personally meaningful social interaction with the people living in the dwellings that surround them. People in the share-home will be seen as different, thereby facilitating prejudice, most particularly if they evidence behavior problems (Pagel & Whitling, 1978). They will not be viewed as a valuable resource, the share-home is likely located in a middle-class location where neighborhood social capital is low, and there is unlikely to be a shared source of threat to bond neighbors with members of the share-home. So, for all these reasons, it would be very surprising to find that a sense of community featured strongly in the subjective life quality of people in share-home accommodation.

Life Quality Following Deinstitutionalization

There is a universal understanding in the disability literature that accommodation located among dwellings of the general population, and shared with other people who also have an intellectual disability, is a better option than living in an institution. At a general level, this view is not contested, certainly when compared against traditional institutional living which involves highly constrained and regimented conditions, as has been discussed (see also Wolk & Telleen, 1976). However, the nature of this superiority warrants examination.

The driving force behind deinstitutionalization was normalization, as has been described. However, at the time of implementation, reasonable evidence that this would improve the life quality of residents had not been established. The closure of Pennhurst was mandated in 1977, yet Conroy and Bradley (1985) wrote “In 1978 there was an extreme paucity of reported research concerning the behavioral benefits of deinstitutionalization” (p. 52). It is, thus, with some interest that the subsequent evidence for efficacy is examined.

Looking back over this remarkable history, finding an improved life quality following the move into share-homes was entirely predictable using objective measures of normalization. This is due to comparison with the awful circumstances of life with institutions. Improvement was also predictable when the measures of success reflect conformity with the intentions of deinstitutionalization legislation. However, a normalization approach to the issue of deinstitutionalization fails to target other forms of outcome. These include the specific nature of the variables comprising objective life quality, together with the essential issue of subjective life quality, based on the actual experience of the relocated individuals. These matters will now be examined.

Objective Life Quality

An emerging body of research on consequences of deinstitutionalization and normalization came into being in the late 1970s and early 1980s. Some of these studies concerned the big picture of life quality, as to whether it was possible to successfully relocate people out of institutions and into share-homes or even into independent living. It was reported that the answer was generally in the affirmative. Inevitably, some people could not make the transition due to special medical needs or, most commonly, behavior that was just too challenging (Keys, Boroskin, & Ross, 1973; Schalock & Harper, 1978). But these people were in a distinct minority.

Other studies concerned the more detailed objective circumstances of living and personal development of the residents who were relocated into share-homes. At that time, subjective indicators of life quality had not become sufficiently mainstream to be included in the evaluations. So the almost universal standard for measuring life quality in share-homes was set by the use of the PASS evaluation (Wolfensberger & Glenn, 1975).

First devised in 1970, PASS is intended as an objective rating, by trained personnel, of the extent to which a share-home meets standards devised from an interpretation of the philosophy of normalization (Wolfensberger, 1972). The instrument is highly complex, both in terms of its administration and scoring. The training of evaluators takes 6 days and the evaluation of each facility one full day, requiring the involvement of senior staff. The manual advises that, in order to be able to make a valid assessment, “assessors must be able to familiarize themselves intimately with the facility, and have access to all aspects of the service system. Assessors must be able to review all records; interview all staff, clients, board members, volunteers, and inspect all parts of all sites at any time” (p. 85).

To give a flavor of the form of data collection, some of the areas rated, selected here to emphasize interpersonal life quality ratings, are program-neighborhood harmony, congregation and assimilation potential, socially integrative social activities, and social overprotection. But other areas cover the full spectrum of service activities, from physical appearance of the dwelling to rights, routines, and financial management.

Rigorous evaluation of the instrument in terms of its psychometric properties and validity was not available at the time the third edition of PASS was published in 1975. The authors cited high internal reliability, which carries little useful information, and unpublished findings that client advancement was correlated with the PASS rating of their facility. However, in the absence of descriptive statistics on the comparative client populations, this cannot be simply interpreted. The authors also cited an unpublished report by Flynn (1974), which reported a factor analysis, but this manuscript could be located through Google Scholar. Pretty clearly, at the time that PASS was being actively promulgated throughout the Western world at least, the instrument remained unvalidated.

Case Studies of Institutional Closure

The first major study of deinstitutionalization was conducted over a 5-year period by Conroy and Bradley (1985). Closure of the Pennhurst State School and Hospital in Pennsylvania had been mandated in 1977 by District Court Judge Raymond Broderick (Halderman v. Pennhurst State School and Hospital & 446 F. Supp, 1977). His was a watershed decision. Whereas previous legal rulings had concerned improving institutional settings, Broderick ruled that this institution was incapable of providing constitutionally appropriate care. He concluded that the residents, those on the waiting list, and any other intellectually disabled person in the community who was “at risk” of institutionalization should be provided with the services they required in less restrictive settings, in the community.

The population of Pennhurst comprised a very challenging group of 1154 people. Their average age was 39 years, and the average period they had been institutionalized was 24 years. In addition, 86 % were severely or profoundly disabled, 40 % displayed physical violence toward others, and around 50 % were nonverbal. This report of the Pennhurst deinstitutionalization outcomes comprises two parts. The first is a cross-sectional study, which is an elaboration on a previous paper by Conroy, Efthimiou, and Lemanowicz (1982). The original paper involved data from 70 people; this later report covered a sample of 191 people. The second part is a longitudinal study. The results from both of these will be integrated with a study in Victoria published some 3 years later.

The first Australian study of deinstitutionalization involved an institution in Melbourne, conducted over the period 1983 to 1986 (Cummins & Dunt, 1988, 1990; Cummins, Polzin, & Theobald, 1990a, 1990b; Dunt & Cummins, 1990). St. Nicholas Hospital had been established in 1964 as a residential institution for children and young adults with severe multiple intellectual and physical disabilities. It offered specialized medical and nursing care in a sheltered environment, and placement was viewed by society of the time as the only practicable way to provide for such children. However, in 1977, an official committee of enquiry into the several institutions for people with an intellectual disability in Victoria reported that they were overcrowded and understaffed. The committee recommended that resident numbers be progressively reduced so that institutions throughout the state could eventually be replaced by small specialized residential alternatives in the general society. These were to conform to normalization principles (Nevo, 1985; Nirje, 1969) by ensuring that "the sizes of the new share-homes never be intended for a larger number of persons than the surrounding neighborhood readily assimilates in its regular everyday community life."

The decision to close St. Nicholas Hospital and to relocate its resident population was announced in 1981. No prior consultation with parents had taken place. Twenty-three share-homes, some purposely built, others purchased, were selected in ordinary residential settings. They were situated away from other institutions but close to amenities such as transport, shops, and parks. Each was furnished according to the principles of normalization (e.g., bedrooms were furnished to reflect the residents' individuality) but with suitable modifications being made to satisfy most design criteria for accommodating people with a range of disabilities. Factors influencing selection of residents (up to five) for a particular share-home were proximity to their families, maintenance of existing friendships and day placement programs, and the separation of children and adults. Each house was provided with a suitable vehicle for the transport of residents. During the working day, children attended special developmental schools or day training centers, while young adults were placed in sheltered workshops or activity centers.

The share-homes were generally similar in their policies and practices. The relevant government department managed them rather an autonomous committee or management. Staffing was generous—a house supervisor lived in for most of the week with a relief supervisor for the remainder of the week. Five trainee mental retardation aides, as well as other casual staff, supported these supervisors.

Unlike St. Nicholas, staff roles were undifferentiated, with all personnel being required to attend to domestic tasks such as shopping and food preparation as well as to the resident's care (as reflected the principles of normalization). The share-homes were required to draw on generic services (i.e., services available to the general population) for health care such as general medical practitioners, dentists, and pharmacists. Few St. Nicholas staff sought appointments to the share-homes. As a consequence, the newly recruited staff generally had little relevant formal experience of working in such situations. So the necessary knowledge and skills were imparted through a training course.

Data for the Pennhurst study were collected before moving in 1978 and after moving in 1983. The reported data are derived from two matched groups of 191 people, one a group of movers and the other a group of stayers. Relocation of the St. Nicholas' residents commenced in July 1984 and proceeded group by group as new homes became ready for occupation. The last group of five residents moved out on March 20, 1985. The study period extended from August to October 1983 (premove) to January to May 1986 (after the move).

Characteristics of the Residents

In order to assess the significance of changes in resident status, it is necessary to consider the characteristics of the study population. By any standard, including the Pennhurst population, the St. Nicholas group was extraordinarily disabled. Not only were the majority profoundly intellectually disabled, but many also had multiple physical disabilities that may include spastic quadriplegia, with contractures and deformities, epilepsy that was difficult to control, deafness and blindness. Also, like the Pennhurst population, most had been subjected to long-term institutionalization.

At the time of relocation, the residents of St. Nicholas were also profoundly growth retarded. As a group, they were lighter and shorter than their non-disabled peers. The cause for this appears to be multifactorial, including undernutrition.

However, there is an established link between severe disability and growth retardation. For example, Kugel and Mohr (1963) found in a study of 879 intellectually disabled children that growth retardation is related to intellectual disability, irrespective of the etiology of the disability. Similarly, in a survey of 514 children with intellectual disabilities, Roberts and Clayton (1969) found that, whereas children with mild or moderate disabilities were more than five times more likely to be below the third percentile in overall growth, children with severe disabilities were 11 times more likely to fall below this level.

The group also had reduced life expectancy. Such reduction was a known characteristic of children who were severely intellectually disabled. Up to one half of profoundly intellectually disabled children residing in institutions had a life expectancy of less than 20 years and considerably less if associated with physical disabilities, such as cerebral palsy (Balakrishnan & Wolf, 1976; Herbst & Baird, 1983) or immobility (Eyman, Grossman, Chaney, & Call, 1990). Thus, the group could be expected over time to show decline in measures of their physical health.

Physical Health and Behavior

Following relocation to the share-homes from St. Nicholas, there were few physical health changes, either positive or negative (Dunt & Cummins, 1990). However, the residents showed meaningful improvement in certain in-home self-help skills (as also reported for other deinstitutionalization projects: Fleming & Stenfert Kroese, 1990) and in positive social behavior. Probably as a result of the increase in self-care and socialization activities, there was a decrease in time spent asleep. Such improvements in self-care and social behavior following deinstitutionalization have been noted elsewhere (Kleinberg & Galligan, 1983; Walsh & Walsh, 1982), and a similar improvement was noted in the Pennhurst study (Conroy & Bradley, 1985).

It seems reasonable to assume that these improvements were due in large part to the new requirements of "normal" life in the share-home and the increased provision of services outside the home. This involved increased variation in the rhythm of the week involving sleeping and meal times (Cummins & Dunt, 1990). It also involved increased opportunity to engage in self-care and share tasks (Walsh & Walsh, 1982) and more intensive educative and rehabilitative services particularly involving day placement programs (Conroy & Bradley, 1985).

For both studies, adaptive and maladaptive behavior was measured, for each resident, before and after relocation. Both studies report a significant increase in adaptive behavior but no significant change in maladaptive behavior. The adaptive behavior gain for the Pennhurst group was positively associated with duration of share-home residency, ambulation, and baseline adaptive behavior. The authors also found no increase in adaptive behavior, while residents remained in Pennhurst, thereby demonstrating that the gains were not simply developmental. The gains in adaptive behavior were also stronger in the early period following relocation and then showed slowing in later measures. This is a typical response to release from deprivation.

The lack of change in maladaptive behavior is somewhat surprising. While an independent study of a separate deinstitutionalization by Walsh and Walsh (1982) reported a decreased level of maladaptive behavior, the result is likely unreliable. Their cross-sectional study involved an unmatched comparison with the stayers, and it is likely that the movers had been selected for their relatively higher levels of functioning and low levels of maladaptive behavior. In conclusion, it seems that changes in maladaptive behavior that may be attributed to deinstitutionalization are more uncertain than positive change in adaptive behavior. Contact with family members seems not to reliably increase following deinstitutionalization (Conroy & Bradley, 1985). This is clearly against the expectations proposed by normalization principles and against one of the decision criteria for placement, which was to relocate residents close to their families.

Staff Attitudes

The circumstances of living in a share-home are going to be highly dependent on the attitudes of the staff. If the staff are discontented, then this is likely to be reflected in poor attention to their duties as carers within the share-home environment. Unfortunately, the results from a variety of studies are not encouraging in this regard. In the USA, George and Baumeister (1981) studied staff turnover and job satisfaction in 47 share-homes. They report high levels of staff turnover and staff dissatisfaction with their work conditions. These included low pay and a lack of appropriate training.

The Relevance of Neighborhood for Objective QOL

In their review, Sampson, Morenoff, and Gannon-Rowley (2002) concluded that while the neighborhood environment has been shown to make a nontrivial, independent difference for a variety of QOL outcomes, the impact of neighborhood on residents is weak. It is not nearly as strong as parental influence, individual characteristics, or economic conditions. Moreover, the means by which neighborhood effects are transmitted to residents is uncertain. The evidence below confirms these views.

The hard reality is that, despite the fond wishes of the proselytizers of normalization and integration, people with a disability, living in share-homes, have far less contact with their non-disabled friends and neighbors than is normal for non-disabled people (Aubry & Myner, 1996). They also tend not to develop more neighborhood friendships over time (Fleming & Stenfert Kroese, 1990; Lowe & Paiva, 1991) even in circumstances when their level of physical interaction with neighborhood has increased (Evans, Todd, Beyer, Felce, & Perry, 1994). Moreover, the relationships that they do make with non-disabled people tend to be quite short term (Kennedy, 1989).

The reasons for this have been outlined in the previous discussion of relationship formation theory and so are not surprising. Most of the people who form the neighborhoods of cities, and who are normally mobile, tend not to choose their friends from among their neighbors. Because they are mobile, they are free to form friendships with people based on criteria other than close geographic proximity. Thus, they choose their friends based on such criteria as shared values or preferred activities. They may meet such compatible people at their workplace, when engaging in their preferred form of activity, or during their travels.

But for people in share-homes these options are more limited. Their mobility is likely restricted, their work is commonly performed in the presence of other people who have a disability, and their activity preferences may involve groups dominated by people like themselves. Thus, as a natural consequence, few people in share-homes have a neighbor in their social network who does not also have an intellectual disability (Allen, 1989; Robertson et al., 2001). This remains true even when the share-home has been established for several years (Evans et al., 1994; Locker, Rao, & Weddell, 1981). While it has been reported that the frequency of activities in the neighborhood is correlated with the number of neighborhood friends (Kennedy, 1990), the actual number of social network members who were neighbors averaged to 0.4 per resident.

This also appears to be the case in locations where neighborly interaction is generally strong. A study in Dublin, where 90 % of a sample claimed they knew 16 or more people in their neighborhood by name, found that only 27 % had ever met a resident of the local share-home established 2 years previously (McConkey, Walsh, & Conneally, 1993). Depressingly, it also appears likely that the situation is not improving. In their submission to an inquiry into social inclusion in Victoria (Family and Community Development Committee, 2014), Occupational Therapy Australia stated that 76 % of residents in supported accommodation had only occasional, or no known contact, with friends and outsiders.

In summary, the residents of share-homes remain generally isolated from the non-disabled people in their proximity (Ager, Myers, Kerr, Green, & Myles, 2001; Emerson, 1985), and it is no surprise to find this also to people living in cluster housing (Emerson et al., 2000). The conclusion is straightforward. Despite their physical location and interaction with neighborhood facilities, people living in share-homes are not socially a part of their neighborhood (Dewees et al., 1996; Myers, Ager, Kerr, & Myles, 1998; Salzberg & Langford, 1981).

Does the integration situation look very different when people with an intellectual disability live with their families? The answer appears to be no. In a study of leisure time, McConkey, Walsh, and Mulcahy (1981, 1982) found only one third of such people took part in any form of neighborhood activity and only 20 % had a non-disabled friend. In a similar vein, Cheseldine and Jeffree (1981) found only 57 % of adolescents living with their parents reported having a friend outside the family, and, for those who did, the friend was almost invariably another adolescent with an intellectual disability.

Various authors have attempted to dismiss these results. Lutfiyya (1991) has declared them as outdated, stating “It was once held that the most likely people to be friends with individuals with learning difficulties are others with the same impairments,” but then fails to provide evidence that the situation has changed. A more direct opposition has come from Young et al. (1998) who, in the abstract to their review of deinstitutionalization, stated “Community-based placements were associated with …improved contact with family and friends.” In support of this, they cited five papers to support their conclusion (i.e., Cummins, 1993; Cummins & Dunt, 1988, 1990; Cummins et al., 1990a; Jones, 1986). But these five papers do not support the contention of Young et al. (1998) that placement in share-homes has significantly improved contact with family and friends. To the contrary, the data are in and the picture is clear. There is a considerable and continuing gap between being physically within and socially a part of the general population (for reviews, see Cummins & Lau, 2003; Myers et al., 1998). It is therefore disappointing to find recent reviews of deinstitutionalization (e.g., Lemay, 2009) which fail to recognize this uncomfortable reality.

Summary of Changes in Objective Life Quality

Previous discussion of the deinstitutionalization process has noted that positive changes in resident life circumstances are guaranteed if the criteria for change are benchmarked against the requirements of normalization or the measures included in the PASS instrument. Such criteria as living close to public amenities and having one’s own belongings can only show improvement from the institution. Despite this caveat, the combined results based on objective measures lead to a simple conclusion. On average, the people who have been deinstitutionalized are better off, or certainly no worse, in every way measured. As Conroy and Bradley (1985) observed, this is a most unusual outcome within the social sciences. The only neutral or negative findings were a lack of improvement in maladaptive behavior and high staff turnover in the share-homes.

QOL in and for Families

There is little reasonable doubt that life quality in institutions is very poor. It may therefore seem that the better option for a child is to remain in the care of their family. Discussion of this issue is, however, highly complex, because it must also consider the effect of that child on the life quality of their family.

An important perspective onto this issue is that the addition of any child to a family will be a stressor. This is true for the addition of both disabled and non-disabled children. So the crucial question is whether, and to what extent, the addition of a disabled child is a more powerful disruptive force. Unfortunately, this question is very hard to answer. Not only are family dynamics complex, but the available studies are simplistic. So any attempt to provide a reasoned view is fraught with caveats.

An early study was conducted by Fotheringham, Skelton, and Hoddinott (1972), who compared the functioning of two groups of families using a variation of the Family Functioning Scale (Geismar & Ayres, 1960). One group had placed their child with an intellectual disability into an institution; the other group had not. One year after placement, they reported no change in the functioning of the family who placed their child. They also reported deteriorated functioning in the family that retained their child. However, this result is very difficult to interpret since there was no comparison against families who retained their non-disabled children. It is also possible, as the authors acknowledged, that the 1-year interval of follow-up was insufficient to erase developed maladaptive patterns of family functioning.

In summary, and in keeping with the preceding text on SWB homeostasis, the life quality of the family caring for a child will depend on the balance of two opposing forces. These are the level of family stress caused by the child and the level of resources available to their family. From this, it can be predicted that, in general, the more internal and external resources (see homeostasis) that are available to a family, the greater the probability that the family will be able to deal with the challenge. However, it is also true that the life quality outcome will be determined by a daunting complexity of interacting variables. This makes prediction at the level of specific families most uncertain.

Subjective Life Quality and Intellectual Disability

Leading figures in the field of intellectual disability have long advocated that subjective life quality should become an integral part of professional management. However, the field has responded with little enthusiasm. While the measurement of SWB has been commonplace in most applied areas of human service delivery for several decades, the adoption of this technology has been much slower in the field of intellectual disability. To give a recent example, within a 441-page report on social inclusion (Family and Community Development Committee, 2014), there is no systematic concern with the happiness or subjective well-being of the people under discussion.

The reticence to adopt such measures is likely due to a number of concerns. Foremost among these is the difficult issue of response validity. As measurement depends on the self-report of a subjective state, it is essential to establish that each respondent is both capable and able to perform the task required. This requirement is at the heart of response validity and reliability. While the solutions to this issue are available, the acquisition of reliable and valid data requires more effort than is normal in simply conducting a survey. It means that time and resources must be spent in establishing, for each person, their capacity as a respondent. However, most researchers seem either unaware of this necessity or are unwilling to spend the time in its implementation. The result is the publication of many unreliable results.

For example, subjective data were gathered for the Pennhurst study (Conroy & Bradley, 1985), but the results are not included in Table 8.1 because they are so obviously unreliable. The authors measured self-reported happiness before and after the move from the institution. While the authors claim higher self-reported happiness after the move, the results are not only based on small numbers of respondents, but also about half of the respondents were severely or profoundly disabled. There is no evidence that people with a profound level of intellectual disability can validly and reliably disclose their level of SWB through self-report.

The second issue that researchers find disconcerting is the commonly found low levels of relationship between objective and subjective measures of life quality. The reason for this is evident in the context of homeostasis theory. However, few researchers evidence this understanding and, instead, attempt to provide alternative reasons that are usually inadequate and unconvincing.

As an example of such inadequacy, Perry, Felce, and Lowe (2000) reported the SWB of people living in share-homes. They measured satisfaction with the domains of recreation and community using the Lifestyle Satisfaction Survey (Harner & Heal, 1993) and with the domains of productivity, intimacy, and community using the Comprehensive Quality of Life Scale (Cummins, 1997b). The authors found virtually no association between the objective characteristics of either the participants or their living conditions, with domain satisfaction. They offered two explanations as: (1) the participants have adapted to their life circumstances, and (2) one of their measured objective characteristics was participant ability. They suggested that the lack of correlation between ability and SWB might be that the people with lower abilities may have lowered their expectations or ambitions, thereby perceiving an equivalent level of satisfaction to that of people with higher levels of ability.

While both of these explanations are reasonable at a surface level of understanding, they are also inadequate. They are reasonable in that they are consistent with SWB homeostasis theory that incorporates adaptation, involving a variety of cognitive processes to maintain SWB within its normative range for the individual. However, these explanations are also inadequate, in that they seem to imply that anyone can adapt to any life circumstances. This is clearly not true and detracts from the view of SWB as a useful indicator.

On the contrary, homeostasis theory explains why levels of SWB may, or may not, be linked to the objective characteristics of the environment. The fact that, as in Perry et al. (2000), the subjective and objective indicators are not linked indicates a benign living circumstance where homeostatic control is being maintained. Only if the correlations were found to be significant could it be concluded that the circumstances of living are threatening, or even overwhelming homeostatic control, and thereby placing the people concerned at risk of depression (Cummins, 2010).

How Sensitive Is SWB as a Dependent Variable?

One of the most significant insights to emerge from homeostasis theory is that the relationship between objective variables, such as physical health or environmental conditions, with SWB, is nonlinear. That is, life satisfaction does not simply fluctuate with changing medical or financial circumstances (Cummins, 2000a). This comes as a surprise to many researchers in medicine and economics, who expect a linear relationship and then describe their nonlinear results as paradoxical. Rather than a paradox, such results are consistent with expectation, while SWB remains under normal operating control of homeostasis. The very role of homeostasis is to ensure that the objective measures of life quality have little or no relationship to SWB, most especially with the passage of sufficient time to allow the system to adapt after perturbation. This phenomenon of apparent SWB insensitivity has been widely observed within the QOL literature, including for people with an intellectual disability (see, e.g., Perry et al., 2000).

The homeostatic devices that have been described earlier in this chapter are very powerful stabilizers of SWB. Even high levels of challenge are often homeostatically manageable, such that the person will experience only a short-term level of change in their normal positivity as they adjust to abnormal circumstances. However, a sufficiently strong and persistent challenge will overwhelm homeostasis. When this occurs, the emotional affect generated by the challenging agent will dominate awareness, and a major shift in experienced affect will occur. This persistent change in experienced affect starts to be evident within groups as their mean score falls below 70 points and for individuals when their SWB falls below 50 points. As this change occurs, the primary manifestation of homeostatic failure will be that objective and subjective measures of QOL show an enhanced level of relationship to one another. This happens because control of SWB levels is being transferred from homeostasis to the challenging agent (for an empirical demonstration, see Cummins, 2000a).

As a consequence of these considerations, homeostasis theory predicts that, under normal living conditions, where homeostasis is maintained, there will be no significant relationship between measures of SWB and the living circumstances of people with an intellectual disability. This will be due to the processes of adaptation that have been described. It is only when the conditions are sufficiently aversive to prevent adaptation that the circumstances of living will cause SWB to decrease below its homeostatic range.

This leads to a crucial understanding about the sensitivity of SWB as a dependent variable. The degree of sensitivity will depend on the level of SWB at baseline. In order to illustrate this, consider two groups of people with an intellectual disability, being compared for their sensitivity to a standard intervention. One group lives in an institution, and the other lives in a group-home. Two possible scenarios and interpretations of results are predicted as follows:

1. *Baseline measures of SWB:* Both groups lie above 70 points.

   Outcome: Following the intervention, both groups show improved objective measures of functioning but no change in SWB.

   Incorrect interpretation: The form of the intervention was inappropriate to raise SWB.

   Correct interpretation: The living circumstances of both groups permitted homeostatic adaptation at baseline. Hence, their baseline scores for SWB were in normal range. Because of this, homeostatic processes determinedly returned raised levels of SWB back into their normal range. Thus, the reason for the lack of change in SWB was not due to the nature of the intervention but to the normal levels of SWB at baseline.
2. *Baseline measures of SWB:* Institution group <70 points, share-home group >70 points.

Outcome: Following the intervention, both groups show improved objective measures of functioning. The institution group shows an increased SWB, while the share-home group does not.

Incorrect interpretation: The form of the intervention was appropriate to raise the SWB of people living in an institution but not for people living in a share-home.

Correct interpretation: The differential change in SWB was not due to the greater appropriateness of the intervention in the institution but to their below-normal levels of SWB at baseline.

It is common to find commentators lamenting that SWB is an insensitive indicator of either the circumstances of living or as a measure of intervention effectiveness. This opinion may be unfounded if the baseline measures of SWB were in normal range. It may therefore be concluded that measuring the level of SWB at baseline is essential to the correct interpretation of results.

Measured Levels of SWB

According to homeostatic theory as outlined above, people are able to achieve normal range SWB under diverse personal circumstances *provided that* such circumstances allow the normal functioning of homeostasis. From this perspective, the chronic SWB level of people with an intellectual disability is more uncertain than it is for people sampled from the general population. There are two reasons. First, these people are more likely to experience additional sources of challenge as a result of their disability. For example, people with an intellectual disability are more likely to encounter discrimination, to be unemployed, and to have ill-health and dependence on care staff. They are also more likely to have low levels of protective resources, such as money and an intimate relationship. So the limits of their adaptive capacity within homeostasis are more likely to be severely tested.

Nevertheless, homeostasis is a resilient process, and it would be expected that, under decent conditions of living with support, most people with ID would have normal levels of SWB. This proposition is tested in Table 8.1, which presents results from seven studies measuring the SWB of people with a mild/moderate level of intellectual disability, living in a variety of community and institutional settings.

As a reminder of what might be expected from the data in Table 8.1, homeostatic theory predicts that group means for life satisfaction and SWB will normally average between about 70 % SM and 80 % SM. Closer specification of the normal range is possible in Australia, where reliable general population normative values are available for both GLS (76.0–79.2 points) and for the PWI (73.8–76.7 points) (Cummins et al. 2013). However, norms for other countries are less certain due to both a lack of reliable data and the phenomenon of cultural response bias, which causes some cultural groups to respond to self-reports in substantially different ways (Lai, Cummins, & Lau, 2013).

A number of observations can be made in relation to the 15 mean scores in Table 8.1 as follows:

1. At the high end of the scale, three (20.0 %) of means exceeded 80 % SM which is the top of the theoretical normal range. There are four likely reasons. First, the scale is not a pure measure of SWB. It is notable that two of these values come from studies using the PALS instrument. Second, the response choice is too gross to allow a reliable measurement. Notably, the PALS instrument uses a binary scoring system. Third, the respondents were not pretested to ensure they were competent to respond as required. Fourth, the data were not screened for acquiescent responses, most commonly represented by a positive response set, or "Yes saying" (Sigelman, Budd, Spanhel, & Schoenrock, 1981). As shown in Table 8.1, two studies did test for acquiescent responding, and the three samples investigated revealed that they contained between 25 and 40 % of acquiescent responses.
2. At the lower end of the distribution, eight (53.3 %) of the values from Heller et al. (1998) fell well below the lower normative value of 70 points. There are two likely reasons. First, the data may not fairly represent SWB due to the inclusion of negatively valenced items in the scale. Second, and this is the more likely reason, the low scores are valid and represent a preponderance of homeostatic failure within the groups. Evidence of such disadvantage is evident within Heller et al. (1998), as 2 years after moving from a nursing home environment into a share-home, SWB levels increased to lie within the normative range.
3. The remaining four (26.7 %) group mean scores lie within the normal range of 70–80 points. The origin of these scores is interesting. One of these by Heller et al. has been mentioned above and followed relocation from a nursing home into a share-home. The other three values all come from a study that used a genuine measure of SWB (i.e., Comprehensive Quality of Life Scale), where the researchers had implemented a pretesting protocol to identify, and eliminate, people who were responding in an acquiescent manner.

In summary, these results either are consistent with expectations derived from homeostasis theory or can reasonably be explained as a methodological artifact. These results also emphasize the essential requirement for pretesting and careful data cleaning in order to obtain valid and reliable data.

Share-Home Versus Institutions

Advocates of normalization assume that adults who live in the community, at best independently or at least with their families, or in group homes, have a better QOL than people who live in institutions or cluster housing. However, homeostasis theory makes a different prediction based on personal resources. That is, any of these living environments have the potential to provide the resources to allow homeostatic adaptation or to be so bereft of resources as to cause homeostatic failure. The test of these two predictions is whether any of these living environments predictably cause lower or higher subjective QOL.

There is, however, a methodological difficulty in providing an answer to this question. As Schalock, Keith, Hoffman, and Karan (1989) have noted, the characteristics of individuals are likely a key factor in their degree to which people are suited in these environments, which is the degree of personal independence they provide. Thus, people may be more or less suited to independent living depending on their personal characteristics.

One approach to investigate this question is to use major personal characteristics as covariates and then to measure the residual variance due to independent living. Unfortunately, however, no studies known to me have used this approach, so inferences can only be drawn from simple comparisons between groups.

When such comparisons are made using the QOLQ, it is found that higher scores are derived from people living independently compared with people in group homes (see, e.g., Schalock et al., 1989). This, however, may well be influenced by the objective items in the QOLQ scale. When subjective QOL only is used as the measure, the differences are less predictable. For example, while Yu et al. (1996) found the Lifestyle Satisfaction Scale to discriminate between institutional and community living, the latter was superior on only two of the five subscales and actually inferior on the satisfaction with service subscale.

It is unfortunate that the results in Table 8.1 cannot be used to inform this issue. While the nursing home environment of Heller et al. (1998) clearly produced a subjective QOL score below the normal 70–80 point range and the valid share-home data are within the range, there are too few results for these comparisons to be informative.

The Domains of Subjective Life Quality

Within the generic literature on SWB, general life satisfaction (GLS) has emerged as a key variable by which to measure subjective well-being. It is measured by a single question asking people to rate their satisfaction with their "life as a whole." However, there is also wide recognition that GLS can be deconstructed into a number of domains, as was first suggested by Andrews and Withey (1976). The measurement of domain satisfaction has the advantage of providing more refined information than GLS. Moreover, if the domains are appropriately identified, they can be formed into a parsimonious scale wherein their average score is a close approximation to GLS (Cummins, 1996). How, then, should such domains be selected?

The most widely used domain-level scale is the Quality of Life Questionnaire, developed over several decades by Schalock and colleagues. During the period of this scale development, the number of domains has varied between four and eight. However, the choice of domains has been informed by ideology rather than theory, and the construction of the domains has never been empirically verified by either the publication of a detailed factor analysis or unmodified confirmatory analysis. While the manual (Schalock & Keith, 1993) presents the results of a factor analysis in their Table 5, it is just a summary and does not present cross-factor item loadings. So the QOLQ scale remains empirically unverified.

Several other authors (e.g., Andrews & Withey, 1976; Felce & Perry, 1997) have suggested alternative sets of domains, and in a review of the domain literature, Hughes, Hwang, Kim, Eisenman, and Killian (1995) identified 14 frequently cited quality of life domains. However, none of these alternative sets have been rigorously tested, with the exception of one.

The seven domains of the Personal Wellbeing Index (PWI) have been selected on the theoretical basis that they represent the first-level deconstruction of GLS (International Wellbeing Group, 2013). Thus, these seven domains should represent the most parsimonious set of domains to account for variance in GLS, and, according to the criteria for domain selection presented in the PWI manual, each domain should account for significant unique variance in GLS (see also Cummins, 1996).

This criterion has been tested as detailed in the scale manual. The domains are generally confirmed; however, some are more consistent than others. The three strongest are relationships, standard of living, and achieving in life. The weakest are safety and connection to community. Moreover, the seven domains are only partially valid for children. Within this group, Tomyn and Cummins (2011) have shown "happiness with school" to be a valid domain. So the possibility of additional or alternative domains fulfilling the requirements for inclusion remains a distinct possibility for future research to discover.

An important insight that can be derived from domains is whether the pattern of satisfaction is similar between samples from the general population and samples of people with an intellectual disability. A pattern that is similar would lend weight to the idea that the seven domains are universal and provide credibility to the claim that the PWI scale is a valid measure of SWB for this group. This has been verified by two published studies using ComQol-ID (Ager & Hatton, 1999; Verri et al., 1999) which both show a similar pattern. The domain of community retains its relative position at the bottom, while the domains providing the most satisfaction are relationship and standard of living. This provides further verification that the data derived from the ComQol and PWI are valid measures of SWB.

The key domain influencing SWB is personal relationships. People who are in a supportive relationship are highly resilient and maintain high levels of SWB. People in aversive relationships, on the other hand, are vulnerable and maintain low levels of SWB (Cummins, Walter, & Woerner, 2007). However, once again the objective versus subjective dichotomy is crucial to understand this area.

The focus of normalization is on objective measures. This objective focus is unfortunate in terms of linking relationships to subjective life quality. A huge literature, spanning many decades, attests to the fact that SWB is little influenced by the number of friends or relationships that someone has. The crucial link is with the quality of those relationships, and, as a general rule, just one high-quality relationship will serve as well as many (Conner, Powers, & Bultena, 1979; Liang, Dvorkin, Kahana, & Mazian, 1980; McLean, Jarus, Hubley, & Jongbloed, 2014).

This finding is no different for people who have an intellectual disability. The quality of social relationships for the residents of share-homes is strongly associated with positive aspect of SWB such as happiness (Chadsey & Beyer, 2001), self-esteem and confidence (Srivastava, 2001), and leisure activities (Forrester-Jones, 2001). Moreover, when relationships are insufficient for people's needs for companionship, they feel lonely. When Barlow and Kirby (1991) asked people in a share-home what kind of follow-up support they would like, about a third said that they would like someone to call or talk to.

Unfortunately, relationships may also be abusive (Cambridge, 1999). In a comparison of people living in an institution or share-homes in Adelaide, Barlow and Kirby (1991) report that when asked what they "liked least" about living in a share-home, around half included lack of people, noise, neighbor or flatmate troubles, and money problems.

The Relevance of Neighborhood for SWB

When researchers compare the level of general society integration using objective criteria, it is obvious that such measures will increase after moving from the institution and into a share-home. Normalization-type integration measures, such as the proximity of non-disabled neighbors, accessibility of suburban facilities, and accessibility of public transport, are bound to increase after the move (for a review, see Young et al., 1998). However, as detailed by Cummins and Lau (2003) in their review of community integration, it is social, not physical integration, that has a reliable positive influence on subjective well-being. Thus, these authors argued, the essential goal of service provision should be to achieve a sense of social connectedness, as perceived by the people living in the share-home. So, the empirical evidence for a subjective sense of integration, by people living in a share-home, will now be examined.

From the objective data previously presented, it is clear that physical interaction between share-home residents and their neighbors is generally minimal. Thus, it can be reasonably concluded that as far as the residents of a share-home are concerned, the people forming their neighborhood are largely irrelevant, at least in a social sense. It would therefore be surprising to find that measures of neighborhood integration had a strong influence on the subjective well-being of the residents. There are, however, two kinds of circumstance that could cause this connection. The first would be because the residents feel deprived at the lack of social interaction with their neighbors. However, there is little, if any, evidence for this. It is the social environment within the share-home that is most relevant.

The second kind of circumstance could come about if neighbors evidenced overt hostility to the residents. However, again, there is little evidence in the literature that this is a common circumstance. For the most part, neighbors evidence disinterest rather than a strong negative opinion (see, e.g., Pittock & Potts, 1988), and, moreover, the level of negativity tends to decrease over time (Seltzer & Litchfield, 1984).

It is, thus, no surprise to find that the frequency of social contact with neighbors (people living on the same city block: Aubry & Myner, 1996) correlates trivially with subjective well-being (Satisfaction With Life Scale: Diener et al., 1985). This is as true for members of the general population (0.15) as for people with a psychiatric disability living in a share-home (0.21).

The above descriptions confirm the normally weak relationship between objective aspects of the neighborhood and subjective life quality. Even more compelling evidence for the low level of association between neighborhood and SWB comes from the data on subjective perceptions of community and neighborhood.

Early results from the major general population studies reported by Andrews and Withey (1976) and Campbell et al. (1976) showed that satisfaction with community or neighborhood has little relevance for subjective well-being. Many researchers have subsequently confirmed this. For example, using general population samples, authors have reported correlations of 0.20 or less between SWB and neighborhood (Near, Rice, & Hunt, 1978) and community satisfaction (Shin & Johnson, 1978). Even the negative aspects of neighborhoods seem to have little relevance for SWB. In heavily urbanized Taiwan neighborhoods, Li and Tsai (2014) found that various forms of local annoyances (e.g., noise, traffic) and advantages (air quality) had a trivial influence on SWB, together accounting for only 6 % of the variance.

Confirmation of these results has also come from using the Personal Wellbeing Index (International Wellbeing Group, 2013). When the seven life domains of this instrument are regressed against general life satisfaction (GLS: "How satisfied are you with your life as a whole?"), around 90 % of the unique variance accounted for comes from just three domains as satisfaction with money (standard of living), a meaningful activity, and an intimate relationship (Cummins, 2014a, 2014b).

Of the four remaining domains, one is "How satisfied are you with feeling part of your community?" In the scale version for people with an intellectual disability (Cummins & Lau, 2005), the simplified version is "How happy are you doing things outside your home?" For both versions of the scale in Australia, community is the second weakest domain in terms of its contribution to GLS. The manual of the Personal Wellbeing Index (PWI) presents a series of nine multiple regressions, based on nine consecutive general population surveys of the Australian Unity Wellbeing Index, in which the seven PWI domains are regressed on GLS. Of the average 50 % of variance accounted for, the domain of community contributes between 0 and 6 % unique variance.

Further confirmation of this weak influence comes from research conducted in rural settings, which are traditionally high in social capital. Bramston, Pretty, and Chipuer (2002) found no reliable contribution of sense of community (Neighborhood Cohesion Instrument, Buckner, 1988) to SWB (Comprehensive Quality of Life Scale—Adult, Cummins, 1997c) in samples drawn from two Queensland country towns.

In conclusion, despite the central billing given to integration within general society by the ideology of normalization, the empirical data provide a different view. Not only are the people living in share-homes very marginally connected socially to their neighbors, but also this seems to matter very little when judged against subjective life quality.

Threats to SWB Validity and Reliability

Comparability with General Population Standards

The item content of early scales to measure QOL for people with an intellectual disability is quite specific to their condition. However, it soon became evident that such scales have three major problems for interpretation. These are as follows:

1. The lack of normative standards by which to judge the QOL for people with an intellectual disability against that of the general population. This is a crucial requirement, which is at the heart of normalization. The life quality of people with an intellectual disability should be judged using the same criteria as for adults without an intellectual disability.
2. In the absence of normative reference standards, the level of the "quality bar" for people with an intellectual disability is inevitably set very low. For example, the PALS asks, "Do you like to draw or paint?" with the assumption that a "no" response is indicative of low life quality. There is no justification for this by reference to the general population. As a second example, the QOLQ asks "When can friends visit your home?"
3. The items tend to focus on the adequacy of service provision, rather than the extent to which such provision allows the recipients to experience normal levels of QOL.

As these concerns became understood, it was clear that two different forms of scale were required. One was needed to measure the adequacy of support through service provision. The other was needed to measure life quality against normative standards. Moreover, scales that mixed the responses to these two forms of measurement produced a metric that was essentially uninterpretable.

While the measurement of objective items is fairly straightforward, the construction and delivery of the subjective scales are not. There are many pitfalls to the measurement of SWB even in the general population, and these are magnified when applied to the area of ID. Two such areas of methodological difficulty will now be described.

Yea-Saying and Acquiescence

People with an intellectual disability are more likely than is normal to respond in a way that is in agreement with a question that they are asked. There are two reasons. One is that they may not understand the question and have discovered through experience that the simplest way to deal with such a situation is to agree or give a maximally positive response. The second is that they have formed a habit of responding in an acquiescent manner. That is, they may say "yes" even when they understand the question and actually disagree. Such behavior is a learned response to avoid confrontation. People have learned that agreeing with the views and suggestions made by staff and other people is a good way of avoiding further accountability because they are less likely to ask follow-up questions than if the respondent had said "no."

This behavior has been termed acquiescent responding (Sigelman et al., 1980) and "Yea-saying" (Sigelman et al., 1981). It results in the production of positive response sets in the data, which are clearly invalid for the intended purpose of measurement. The inclusion of such data in statistical analyses has the potential to invalidate the results. It is disconcerting to note how rarely authors report that they have checked their data for acquiescent response sets.

While acquiescent responses are found in data sets from the general population, they are far more common among people with an intellectual disability (see, e.g., Verri et al., 1999). Moreover, the probability of such responses is (inversely) related to IQ (Sigelman et al., 1980). This causes response data to simple verbal questions, from people with a severe level of intellectual disability, inherently unreliable. It is the responsibility of the researcher to take counteractive measures and the responsibility of the reader to dismiss published results from such groups where the researcher has not.

Proxy Responding

Due to the nature of the person's disability, there are substantial limitations to the complexity of the questions that they can answer. Moreover, at severe levels of intellectual disability, it is not possible to have confidence that people are able to respond to SWB questions in a reliable and valid manner. This poses a major problem for both caregivers and researchers who wish to ascertain how the people feel about their lives. The traditional solution to this problem is to use a proxy respondent.

Proxy responding, or providing answers for another person, seems intuitively sensible in such situations. Since the proxy is more intellectually able or more highly trained than the person about whom the information is being sought, then surely it is sensible to seek information from someone who knows the person well and who feels confident that they can respond on the person's behalf.

This view has been particularly encouraged within medicine, and, so, since the medical model held sway for so many years within institutional settings, it has been regarded as normal practice. Consider, for example, these two quotations:

> What every physician wants for every one of his patients old or young-is not just the absence of death but life with a vibrant quality that we associate with a vigorous youth. This is nothing less than a humanistic biology that is concerned, not with material mechanisms alone, but with the wholeness of human life, with the spiritual quality of life that is unique to man. Just what constitutes this quality of life for a particular patient and the therapeutic pathway to it often is extremely difficult to judge and must lie with the consciousness of the physician. (Elkinton, 1966, p. 712)
>
> I maintain that indices can be designed so that clinicians can score the patient's quality of life or health status after observing or examining a patient even without eliciting information from the patient about how he or she feels at any given point in time. (Spitzer, 1987, p. 469)

Each of the above authors provided only anecdotal support for the idea that clinicians can make valid SWB judgments on behalf of their patients. The empirical literature, however, casts serious doubt on such ability. Indeed, the difficulty of interpreting proxy reports has been specifically documented in relation to medical patients (Sprangers & Aaronson, 1992). In relation to children and adolescents, two reviews have concluded that proxies cannot be reliably substituted for self-reports either in relation to behavioral/emotional problems (Achenbach, McConaughy, & Howell, 1987) or the feelings experienced by children with disabilities (Yuker, 1988). A review on the dangers of proxy responding for people with an intellectual disability is also available (Cummins, 2002).

Rather insidiously, internal scale reliability can be acceptable even while the proxy responses are invalid. An early investigation by Reynolds (1979) involved 100 adolescents who self-rated 30 statements of behavioral competence. Despite acceptable estimations of internal consistency, the concurrent validity with teacher ratings was $r=0.21$.

Unfortunately, despite this broad and coherent literature confirming that proxy responding for subjective states is invalid, the practice remains quite common. The attraction of proxy responses is that, to the naïve researcher, they appear very useful as a means to determine the subjective state of people who are so disabled that they cannot make a self-report. The result is quite predictable. The researcher will then typically report that the people in question appear to be quite happy and contented (see, e.g., Jones, 1986).

Other authors (e.g., Halpern, Nave, Close, & Nelson, 1986) fail to report whether the data were collected by self-report or by proxy. Others recommend that proxy data be used to "validate" self-report data from people who are disabled (e.g., Atkinson, 1988; Flynn, 1986) with the clear assumption that such proxy data are superior. As a consequence of understanding the invalid nature of proxy responses, the findings from all of these studies must be considered unreliable.

The inappropriate use of proxy data is not confined to the intellectual disability literature. For example, in their study of elderly people, Bowling, Farquhar, Grundy, and Formby (1993) combine proxy and self-report data as though they are equivalent. In relation to subjective QOL, papers continue to be published using proxy data with no acknowledgment that the results are likely to be invalid (e.g., Garcıá-Villamisar & Dattilo, 2010; Horovitz, Shear, Mancini, & Pellerito, 2014). Indeed, Tobin, Drager, and Richardson (2014) used the results from Garcıá-Villamisar and Dattilo (2010) in a systematic review of QOL.

Proxy responding is also encouraged by some instruments; indeed, the Quality of Life Interview

Schedule (Ouellette-Kuntz, 1990) has been specifically designed for the purpose of collecting subjective proxy data. The authors contended, “It has been our experience that family members, friends, and paid staff are very able to empathize and communicate on behalf of people with disabilities” (Ouellette-Kuntz & McCreary, 1996, p. 274). At around this same time, I also developed a scale to be used by proxies within the manual of the Comprehensive Quality of Life Scale for people with an intellectual disability (Cummins, 1997b). Even though this manual urges caution in the interpretation of resultant data, the fact of its inclusion provides tacit support for the use of this response mode if the people are unable to respond for themselves. It was not until 2004 that this instruction was amended, when the ComQol metamorphosed into the Personal Wellbeing Index (Cummins & Lau, 2004). This new version then carried the warning “The scale must be administered on an individual basis to the person with an intellectual disability. It is NOT to be answered “on behalf of the person” by a caregiver or someone who “knows the person well.” Such proxy responses are invalid in relation to subjective measurement.”

SWB Scales and Intellectual Disability

There are many scales to measure SWB in the general population, and a recent review is available (Cummins & Weinberg, 2015). While some of the scales listed are suitable for people with an intellectual disability, some reviews specific to scales suitable for people with an intellectual disability have also been published (Cummins, 1997d, 2005). Some aspects of Cummins (1997d) have been challenged (Ager & Hatton, 1999) and answered (Cummins, 2001). These reviews have discussed the many problems that are evident in the construction of SWB scales for people with an intellectual disability, both conceptual and psychometric. The conclusion that must be drawn is that few scales are adequate as reliable and valid indices of SWB for this population. An updated evaluation of these assessments follows with the choice of scale limited to those that have supplied results for Table 8.1. The scales are presented in alphabetical order.

Lifestyle Satisfaction Scale (Heal & Chadsey-Rusch, 1985)

The authors stated that the LSS was developed “to assess mentally retarded persons’ satisfaction with their residence and its community setting and associated services” (Heal & Chadsey-Rusch, 1985, p. 475). However, the more recently published manual states, “The instrument is designed to measure satisfaction with the different lifestyle components contributing to one’s quality of life” (Heal & Harner, 1993, p. 4).

The original version contained 29 items divided between five subscales as community satisfaction (9), friends and free-time satisfaction (6), satisfaction with services (7), general satisfaction (5), job satisfaction (1), and three question pairs to measure acquiescent responding. Scoring is on the basis of interviewer ratings linked to an open-ended question that is read aloud. Response scoring is binary as + for a “yes” response and – for a “no” response. The items are an eclectic mix. Example items, plus my comments, are:

> “How do you like your home where you live?” [This cannot be answered by a “yes” or “no”]
> “Can you think of a better place to live?” “Where would that be?” [A complex item]
> “Whom do you live with here?” [An objective item]

The authors do not report a factor analysis. The scale contains overly complex items, mixes subjective and objective, and does not measure SWB as conceptualized for this chapter.

The 1993 version contains 57 items forming the following subscales: community satisfaction (12 items), recreation satisfaction (24 items), job satisfaction (7 items or 1 item if unemployed), and an acquiescence scale (14 items). The authors suggested that scores from the first three scales might be combined to yield total satisfaction. The evaluative comments made above in relation to the 1985 version also apply to this 1993 version.

PALS (Rosen et al., 1995; Rosen & Simon, 1995)

The stated purpose of the PALS is to be a "subjective measure of quality of life" for people with an intellectual disability (Rosen & Simon, 1995). Its name is an acronym composed from the four subscales as perceived stress, affect, loneliness, and satisfaction in people with intellectual disability. These subscales comprise 7, 18, 21, and 11 items, respectively.

The authors reported a factor analysis of the 46 items which reveals that their four dimensions emerged as eight separate factors and no superordinate factor. The provenance of the 11 original items forming their published PALS satisfaction subscale was from Campbell (1976). However, the seven-item factor labeled "satisfaction" that emerged from their factor analysis contained only two of the original 11 items. The remaining five items were drawn from their original subscales of affect (four items) and loneliness (one item). In summary, there is no justification for either using the four subscales as they are presented in the PALS scale or combining all scores to create a single metric. The items seem to form a hodgepodge scale for which the epithet "satisfaction" is a misnomer. The PALS does not measure SWB as defined in this chapter. In their published report of results (Rosen et al., 1995), the authors used their original 11-item satisfaction scale.

Personal Wellbeing Index (Cummins & Lau, 2005; International Wellbeing Group, 2013)

The fifth edition of the Personal Wellbeing Index (PWI: International Wellbeing Group, 2013), which is designed for use with general population adults, has a unique construction. It is intended to represent the first-level deconstruction of the highly abstract question, "How satisfied are you with your life as a whole?" (general life satisfaction (GLS)). In order to achieve this intention, each of the seven items (domains) has two important characteristics. The first is that each question is phrased in semiabstract terms, such as "How satisfied are you with your safety?"

This format is deliberately nonspecific. It allows the response that people give to be dominated by the positive mood affect described earlier as homeostatically protected mood (HPMood). That is, in answering these semiabstract questions, people do not rely on cognitive processing. Rather, they use their level of HPMood as information (Schwarz, 1999; Schwarz & Strack, 1991). Their response is also slightly flavored with cognitions attached to the question target (personal safety). If a more specific question had been asked, such as "How satisfied are you with your safety in the street?" this would elicit a more cognitively driven response because the respondent has a more concrete reference to inform their answer. The second special characteristic of the seven domains is that, when they are regressed together against GLS, each one contributes unique variance. These matters of theoretical and empirical construction are elaborated in the test manual.

Each item is rated on an end-defined 0–10 scale (Jones & Thurstone, 1955) that is anchored by "no satisfaction at all" and "completely satisfied." This form of response scale is superior to a Likert scale (Cummins & Gullone, 2000). The data are then averaged across the seven domains for each respondent, and the result transformed onto a 0–100 scale.

The PWI-Intellectual Disability (PWI-ID) is designed as a parallel version of the PWI-A (Cummins & Lau, 2005). It uses the same theoretical basis and domain structure as the PWI-A. It also includes modifications designed to augment its suitability for respondents with a cognitive disability, thereby increasing the likelihood of data validity and reliability. These modifications are as follows:

Item Wording

The wording of each item is simpler and more concrete than the original, and the term "satisfaction" is substituted by the word "happy." For example, the question in the PWI-A "How satisfied are you with your health" has been simplified in the PWI-ID to "How happy do you feel about how healthy you are?" However, it should be noted that these modifications are also problematic for two reasons. The first is uncertainly as to whether they veridically represent the construct of the original wording. The second problem is related in that, since the reworded items are more concrete and specific, they are further away from being a valid measure of SWB. Nevertheless, despite these two concerns, the Index does produce data very similar to those of the PWI-A, as is shown in Table 8.1.

Response Choice

A further modification is the flexibility in response formats. This comprises three alternative reduced-choice formats (5-, 3-, and 2-point scales) for those who cannot cope with the standard 11-point response scale. This reduced-choice format is pictorial, represented by a series of outline faces (from very happy to very sad) to enhance comprehension. Importantly, however, despite the use of these simplifying procedures, there is a minimum level of cognitive abstraction that is required to respond validly to the scale. In practice, we have found that the PWI-ID is appropriate for people with a mild or upper-moderate level of cognitive impairment. It cannot be reliably used to test anyone with a severe or profound level of disability. Such people do not have the ability to provide valid self-reports of this type (Chadsey-rusch, DeStefano, O'Reilly, Gonzalez, & Coller-Klingenberg, 1992).

Pretesting

A unique feature of the PWI-ID is the pretesting protocol, designed to exclude people who are unable to respond validly to such scales. This protocol includes an initial test for acquiescent responding. If people are found to display this characteristic, testing is terminated. It also includes a test for response scale competence on the 0–10 scale format. This involves assessing whether they can count to ten. If they can, they are asked various questions establishing whether they can reliably respond to this scale format. If a respondent is unable to count to ten, or fails to provide a reliable response to questions using the 0–10 scale, they are tested for their ability to use a reduced-choice, pictorial response format. If they fail to demonstrate competence in these tasks, testing is discontinued.

It is notable that studies using other scales rarely provide clear information about the method they used, if any, to exclude participants with severe cognitive impairment (see, e.g., Reed & Roskell-Payton, 1996; Riemsma, Forbes, Glanville, Eastwood, & Kleijnen, 2001). Other authors have used unreliable exclusion methods, such as subjective decisions made by a third-party informant (e.g., staff members of a nursing home: Bland, 1996). Such procedures may well result in the inappropriate omission of people who are, in fact, capable of rating their own SWB.

Quality of Life Questionnaire (Schalock, 1990; Schalock & Keith, 1993)

Even though results from the QOLQ have not been included in Table 8.1, it is mentioned here because it remains the most commonly used instrument to measure the QOL of people with an intellectual disability. It has a parallel form for school-age adolescents (Keith & Schalock, 1995) and has been constructed to operationalize the following definition: "QOL is the outcome of individuals meeting basic needs and fulfilling basic responsibilities in community settings (family, recreational, school and work). Individuals who are able to meet needs and fulfil responsibilities in ways satisfactory to themselves and to significant others in community settings experience a high QOL in those settings" (Schalock, 1990, p. 143).

A previous critique of the 1990 QOLQ (Cummins, 2005) concluded that the scale is not an adequate measure of SWB. There are two reasons. The first is that it includes items measuring objective variables, such as "Do you have a key to your home?" and combines such data with other subjective data to create a composite score (see, e.g., Horovitz et al., 2014). This process creates an invalid variable. The second is that the 40 items are equally distributed between four subscales, only one of which is labeled "satisfaction." The other three are competence/productivity, empowerment/independence, and social belonging/community integration.

As evidence that the total scale does not measure SWB, Yu et al. (1996) found the QOLQ total score did not correlate with SWB as measured by the Lifestyle Satisfaction Scale (Heal & Chadsey-Rusch, 1985). Even data from the "satisfaction" subscale seem not to represent SWB. For example, Rapley and Beyer (1996) reported a satisfaction subscale score of 36.5 points for people living in community-based homes. This value is way below the normative range for life satisfaction calculated in Cummins (2003) as 70–80 points. The likely reason is that the items comprising the satisfaction subscale do not simply measure "satisfaction." In fact, only one of the ten items actually asks about satisfaction ("How satisfied are you with your current home or living arrangement?"), and this is the evaluation of a distal target. Three other items involve frequency responses (e.g., how often do you feel out of place in a social situation?), while four ask for a comparison against other people (e.g., do you have more or fewer problems than other people?) instead of against their own internal standards. As a consequence, the data from the satisfaction subscale are not considered to measure SWB.

There are also severe procedural issues that cast doubt on the validity of the data derived from this scale. Perhaps the most important is that the questions are read orally, with the respondent using a 3-point response scale. Notably, while engaging in this process, the respondent must hold the question stem in memory while then processing the multiple response options. This procedure was abandoned by Halpern, Raffeld, Irvin, and Link (1975) in favor of a simple yes/no response as the task requirements were found to be beyond the capacity of their adolescent group with an IQ 68 ± 8.4.

Schalock et al. (2002) reported the creation of a new version of the questionnaire, modified in the following respects: (a) the questions have been simplified; however, the new questions are not provided. (b) The response task has been simplified by using a flash card containing three stylized faces. Thus, the respondent can respond by pointing instead of verbally. While this new feature is more likely to allow valid responding, the previous issues of scale content remain. This new version also includes ten new items representing a subscale called dignity.

Most recently, Reinders and Schalock (2014) have expanded the four domains of the QOLQ and claimed "Personal well-being can be defined operationally in reference to eight core QOL domains: personal development, self-determination, interpersonal relations, social inclusion, rights, and emotional, physical, and material wellbeing." This statement is made despite the lack of factor confirmation as a single index and seems to take the constructs being measured even further from SWB.

Conclusion

Two important factors have biased research into the life quality of people with an intellectual disability. The first is the ideology of normalization, which continues to influence the whole industry of accommodation and service delivery to people who are intellectually disabled. While this ideological influence has been generally positive, the negative consequences have not received the attention they deserve. For example, a major aim of normalization was to enhance the public's acceptance of intellectual disability by actively discouraging friendship networks between persons with an intellectual disability (see Rhoades & Browning, 1977). The major strategy to achieve this was to distribute such people through the "community," in order that they may more easily form social relationships with non-disabled people. So, this frame of reference does not recognize social relationships between people with an intellectual disability as a positive aspect of life. Moreover, as has been demonstrated, friendships involving non-disabled people are uncommon. Thus, measures of normalization should certainly not be used alone as the basis for quality of life evaluations. This caution has been raised by many authors (see, e.g., Cummins & Lau, 2003; Evans, Beyer, & Todd, 1988).

The second biasing factor for researchers is the ubiquitous use of "community" to describe the location of a share-home situated in the general community. This is an important misnomer. The powerful positive affect attached to this term has impeded critical research into share-home accommodation. In the first place, researchers commonly simply assume that share-homes are a superior form of accommodation to institutions. While overall this is likely to be correct, the assumption is actually based on few empirical data using contemporary institutions for comparison.

This strong positive affect attached to "community" also creates a second problem. It has the potential to blind researchers to two aspects of living, which are crucial to life quality. One is the dark side of living either alone or in a share-home.

Their home is almost inevitably positioned some considerable distance away from the homes of other people with an intellectual disability, in a setting surrounded by members of the general public, whose overwhelming response is exclusion rather than inclusion. Obvious issues that arise are loneliness (McDevitt, Smith, Schmidt, & Rosen, 1978), the low probability of friendships outside the household, and the problem of toxic interpersonal relationships within share-homes. These people do not normally choose their coresidents, and, if they experience an unpleasant social environment within the household, their options for relocation are very limited.

The second aspect of resident's lives, which gets far too little attention, is the within-home variables that enhance the experience of life quality. These include friendships, personal control over the living environment, the acquisition of personally meaningful possessions, and the desired level of privacy. It is symptomatic of researcher blinding by ideology that these issues are so rarely mentioned in the research literature.

In short, an important legacy of normalization is that people with an intellectual disability have been discouraged from finding their own community. Instead, they have been asked to join the communities of other people, with whom they have little in common. The understanding of why such an expectation is unrealistic has been around for many decades (see, e.g., Rhoades & Browning, 1977). So it is certainly disappointing to find contemporary authors (Graske et al., 2014) who advocate that share-homes enhance "connections with the neighborhood" without also acknowledging the issues that have been raised in this chapter.

As has been said several times before, the overall influence of normalization has undoubtedly been positive for the life quality of people with an intellectual disability. The public shame caused by intimate knowledge of life in institutions was the most powerful force causing their systematic closure. However, it is now time to move into another era, where the circumstances of living are no longer dictated by ideological statements but by data-based decisions and policy. The dominant criterion for policy in this new era must be the optimization of life quality as determined by valid and reliable measurement.

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Functional Skills

9

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Introduction

The acquisition and maintenance of functional skills are among the most important educational targets for individuals with intellectual and developmental disabilities. Functional skills are those skills we possess that allow us to take care of ourselves and function independently in our natural environment. For most of us, these skills are readily acquired through typical life experiences. For individuals with cognitive impairments, these skills may require specific teaching strategies. The acquisition of functional skills results in several favorable outcomes, including increased opportunities for community integration and better overall quality of life (Ayres, Lowrey, Douglas, & Sievers, 2011). In addition, functional skills allow individuals with disabilities to have more opportunities to access reinforcers and make choices in their daily lives, which has shown to have positive effects on work completion and inappropriate behavior (e.g., Shogren, Fagella-Luby, Bae, & Wehmeyer, 2004; Watanabe & Sturmey, 2003).

The goal of any educational program should be to prepare individuals to function as independently in their environment as their abilities will allow. Experts have noted that individuals with intellectual and developmental disabilities encounter a myriad of challenges as they transition out of school placements, including increased unemployment and placement in more restrictive programs (Ayres et al., 2011; Courtade, Spooner, Browder, & Jimenez, 2012). Consequently, these researchers have argued that functional skills should be incorporated into students' individualized educational programming and practiced on a daily basis. Ideally, each educational goal should be linked to a terminal skill that will be useful to the individual in the natural setting (Bannerman, Sheldon, Sherman, & Harchik, 1990; Favell, Favell, Riddle, & Risley, 1984). This should be accomplished through systematic assessment and planning which allows parents and practitioners to produce the best outcomes for this population.

What Are Functional Skills?

Functional skills refer to a broad range of abilities that are needed to navigate the demands of everyday life. Functional skills are often referred to by a variety of names, such as self-help skills, life skills, or skills of daily living. Functional skills, simply put, are those skills that are

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practical and helpful in fostering independence. According to Brown et al. (1979) functional skills are "… the variety of skills that are frequently demanded in natural domestic, vocational, and community environments. Functional skills are not limited to performances, which affect the actual survival or physical well-being of an individual; they also include the variety of skills which influence a student's ability to perform as independently and productively as possible in home, school, and community. Nonfunctional skills, by contrast, are those that have an extremely low probability of being required in daily activities." (p. 83).

All too often, practitioners implement academic goals that have no functional outcome. For example, an instructor may teach an adolescent to put plastic shapes into a shape sorter while they are unable to place coins in a vending machine. Students may be taught to identify the pictures of lesser-known U.S. Presidents (e.g., James K. Polk) or list the characteristics of sedimentary rock as a part of their academic programming. These kinds of goals can be a concern in that they do not translate in any meaningful way to an individual's daily life. From this perspective, instructional time that is devoted to teaching nonfunctional skills is a waste of valuable educational resources. The failure to acquire functional skills across domains results in more restrictive placements as a result of the need for additional support and resources.

Many of us take the ability to perform functional skills for granted, such as feeding oneself, toileting oneself, and the ability to interact successfully with the world. While these skills are established during the normal developmental process, most individuals with intellectual and developmental disabilities, require specific and sometimes intensive instruction to acquire these skills. The spectrum of functional skills is quite diverse. Functional skills encompass multiple domains of performance, such as self-care, domestic, recreational, community safety, prevocational/vocational, social and behavior management skills.

Types of Functional Skills

Self-Care Skills. Self-care skills are among the most important and basic kinds of functional skills in that they contribute to the maintenance of well-being and are necessary to sustain one's health. Self-care skills include the ability to bathe oneself, self-grooming (e.g., teeth brushing, shaving, hair brushing, putting on deodorant), washing (e.g., hand and face washing, showering), self-toileting, and getting dressed (e.g., choosing clothes, tying shoes, dressing independently).

Domestic Skills. Domestic skills encompass skills related to household affairs. These skills involve maintaining one's home as well as providing necessary daily sustenance. Domestic skills may include food preparation and safety (e.g., using a microwave or an oven to cook food), meal planning, sweeping/vacuuming the floor, doing dishes (e.g., loading a dishwasher), making a bed, and doing laundry (e.g., washing, drying, folding, and sorting clothing),

Community Skills. Community skills include those abilities that are required to navigate and access resources within one's specific locality. Important community skill targets may include the ability to cross a street safely (e.g., using a crosswalk, observing "Walk/Don't Walk" signs), the ability to recognize stores (e.g., grocery store, pharmacy, laundromat), the use of public transit (e.g., using the bus or train), or purchasing items in a store (e.g., paying for items, counting change).

Vocational Skills. A common goal for many individuals with intellectual and developmental disabilities and their families is the procurement of employment. Vocational skills include those skills that involve the production aspects of jobs, such as the ability to bus tables at a restaurant or filing paperwork at a doctor's office. Vocational targets often depend on a number of factors, such as opportunities in the community, individual skill level, and parent/student preference. Such instruction may begin with prevocational skills to teach the prerequisite skills (e.g., sorting tasks, discrimination tasks) that are components of more complex skills (e.g., delivering inter-office mail).

Recreational Skills. Recreational skills typically involve an individual's engagement with activities or items that they find interesting, rewarding, relaxing, or enjoyable. For most individuals, recreational activities are acquired without specific training as a part of typical development. The ability to exercise (e.g., running), playing games/sports (e.g., bowling, soccer, playing "Tag"), or engaging in leisure activities (e.g., playing video games, reading a book) are learned by most without teaching. Alternatively, individuals with intellectual and developmental disabilities may require formal teaching strategies in order to encourage the development of repertoires of appropriate leisure-time activities.

Social Skills. An individual's ability to participate in their community is, to a large extent, dependent upon their ability to interact with others. Social skills are those skills that facilitate interaction and communication with others. Under normal circumstances, social rules and relations are developed without specific teaching. However, for individuals with intellectual and developmental disabilities, specific teaching strategies may be necessary to develop appropriate social behavior, such as respecting personal space, perspective-taking, conversation skills, turn taking, sharing with others, asking for or offering to help, giving an appropriate greeting, and giving/accepting compliments.

Behavior Management Skills. The ability to be integrated into the community is often directly dependent on the absence of maladaptive behavior. Individuals exhibiting problem behavior often have significant limitations in their ability to participate in functional activities. Effective, function-based behavioral intervention is imperative for improving outcomes in individuals with intellectual and developmental disabilities. Behavioral intervention should involve a systematic plan that includes antecedent strategies to prevent the occurrence of problem behavior, the reinforce-

Table 9.1 Types of functional skills

Functional skill type	Examples
Self-care skills	Self-bathing/showering oneself
	Teeth brushing
	Hair brushing
	Wash/dry hands
	Self-toileting
	Dressing independently
	Self-feeding
Domestic skills	Using a microwave
	Cutting fruits/vegetables
	Washing, drying, folding, and sorting clothing
	Vacuuming
	Sweeping
	Doing dishes
	Making the bed
Community skills	Street crossing
	Store recognition
	Using public transit
	Making purchases
	Counting money/change
Pre-vocational skills	Sorting
	Alphabetizing
	Reading
	Simple assembly (components of a larger task)
Vocational skills	Product assembly
	Filing
	Mail delivery
	Cleaning (e.g., mopping, washing windows)
Recreational skills	Exercise
	Bowling
	Playing video games
	Reading a book
Social skills	Respecting personal space
	Perspective-taking
	Conversation skills
	Turn taking
	Sharing
	Asking for or offering to help
	Greeting others
	Giving/accepting compliments
Behavior management skills	Choice making
	Communicating preferences
	Functional communication
	Self-management

ment of appropriate alternative behavior, and strategies for responding to problem behavior (e.g., extinction). In terms of functional behavior management skills, individuals should be taught to make choices and state their preferences, functional communication skills (e.g., appropriate ways to ask for a break, attention, preferred items and activities), in addition to various strategies for managing their own behavior (i.e., self-management techniques).

It is important to note that the list of functional skills provided in this chapter is not all encompassing (see Table 9.1). In fact, functional skills span a wide variety of domains, are specific to an individual's natural environment, and are more than just what an individual needs to survive. These skills are essential to achieving independence and can significantly affect quality of life for both an individual and their caregivers. More specifically, if an individual is unable to perform these skills on their own, they will require more restrictive environments with fewer opportunities for choice and produce greater strain for caregivers.

Functional Skills Across the Life Span

Many practitioners make the mistake of assuming that functional skills only become a priority immediately prior to aging out of educational programs. Instruction designed to encourage the development of functional skills for young children with intellectual and developmental disabilities often involves a primary focus on language skills and social behavior with little time spent targeting other functional life skills. In many cases, school curriculum requirements result in teachers focusing on academic tasks that have little functional value (e.g., learning the life cycle of insects). In fact, in some cases, practitioners maintain this focus at the exclusion of other important functional tasks. This can result in adolescents who make limited gains in some nonfunctional domains but lack the ability to adequately care for themselves (e.g., the individual can discriminate colors in a discrete trial format but is unable to tie their shoes or make a sandwich).

While there is no universally correct stance as to when it is most appropriate to shift curricular focus for students with disabilities to the acquisition of functional skills, the severity of an individual's intellectual disability may require that educators target these skills early in the educational process. Brown et al. (1979) argue that a decision to focus on the development of functional skills should be guided by an examination of the settings, which encompass a learner's "natural environments." In this approach, the focus on functional skills as a primary objective is not linked to chronological or mental age, but to the degree to which a particular objective is meaningful within the least restrictive environments that a learner is likely to inhabit. That is, caregivers and educators should work toward building functional skills as they are needed in their daily environment, rather than arbitrarily based on their age.

When children are young, focus is usually placed on language acquisition as well as conceptual learning tasks, such as sorting, sequencing, or grouping items. As children grow older, targeted functional skills should change to adapt to the living circumstances of the individual with a focus on those skills that will make them more independent. As a general rule, it may be helpful to shift from conceptual learning or from teaching a developmental language sequence to more practical skills that are immediately useful and can assist the individual to become less dependent on others as the individual ages. Functional skills should be taught as early as possible, starting with simple skills. For example, children can be taught to pick up toys, wash their hands, and put dirty clothes in a hamper. As they grow older, they may be taught to fold and put away clothes, bathe themselves, or assist with housekeeping. The teaching of functional skills is a process that should continue throughout the life span, and will allow the individual increased independence as well as the opportunity to play a more active role in the home and community.

Unfortunately, many of the barriers encountered by students are those imposed by parents and caregivers. In the interest of saving time or protecting them from failure, parents and teachers often neglect to create opportunities for students to do things independently. While these may seem like logical options in the short term, they can have significant side effects. Slow progress and the increased likelihood of prompt dependence (relying on prompts from others to complete tasks) are consequences of not providing opportunities to complete tasks independently.

Functional skills training is best approached as a lifelong process. The development of functional skills is important for individuals of all ages. There will always be skills that can lead to increased independence, better social skills, and less dependence on others. The selection of appropriate functional skills to be targeted for instruction is a complex process which should be determined by considering an individual's cognitive ability, environment, and lifestyle rather than his/her chronological age. These factors highlight the importance of systematic assessment to select appropriate functional goals.

Functional Skills Assessments

In order to evaluate an individual's current level of functioning and identify skills to target for intervention, it is important for practitioners/caregivers to conduct assessments of an individual's capacity to perform various functional skills. Specifically, functional skill assessments may be valuable in the identification of meaningful instructional targets, in determining the level and type of support that an individual may need in a residential setting, or in the identification of appropriate vocational placements. These evaluations are typically conducted via indirect assessment involving the completion of an interview or survey by the individuals themselves or their primary caregivers. Alternatively, functional skills assessments can be conducted via direct methods involving planned observation of an individual's behavior in a natural setting or via the completion of a performance-based evaluation involving the exposure of the individual to a battery of contrived tasks related to general functional ability.

While there are numerous assessments of functional skills for individuals across various populations in existence (for a thorough review see Moore, Palmer, Patterson, & Jeste, 2007), there are only a handful of assessments that are recognized as being appropriate for use specifically with individuals that have intellectual and developmental disabilities. The assessments that are most widely used for evaluating the existence of functional skills among individuals from this population are the Vineland Adaptive Behavior Scales II (Sparrow, Cicchetti, & Balla, 2008) and the Scales of Independent Behavior-Revised (Bruininks, Woodcock, Weatherman, & Hill, 1996). In addition to these more established evaluations, the Assessment of Functional Living Skills (Partington & Mueller, 2012) is a recent addition to existing assessments designed for the evaluation of functional skills among individuals with autism and developmental disabilities.

While observational methods of assessment are regarded as the most accurate means of determining an individual's true ability with regard to functional skill, these methods are also the most time consuming. Consequently, when conducting assessments related to functional ability, caregivers and professionals often attempt to strike a balance between acquiring an accurate representation of a learner's abilities and completing an assessment in the most efficient way possible via the use of indirect methods of assessment such as surveys or interviews. The aforementioned commercially available assessments of functional ability are similar in that they provide an extensive list of functional skills in order to provide the caregiver with the ability to either approximate the learner's ability based on their previous observations or by staff accounts of the learner's ability, or conduct some form of direct assessment to determine the current level of functioning. However, there are distinctive characteristics of each assessment that may make them more or less appropriate for use with a particular learner.

The Vineland Adaptive Behavior Scales (ABS), which was first published in 1984 (Sparrow, Balla, & Cicchetti, 1984), and the revised edition of the assessment the Vineland Adaptive Behavior Scales II (Vineland II) which was released in 2005 and expanded in 2008 (Sparrow, Cicchetti, & Balla, 2005/2008), are regarded as the most widely used adaptive behavior tests in the world. There have been thousands of research studies involving all forms of intellectual disability conducted using the ABS and the Vineland II since its initial publication in 1984 (Sparrow, 2011). The Vineland II has four forms, two of which (Survey and Expanded report forms) are completed via structured interviews with parents or caregivers and two that involve the completion of a rating form by a teacher or parent/caregiver (Parent/caregiver and Teacher report forms). The Survey, Parent/caregiver, and Expanded report forms of the Vineland II are deemed appropriate for learners from birth through 90 years of age and beyond, while the Teacher report form of the Vineland II is appropriate for learners from 3 to 21 years of age.

The Vineland II assesses performance across four domains of adaptive behavior including communication, daily living skills, socialization, and motor skills. In addition, the Vineland II includes an optional Maladaptive Behavior Index to assess the degree to which problem behavior is likely to interfere with adaptive functioning. Each of the four primary domains of adaptive behavior are further categorized by multiple subdomains. For example, the communication domain is broken down into the subdomains: receptive, expressive, and written forms of communication. The daily living skills domain is separated into the subdomains personal, domestic, and community skills. The socialization domain is organized by the subdomains interpersonal, play and leisure time, and coping skills. The motor domain is separated into tasks that either require gross motor or fine motor performance. Lastly, the subdomains of the optional primary domain for maladaptive behavior is organized by behavior that is described as internalizing, externalizing, or other.

The Assessment of Functional Living Skills (AFLS) was developed as an extension of the widely used Assessment of Basic Language and Learning Skills (ABLLS-R) as a means of focusing primarily on the evaluation of learners' abilities within the realm of functional performance (Partington & Mueller, 2012). The AFLS is a tool for caregivers that meets the needs of learners from 2 years of age and extending throughout the life span for which a guiding assessment, tracking grid, and curriculum is needed. The creators of the AFLS define the term "caregiver" as an individual who knows, cares for, supports, and works with a learner. Caregivers include parents, teachers, paraprofessionals, behavior analysts, group home staff, community or government-agency personnel, and a variety of other professionals. The AFLS consists of six assessment modules designed to evaluate an individual's performance of functional skills across the domains of *Basic Living Skills, Home Skills, Community Participation Skills, School Skills, Vocational Skills,* and *Independent Living Skills*.

Specifically, the skills that are targeted in the *Basic Living Skills* module of the AFLS include those skills related to self-management, basic communication, dressing, toileting, grooming, bathing, health, safety and first aid, and nighttime routines. The *Home Skills* module targets skills related to living at home with a caregiver including the consumption of meals, doing dishes, laundry, chores and general housekeeping, household mechanics, kitchen-related tasks, cooking, and leisure activities. The *Community Skills* module targets an individual's ability across the categories of basic mobility, community knowledge, shopping, eating in public, money, using a phone, telling time, and social awareness and manners. The *School Skills* module targets those skills related to academics, school routines, navigating the school environment, and social skills. The *Vocational Skills* module includes job seeking skills, compliance, rule following, vocational interests, conflict resolution, job readiness skills, working with others, hygiene, transportation, job training skills, social skills, clerical skills, attendance, punctuality, organization, and financial issues. The *Independent Living Skills* module targets household organization, household maintenance, household cleaning, community travel, transportation, advanced kitchen skills, meal planning, cooking, advanced self-care, advanced health, social awareness, social skills, social interactions, relationships, sexuality, financial planning, banking, self-management, emotional regulation, and living with others.

The information to complete the AFLS is typically obtained from three sources, including caregiver report, direct observation of the learner in a natural setting, and through contrived performance-based measures. To complete the AFLS via indirect assessment, information is gathered from individuals who are well-acquainted with the individual's skill level. The AFLS assessment guide specifically notes the importance of using reporters who know the learner's true skill level rather than those who may guess about skill levels. This is critically important as the utility of the assessment results is largely dependent upon the accuracy of the person reporting on skill levels in the different content areas. If the learner's true skill level is not known, it should be obtained via observation of the completion of tasks in a natural setting or through the formal presentation of the tasks.

The Scales of Independent Behavior (SIB-R) is described as a comprehensive measure of functional independence and adaptive functioning in school, home, employment, and community settings for use with individuals from infancy to age 80 years and older (Bruininks et al., 1996). The information to complete the SIB-R is obtained either via a structured interview with a family member or other caregiver that is well acquainted with an individual's ability related to the performance of functional skills or alternatively the family member or caregiver can complete a series of checklists directly in the SIB-R response booklet. The administration of the SIB-R can be customized to meet the needs of the practitioner giving the assessment or the individual being assessed in that there are four separate forms that can be given independent of one another or combined in various configurations. The SIB-R forms include the *Full Scale,* the *Short Form,* the *Early Development Form,* and the *Problem Behavior Scale*.

The SIB-R Full Scale is designed to be a broad measure of adaptive ability across four categories of functioning including motor function, social interaction and communication, personal living, and community living. Each of the four categories is further divided into 2–5 subscales with each subscale comprised of approximately 20 specific skills/tasks to be assessed for a total of 259 assessable items. The SIB-R Full Scale is designed to be administered in less than an hour. The SIB-R Short Form is designed to be a brief overall screening tool containing a total of 40 assessable items from across all 14 of the subscales of the SIB-R Full Scale that can be completed in 15–20 min. The SIB-R Early Development Form is designed to focus on the functional skills that are relevant to the development of learners from infancy to 6 years of age. The Early Development Form consists of 40 assessable items from the developmental areas of the SIB-R Full Scale that are suitable for the assessment of preschool aged children or older learners with severe developmental delays.

The Problem Behavior Scale is designed to be used alone or in conjunction with any of the other three forms of the SIB-R. The Problem Behavior Scale is designed to assess the severity of maladaptive behavior across eight categories including behavior that is hurtful to self, unusual or repetitive, involving withdrawal or inattention, socially offensive, uncooperative, hurtful to others, destructive to property, or disruptive to others. One aspect of the SIB-R that many practitioners find useful is the ability to devise a "Support Score" which combines an individual's score from The Problem Behavior Scale and their raw score from the other SIB-R scales to determine the level of caregiver support that an individual is likely to need.

Another distinctive feature of the SIB-R is that it has a direct relationship to the Woodcock-Johnson Psycho-Educational Battery (WJ-R) in that scores from the SIB-R can be used in combination with those from the WJ-R to devise a comprehensive assessment of an individual's ability across the dimensions of adaptive behavior, problem behavior, cognitive ability, language proficiency, and achievement. Additionally, each of the forms of the SIB-R provides a procedure for comparing an individual's current level of functioning with respect to their adaptive behavior to his or her cognitive ability as measured by the WJ-R. This aspect of the SIB-R makes it a useful tool for diagnostic purposes with individuals with intellectual disability.

Summary. The ABS/Vineland II, AFLS, and SIB-R are all valuable instruments for the identification of strengths and weaknesses related to functional skills (see Table 9.2). They can be a useful guide for parents and practitioners when selecting curricular targets. These measures provide an objective way to guide programming and can be used to determine socially significant short and long-term goals

Although a wealth of knowledge can be gathered through indirect means, it is also important to include direct measures of performance in the assessment process as indirect assessments may not always yield results that are indicative of a learner's true ability. Direct measures may include presenting tasks (or components of tasks) to the individual in natural context or in a more contrived setting and evaluating his/her performance (i.e., how independent they are). For example, during the assessment process, a reporter might state that the individual being evaluated is capable of brushing their teeth independently. The evaluator may then observe the individual completing the skill directly and document which steps they are capable of completing independently (e.g., Are they brushing all surfaces? Are they brushing long enough?). Another scenario could be a practitioner seeking possible job placements for a student. While assessments may suggest some of the job skills the individual possesses (e.g., they are capable or sorting), they may not provide a reliable measure of their preference for jobs or if they have the skill to perform a skill fluently enough to meet the needs of an employer. Direct measures, such as job sampling, could allow practitioners to determine job preference and job aptitude under controlled conditions. While using direct measures can be more labor-intensive and time-consuming, they can help to confirm or deny the findings from assessments conducted in an interview format and can lead to a more precise measure of functioning. Direct measurement can strengthen the assessment results and help parents and practitioners to prioritize skill deficits in need of intervention.

Table 9.2 Primary features of assessment instruments

Instrument	Age range	Assessment method	Duration	Domains
ABS II	Parent = birth and up	Rating scales	<60 min	Communication
	Teacher = 3–21 year			Daily living
				Socialization
				Motor skills
AFLS	2 years and up	Rating scales		Basic living
		Direct naturalistic observation[a]	Varies	Home
		Performance measures[a]		Community participation
				School
				Vocational
				Independent living
SIB-R	Infant and up	Rating scales	<60 min	Motor function
		Checklist		Social interaction
				Communication
				Personal living
				Community living

[a] May be included if rating scales yield inconsistent results

Benefits of Functional Skill Development

The potential benefits of functional skills training are immense. First and foremost, the acquisition of functional skills can lead to increased independence. The ability to function independently is a primary determinant of the quality of life for all parties involved (e.g., the learner, family members, teaching staff). The ability to function independently can significantly reduce the burden placed on parents and caregivers. Independent functioning can also reduce the need for support staff and reduce costs for family members and/or taxpayers. The ability to be self-sufficient and care for oneself can also lead to less restrictive placements. Individuals who can function independently are more likely to be maintained with minimal support *outside* of institutional settings.

Related to the above point, functional skill development allows individuals to be more integrated with their community. In general, functional skills training should allow individuals to navigate their community without support (or with minimal supports). The ability to order meals in a restaurant, go to a movie, or take the bus to work, are skills that allow learners to participate in their community. The acquisition of functional skills can also increase opportunities for employment/job placement. The ability to procure employment and contribute to society in a meaningful way is a right we all share. Our ability to do so largely depends on how well we are prepared for the workplace. With well-designed functional skills training, individuals can be prepared for employment opportunities to the extent that their skills allow (e.g., competitive employment, supported employment, secured/segregated employment). The ability to navigate our community and maintain employment can increase opportunities for social integration and allow individuals to be active members in their community.

The acquisition of functional skills also encourages appropriate interests and activities where none had existed previously. In many cases, individuals with intellectual and developmental disabilities may have a restricted range of interests, some of which may not be particularly adaptive (e.g., playing video games, watching videos on YouTube). Functional skills training can lead to the development of adaptive hobbies and leisure activities (getting involved in sports, jogging, taking a sewing class). Exposing individuals to different kinds of leisure activities can help broaden their interests and lead to more rewarding lifestyles.

The development of functional skills can also improve social interactions and allow individuals to establish meaningful relationships with others. Our ability to have social relationships with those around us dramatically affects our quality of life. Social skills affect many areas of daily functioning, such as the ability to be employed, or to navigate their community. As such, social skills should be primary intervention targets. In addition, improved social ability can also minimize stigmatizing social behavior that interferes with social relationships and may lessen the likelihood of bullying.

Perhaps one of the greatest benefits of functional skills is that they afford choices. Our level of functional ability is directly related to the amount of choice we have in our lives. The more independently we function, the more choice in life we have. Choice is a right not always afforded to those with intellectual and developmental disabilities, which can lessen their quality of life and lead to poor outcomes (e.g., depression, behavioral problems). The ability to make choices can improve many areas of functioning and lead to a better quality of life overall (e.g., Shogren et al., 2004; Watanabe & Sturmey, 2003).

Conclusion

Functional skills are among the most important skills to teach for individuals with intellectual and developmental disabilities. The acquisition of these skills allows individuals to be more independent, have increased opportunities to make choices, and fully participate in their community. Functional skills encompass a wide range of areas including self-care, domestic, vocational skills, social skills, and behavior management skills.

The absence of these skills leads to placement in more restrictive environments, greater demand on caregivers, and decreased quality of life.

Oftentimes, functional skills are overlooked for individuals with intellectual and developmental disabilities and the focus of educational programming is placed solely on academic skills. Although individuals with disabilities should be given the same opportunity to advance academically as their typically developing peers, they will ultimately be limited if functional skills are not also taught. Therefore, identification of functional skills requires planning and assessment on the part of caregivers to ensure individuals can reach their full potential. Particular goals should be selected with the consideration of the individual's specific strengths and preferences rather than programmatically.

Every individual, regardless of level of functioning, can be taught new skills that can help increase independence. Some individuals, however, may experience more difficulties in learning such skills than others. This is particularly apparent in individuals with intellectual and developmental disabilities. Unlike typically developing children who may be able to learn these skills from their environment, children with intellectual and developmental disabilities need more direct instruction in order to acquire such skills. The development of functional skills is critical in this population in order to increase their independence in the home, school, and community environments.

When selecting skills to target, it is important to take into consideration the individual's age and current abilities, as well as family values. Finding out which skills are important to family members or caregivers can help not only increase the individual's independence, but also lessen the burden on those responsible for supporting the individual. In addition, functional skills training can benefit the individual by helping to reduce social stigma or bullying, making social interactions or community outings easier, encouraging appropriate interests and increasing access to leisure activities, and increasing the likelihood that the individual can participate in vocational tasks or advanced education in adulthood.

There exist a number of assessments to guide practitioners in the selection of functional skills targets. The ABS/Vineland II, AFLS, and SIB-R are all valuable instruments for the identification of strengths and weaknesses within the realm of functional skills. These measures can be a useful guide for parents and practitioners when selecting curricular targets. These measures provide an objective way to guide programming and can be used to determine socially significant short- and long-term goals. During the assessment and planning process, the relevant caregivers should be interviewed and information about the post-school environment should be gathered. Programming should be geared toward the environment in which the individual will be living after aging out of the educational system. In addition to indirect measures, direct assessments (i.e., watching the individual perform the skills) are necessary. Direct assessments help to confirm findings from rating scales or checklist, determine the current level of support needed, and provide feedback on the individual's progress during the training process.

Functional programming leads to a number of tangible benefits including increased independence, more opportunities for community integration, the broadening of interests and leisure activities, more opportunities to establish meaningful social relationships, and the opportunity to make choices for oneself.

The importance of appropriate goal selection for individuals with intellectual and developmental disabilities cannot be underestimated. Functional skills assessments allow us to select these goals appropriately. We should always be focused on the acquisition of skills that are immediately useful, practical, helpful, and beneficial. As parents and practitioners, we should question the need for each goal being addressed. Is this skill important? Is this skill a component of a larger, important skill? Is this goal going to make a meaningful difference in 10 years? Will this skill make the individual more independent at some point in the future? If the answer to any of these questions is "no," then we need to seriously consider why the goals are being targeted. All too often, goals are selected for the wrong reasons (e.g., because other students in a classroom are working on similar goals), which can lead to wasted time and frustration on the part of the individual. As a general rule, if a program is not promoting independence, parents and practitioners should be doing something else. Everything that we target as educators should prepare individuals with intellectual and developmental disabilities for the post-school environment that they will be living in.

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Part II

Treatment and Training Modalities

Complementary and Alternative Therapies

10

Marianne M. Glanzman and Marisa Toomey

Introduction

Complementary and alternative medicine (CAM) is comprised of a diverse group of medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine (National Center for Complementary and Alternative Medicine, 2012). Complementary medical practices are used together with standard medical practices (e.g., the use of massage to reduce pain following an injury) while alternative medicine practices are used in place of standard medical care (e.g., use of a macrobiotic diet rather than chemotherapy to treat cancer). Generally, complementary and alternative practices are discussed as a group, thus the use of the term CAM. For the most part, replicated well-designed scientific studies that prove the safety and efficacy of CAM treatments have not been conducted. The list of specific CAM practices changes over time, as some are proven safe and effective and become part of conventional medical practice.

CAM treatments typically fall into specific categories, thus distinguishing them from "standard" treatments for which there is simply not yet enough evidence. These include alternative medical systems (e.g., homeopathy, naturopathy, ayurveda, and traditional Chinese medicine), mind-body therapies (e.g., meditation and sensorimotor therapies), and ingestive therapies (e.g., nutritional supplements, herbs, and elimination diets). In contrast, standard treatments typically involve medications and surgery.

Intellectual disabilities (ID) include a range of disorders, some of which have specific, known biological etiologies while others remain idiopathic. There are few studies of CAM treatments in study populations specifically selected for ID. These treatments are most often studied in diagnostically more narrow subgroups of patients (e.g., autism, specific genetic disorders, brain injuries, prematurity). While these groups have a higher incidence of ID than the general population, it is by no means certain that all study participants included based on these categories will have ID. Many studies provide little information about the intellectual abilities of

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study participants when they are included because of another diagnosis. An additional limiting factor is that many therapeutic studies specifically exclude individuals with ID due to the complexity of obtaining informed consent or assent.

When reviewing the evidence for a particular treatment, it is important to understand the available level of evidence. This should include the type of study and number of individuals involved which together provide a measure of the size and certainty of treatment effect. One should also take into account the risk–benefit ratio of the treatment on meaningful outcome measures. Ideally, data should be available from more than one randomized clinical trial or meta-analyses involving several different populations. Next best would be well-designed cohort or case–control studies. Uncontrolled or observational studies and anecdotal reports can provide the basis for further study, but are not convincing as evidence for effectiveness.

CAM treatments are widely used in the general population as well as in individuals with ID, in spite of the limited research base for evaluating their safety and effectiveness. In one recent study of 578 2- to 5-year-olds with either developmental delay or autism spectrum disorder (ASD), 30 and 39 % of the groups, respectively, were using CAM therapies (Atkins, Krakowiak, Angkustsiri, Herta-Picciotto, & Hansen, 2014). More hours per week (>20) of conventional therapy and a higher level of parental education were associated with greater likelihood of CAM use. Families may or may not seek the advice of trusted clinicians when considering or using CAM therapies. In another recent study of the use of CAM in children with ASD, 82 % of families were using CAM therapies, and over 50 % were satisfied with these therapies, but only a small percentage felt their physicians were knowledgeable or interested in learning more about then (Huang, Seshadri, Matthews, & Ostfeld, 2013). Clinicians should support the ability of families to openly discuss all therapies they are using, by being knowledgeable about existing data and open to new information. In this chapter we review available information on some of the most commonly used therapies with the goal of allowing clinicians to knowledgeably advise families who seek their advice and participate in the evaluation of effects and side effects when families choose CAM.

Elimination Diets

The Feingold Diet. (Also Called the Kaiser-Permanente, or K-P Diet)

Feingold (1974), an allergist, recommended eliminating tartrazine (yellow dye #5) and aspirin in some patients, as it is accepted that a small number of atopic individuals are sensitive to these substances. As the number of artificial colors, flavors, and preservatives began to grow in the food supply, he considered the possibility that these chemically similar small molecules might behave like tartrazine, and that foods with high levels of natural compounds that are structurally similar to salicylate might behave like aspirin. In the course of seeing a patient with particularly treatment-resistant hives, he employed this broader elimination strategy and achieved successful resolution of her hives. Unexpectedly, her psychiatrist reported a coincident and remarkable resolution of her significant psychiatric symptoms. Admittedly not an expert in behavior, Feingold tried this broader elimination strategy with several children in his allergy practice who were also diagnosed with “hyperkinesis-learning disability.” He noted clinically that approximately 50 % improved in terms of their hyperkinesis and school performance, but also in irritable mood and the quality of their sleep. He noted that, although they are not allergens, these small molecules behaved like allergens, with just a miniscule exposure causing a full reaction, which typically started gradually and lasted from 24 to 72 h (Feingold, 1974). As public awareness of the disorder currently called attention deficit hyperactivity disorder (ADHD) grew, this diet became associated with this disorder, though there was never direct overlap in the symptoms

Feingold described as improving, and the diagnostic criteria for ADHD.

In the USA, the Feingold program is supported by the Feingold Association (www.feingold.org), a nonprofit group of parents and professionals who provide support for families who wish to try this elimination diet. The diet begins with a 6 week elimination of all artificial colors, all artificial flavors, the preservatives BHT (butylated hydroxytoluene), BHA (butylated hydroxyanisole), and TBHQ (tertiary butylhydroquinone), synthetic sweeteners, and the foods that Feingold identified from early high-performance liquid chromatography data as being high in salicylate-like compounds (tomatoes, peppers, cucumbers, apples, grapes, raisins, oranges, tangerines, peaches, nectarines, apricots, plums, prunes, cherries, all berries, currants, almonds, cloves, chili powder, paprika, oil of wintergreen, birch, rose hips, cider and wine vinegar, tea and coffee). If improvement is seen over 6 weeks, the salicylate foods are reintroduced, one at a time for several days, and the individual is observed for a behavioral reaction. Because the eliminated substances do not necessarily need to be listed on labels, a true trial cannot be accomplished just by reading labels. The Association provides a compendium of acceptable and nonacceptable processed foods available in grocery stores by region of the country based on inquiries to manufacturers, as well as additional materials to make an accurate trial feasible. If a limited response is observed, the Association can provide a list of other substances that have historically also caused reactions in some responders (e.g., sodium benzoate, corn syrup, nitrates/nitrites, gluten, casein) (Feingold Association of the U.S., 2014).

Research

After the publication of several positive anecdotal reports by Feingold and others, experimental studies of varying quality began to appear in the late 1970s and early 1980s. Early clinical studies reported a much lower level of response (5–15 % depending on how "response" was defined), or significant positive response in only a small number of participants, and research in the USA slowed almost to a halt by the end of the 1980s. However, it is important to note that there has not actually been a study, regardless of quality of research design, that followed the Feingold program fully as described above. For a variety of reasons (i.e., just eliminating and testing with artificial colors, using less than the average intake of artificial colors in challenge studies, only assessing for core ADHD symptom change, not taking into account the 3-day reaction duration or considering infractions during the study), studies were flawed in ways that may have minimized positive results (Breakey, 1997). Two studies that used full replacement diets for participating families (rather than asking families to eliminate certain substances on their own and challenging with those substances) showed strongly positive results in the youngest (preschool-aged) participants (Harley et al., 1978; Kaplan, McNicol, Conte, & Moghadam, 1989). Though it was not a randomized trial, Kaplan's study had the benefit of including a sham diet phase as well as control and experimental diet phases. Kaplan et al. proved that parents were blinded by showing that they were more likely to guess that the sham diet was the experimental diet rather than the "real" experimental diet.

Given the observation of positive responses in preschoolers, research continued in Canada, England, Australia and New Zealand, where a modified Feingold diet is used. The "European" diet eliminates artificial colors and flavors, and the preservative sodium benzoate. These studies continued to show positive results, though effect sizes are relatively small (Bateman et al., 2004; McCann et al., 2007). Preliminary data suggests that polymorphisms in histamine degradation genes may moderate the effects of artificial food colors and sodium benzoate on ADHD symptoms (Stevenson et al., 2010). Reviews and meta-analyses indicate that there are actually more data in favor of this approach in young children than there are for other nonpharmacological approaches (Millichap & Yee, 2012; Schab & Trinh, 2004; Sonuga-Barke et al., 2013; Stevens, Kuczek, Burgess, Hurt, & Arnold, 2011).

The "hyperkinesis-learning disability" label used at the time of Feingold's early observations likely included children with a wide range of learning and behavior regulation difficulties. The emphasis on "hyperkinesis" in the 1970s that evolved over the years into the current conceptualization of ADHD is likely largely responsible for the continued focus on children specifically with ADHD as potential targets for this approach to treatment. Although we are unaware of any studies of this diet in individuals with other conditions except for the one described below, parent reports of improvement in reading, writing, mood, tics, autism and behavior after traumatic brain injury may eventually result in studies of diet effects in these conditions (www.feingold.org.).

Harner and Foiles (1980) completed a double-blind, crossover, experimental study involving 30 individuals with intellectual disability between the ages of 4 and 25 years who were living in a residential facility. The participants were randomly assigned to either the Feingold diet or the control group. A brief ADHD rating scale was the only outcome measure. No statistically significant differences were found between the control and experimental groups. To date, there have been no attempts to replicate this study in individuals with intellectual disability.

The Oligoantigenic (Low Allergy) Diet

At about the same time as Feingold presented his hypothesis, European neurologists were investigating the role of food sensitivity in various neurologic symptoms, including behavior. A subset of these subjects had additional neurologic symptoms, including headaches and seizures. These researchers hypothesized that non-IgE-mediated immunologic reactions to foods could cause a variety of neurologic symptoms.

Research

This hypothesis was typically studied by instituting an oligoantigenic diet, a diet consisting of only a few low-allergenic foods (such as lamb, chicken, potatoes, rice, banana, apple, brassica vegetables, water, and supplements). Those who improved had other foods reintroduced sequentially to identify which foods caused an exacerbation of symptoms, and a subset underwent blinded challenges of these identified "suspect" foods. Outcome measures included ADHD rating scales, activity meters, and brief psychometric tests. Seventy-six "overactive" children had the open oligoantigenic phase, and 62 were reported to improve, with 21 achieving normal behavior scores. Of the 62 who reported improvement, 28 underwent a double-blind, placebo-controlled, crossover trial to test suspect foods. Symptoms reoccurred or worsened significantly more often during active compared with placebo challenge. It was found that children who had deteriorations in behavior in response to foods always reacted to more than one food and always also reacted to artificial colors. Following the artificial colors, the most commonly provoking foods included soy, dairy, wheat, cheese, eggs, peanuts, corn, fish (note that, with the exception of corn, these are also the most common causes of IgE-mediated food allergy). The next most common were several of Feingold's high salicylate foods, including grapes, oranges, and tomatoes (Egger, Carter, Graham, Gumley, & Soothill, 1985). Carter et al. (1993) replicated this study with similar results. A subsequent double-blind, placebo-controlled study of this approach indicated improvement by direct assessment of trained behavior raters in different settings in 24 % of 49 children hospitalized for disruptive behavior. Although a greater percent responded to methylphenidate compared with diet (44 vs. 24 %), the degree of improvement was similar among respondees (Schmidt et al., 1997). A randomized, controlled, but unblinded study of 27 children who met criteria for ADHD showed an average improvement of 50 % or more on parent and teacher ratings during an oligoantigenic diet trial compared with the wait-list control condition. Of note, oppositional defiant disorder symptoms also improved to a similar degree (Pelsser et al., 2009). Finally, a recent randomized study of 100 children using an oligoantigenic versus (healthy) control diet to identify responders, followed by a 4 week, double- blind, crossover food challenge phase, also identified a positive response to the restricted diet and a relapse of symptoms with active challenge. In this study, children were tested for food-specific IgG levels to several foods (ELISA), but level of reactivity did not predict which foods would cause a clinical reaction (Pelsser et al., 2011).

The Gluten/Casein-Free Diet

Gluten is a protein found in grains such as wheat, barley and rye, while casein is a protein in dairy products. The gluten-/casein-free diet (GCFD), most often reported to improve symptoms of ASD, involves complete elimination of all foods containing gluten and casein. Celiac disease, caused by a chronic autoimmune reaction to gluten, leading to villous atrophy, typically presents with gastrointestinal symptoms. Recently, it has been hypothesized that an even higher percentage of individuals have gluten sensitivity. Gluten-sensitive individuals are more likely to have extra-intestinal symptoms, including neuropsychiatric manifestations (Jackson, Eaton, Cascella, Fasano, & Kelly, 2012).

A large study in Sweden did not find an association between a diagnosis of ASD and a diagnosis of celiac disease or small intestinal mucosal inflammation (Ludvigsson, Reichenberg, Hultman, & Murray, 2013). The study did find that individuals with ASD had an increased risk of elevated serum markers for celiac disease, even in the absence of mucosal inflammation, although the clinical significance of this remains unclear.

The original hypothesis of the effectiveness of gluten-free/casein-free diet in ASD did not directly relate to celiac disease. Instead, it was suggested that peptides from gluten and casein might cause symptoms of ASD by passing through a “leaky gut” and inducing immune reactions (Reichelt, Knivsberg, Lind, & Nodland, 1991) or binding to opioid receptors, affecting opioid neurotransmitter activity. Individuals with autism have been reported to have elevated levels of opioids in cerebrospinal fluid and elevated excretion of low molecular weight peptides in urine. (Israngkun, Newman, Patel, DuRuibe, & Abou-Issa, 1986; Reichelt, Saelid, Lindback, & Boler, 1986; Shattock, Kennedy, Rowell, & Berney, 1990). Due to the current inability to detect in vivo binding of gluten and casein to opioid receptors, this hypothesis remains theoretical.

Research

There are mixed results in studies of the effectiveness of the gluten/casein-free diet in individuals with ASD. Only three randomized, controlled trials have been conducted to date. One of the trials included 20 children and showed a statistically significant improvement in traits of ASD on rating scales (Knivsberg, Reichelt, Hølen, & Nødland, 2002). There was no statistically significant improvement in cognitive skills or motor abilities. In another double-blind trial, 15 participants did not have significant improvement on autism rating scales with use of the GCFD, although there were reports of improved behavior from parents while their children were on the diet (Elder et al., 2006). When these studies were reviewed together, three outcomes were consistently improved with the diet: overall autistic traits, social isolation, and overall ability to communicate and interact but several other outcomes either did not differ or could not be combined for comparison (Millward, Ferriter, Calver, & Connell-Jones, 2008).

The most recent randomized, controlled trial was a single-blind study of 72 children with ASD (Whiteley et al., 2010). Half of the study population was maintained on a GCFD for 12 months, and the other half continued with their usual diet. For this portion of the study, there was a statistically significant improvement with use of the GCFD on blinded, direct assessments of communication and repetitive behavior and on parent-rated measures of social, communicative, stereotypic, and ADHD-related symptoms. During the second 12 months, all participants received a GCFD. For the group that received their usual diet for the first 12 months and then the GCFD, the only area of significant improvement with dietary intervention was attention and hyperactivity. For the group that received the GCFD for 24 months, there were improvements from baseline to 24 months in parent-rated social and communication symptoms. This was hypothesized to represent a more significant effect initially that attenuated over time. No adverse events or negative side effects were reported for any of the participants. This study is limited by a significant drop-out rate and inability to blind parent raters.

Conclusions and Practice Recommendations

The research evaluating the Feingold, oligoantigenic, and gluten-/casein-free diets is weakened by methodological concerns, but shows fairly consistent, if small, positive effects. The Feingold program has the most evidence for effectiveness in selected individuals (young children), though there is controversy as to whether this is really a small number of individuals, or a greater number than studies might suggest given the methodological weaknesses. The oligoantigenic diet has been criticized as unsafe and/or impossible to maintain, but it should be noted that it is a “tool” for assessing foods that may be implicated in behavior dysregulation, and not meant to be a diet to be maintained for an extended period. The GCFD has some evidence for behavioral improvement in two studies of children with ASD, though only one was double-blind. The overlap between these three approaches is intriguing. While the core symptoms of a particular disorder have typically been the outcomes assessed when elimination diets have been studied, it appears that sleep, mood/irritability, and hyperactivity may be the symptoms most likely to improve, regardless of diagnosis. Cognitive and language improvements may take longer to see, if they do occur, than the duration of most studies.

Special diets do not seem to have side effects during the typical study periods. They can be difficult to maintain, and costly, and can be, but are not necessarily, a source of struggle between parents and their children. It is generally advised that the entire family keep to the diet within the home. The relatively short trial periods needed to determine whether there is a positive response, at least, should not be nutritionally risky, though extended elimination of many foods can be. Presumably, an extended period of elimination will only be done when the elimination diet is helpful, and therefore the most important role for clinicians is to participate with families in identifying target behaviors and measuring their changes as well as assisting or referring for nutritional consultation if needed.

Nutritional Supplements

Omega-3 Fatty Acids

Fatty acids consist of a carbon chain backbone with attached hydrogen atoms (typically 10–26 carbons in length), a methyl group at one end, and a carboxylic acid group at the other. Three fatty acids are attached to glycerol molecules to make triglycerides, and two are attached to phospholipids with one end hydrophobic and one end hydrophilic as important components of cell membranes. Saturated fatty acids have no double bonds in the carbon chain. Monounsaturated fatty acids have a single double bond. Polyunsaturated fatty acids (PUFAs) have several double bonds in their carbon chains. There are several categories of PUFAs based on the location of the first double bond (omega-3, -5, -6, -7, and -9). The most widely studied are the omega-3 and omega-6 fatty acids, especially the longer-chain PUFAs that are between 18 and 22 carbon atoms in length. Omega-3 PUFAs are synthesized from the 18-carbon precursor, alpha-linolenic acid; omega-6 PUFAs are synthesized from the 18-carbon precursor, linoleic acid. Alpha-linolenic and linoleic acids are called essential fatty acids (EFAs) because they cannot be synthesized, but must be ingested (Skeaff & Mann, 2012). Several of the longer-chain fatty acids may be considered “conditionally essential” because they are not efficiently synthesized. These include arachidonic acid (AA), a 20-carbon omega-6 and docosahexaenoic acid (DHA), a 22-carbon omega-3. Two other important PUFAs are gamma-linolenic acid (GLA), an 18-carbon omega-6 and eicosapentaenoic acid (EPA), a 20-carbon omega-3. Enzymes (elongases and desaturases) using zinc as a cofactor elongate the shorter carbon chains to make 18, 20, and 22 carbon fatty acids, each of which plays a role in the formation of neuronal structural components, cell signaling molecules, or immune modulators. The omega-6 s are abundantly available in the

Western diet, with the primary sources being vegetable oils, and meat, egg, and dairy that are fed a vegetable/grain diet. The omega-3 s are highest in fatty fish, walnuts, and certain seeds, and are less commonly ingested. It has been shown that the recommended ratio of intake of omega-6 to omega-3 fatty acids is somewhere between 4 to 1 and 7.5 to 1 (Gebauer, Psota, Harris, & Kris-Etherton, 2006). Yet studies have shown that in North America, the true ratio of intake is closer to somewhere between 17 to 1 and 25 to 1 (Richardson, 2006; Simopoulos, 2002) and some children with ADHD or ASD have ratios of omega-6 to omega-3 fatty acids as high as 50 to 1 (Mazza, Pomponi, Janiri, Bria, & Mazza, 2007).

DHA is concentrated in the phospholipid bilayer of brain and retinal neural membranes (Bazan, Rodriguez de Turco, & Gordon, 1993; Crawford, 1993; SanGiovanni, Parra-Cabrera, Colditz, Berkey, & Dwyer, 2000). It has been shown to be crucial for proper fetal brain development and can influence synaptic plasticity and stimulate remyelination (Mazza et al., 2007; Salem et al., 2001; Willatts & Forsyth, 2000). EPA is also incorporated into neuronal phospholipids (Mazza et al., 2007). Omega-3 fatty acids therefore have vital roles in synaptic transmission and neuronal activity, as well as their well-known anti-inflammatory effects. The omega-6 PUFAs are generally considered pro-inflammatory with the exception of GLA.

Deficiencies of PUFAs can lead to dry skin or a scaly rash, decreased growth in children, susceptibility to infection, poor wound healing, neuropathy, excessive thirst or urination, and visual and cognitive problems. Individuals receiving parenteral nutrition that is not adequately fat-supplemented, those with conditions that reduce fat absorption, and infants born preterm or who are in a nutritionally deficient prenatal environment during the last 3 months of pregnancy are particularly susceptible.

In order to ingest recommended levels of the essential fatty acids DHA and EPA, one would have to eat two to three servings of fatty fish per week (Mazza et al., 2007). Due to concerns that frequent consumption of fatty fish could lead to increased ingestion of mercury, dioxin, and polychlorinated biphenyls, dietary supplements of DHA and EPA have become increasingly popular. DHA alone is available from plant sources, most often algae, and mixed DHA and EPA are commonly available as “fish oils.”

The Food and Drug Administration has not yet established recommended daily allowances of PUFAs for adults or children. In 2002, the Food and Nutrition Board of the US Institute of Medicine established adequate daily intakes of omega-3 and omega-6 fatty acids for children, adolescents, adults, and for pregnancy and lactation. For omega-6, these range from a low of 4.4 g/day in infants to a high of 13 g/day in pregnant and lactating mothers. For omega-3, these range from a low of 0.5 g/day in infants to 1.3–1.4 g/day in pregnant and lactating mothers (Institute of Medicine, 2002). The International Society for the Study of Fatty Acids and Lipids (2014) recommended a minimum daily intake of 500 mg/day of combined EPA and DHA for cardiovascular health in healthy adults (www.issfal.org.uk). The European Food Safety Authority (2009) recommended a daily intake of 10 g/day of omega-6 linoleic acid, 2 g/day of omega-3 ALA, and 250 mg/day of mixed DHA/EPA (European Food Safety Authority, 2009). The Food and Drug Administration (2009) recommended daily intake of less than 3000 mg of fish oils (Brulotte, Bukutu, & Vohra, 2009). A 1000 mg fish oil capsule generally contains 120 mg DHA and 180 mg EPA (Mazza et al., 2007). Potential side effects of omega-3 acids include gastrointestinal upset (e.g., nausea, diarrhea, flatulence, and a sensation of “heartburn”), hypotension, changes in the body’s immune response, and mild fever (Amminger et al., 2007; Brulotte et al., 2009; Peet & Stokes, 2005). Ingestion of high doses of fish oils can potentially increase the risk of bleeding because DHA and EPA can inhibit platelet aggregation (Hagg, 2003). Fish oils may interact with antiplatelet drugs and/or anticoagulant medications, and they may also oppose the action of statins (Burrowes & Van Houten, 2006; Goodnight, Harris, & Connor, 1981; Wensing, Mensink, & Hornstra, 1999). Those with seizures are advised to avoid large doses of evening primrose and other GLA-rich oils (Hendler & Rorvik, 2001). For adults, 3000–4000 mg standardized fish oils per day appear to be safe (Albert, Hennekens, & O'Donnell, 1998; Krauss et al., 2000; Kris-Etherton, Harris, Appel, & Nutrition Committee, 2002; Mazza et al., 2007; Werneke, Turner, & Priebe, 2006). However, safety as described above is based on the lack of promptly measurable side effects. Monitoring of levels has not typically been done as part of ongoing clinical care. Given that all of the PUFAs and their intermediates play known or potential roles in physiologic functions, there is currently insufficient information about the implications of possibly "unbalancing" the ratio of one PUFA to another by giving large doses of specific omega-3 PUFAs over an extended period of time.

Research

To date, there has not been research into the role that omega-3 fatty acids may play in the treatment of individuals specifically with ID. There has been limited research into the potential benefits of PUFA supplementation for cognitive development in infants and protection from cognitive decline in the elderly, and in mood, autism spectrum disorder, learning, and ADHD. There has been more extensive research into the protective effects of omega-3 PUFAs on cardiovascular health and in cardiovascular conditions which is beyond the scope of this chapter (see Kris-Etherton et al., 2002).

Infant Development

Maternal stores of DHA during pregnancy and DHA in breast milk are the main sources of DHA in infants, which is the predominant structural fatty acid component of the brain and retina. Breast milk DHA levels are dependent on maternal intake and infant DHA levels increase with increasing breast milk levels until a certain point (Makrides & Gibson, 2000). There are small but significant neurodevelopmental advantages at follow-up in infants who were breastfed versus those were formula-fed (Simmer, Patole, & Rao, 2011). This neurodevelopmental advantage is more prominent in preterm infants (see section on American Academy of Pediatrics, Section on Breastfeeding, 2012), who are both less likely to have accumulated sufficient stores of long chain PUFAs and are less likely to be able to effectively elongate precursor PUFAs. In some, but not all, studies, better cognitive and visual development are associated with higher DHA levels in the mother and child (Bakker, Hornstra, Blanco, & Vles, 2009; Escolano-Margarit et al., 2011; Makrides et al., 2010). However, a meta-analysis of six randomized, controlled trials of AA and/or DHA supplementation of lactating mothers did not show consistent benefits for development in term infants (Delgado-Noguera, Calvache, & Bonfill Cosp, 2010). Preterm infants may show some benefit from supplementation with DHA and AA in terms of their visual (SanGiovanni et al., 2000) and attentional development (Westerberg et al., 2011). A review of 15 randomized studies (through April, 2011) of direct supplementation of term infants with DHA or DHA+AA (in contrast to un-supplemented formula which contains precursor PUFAs) did not show overall benefits in terms of visual acuity, cognitive development, or physical growth (Simmer et al., 2011). Four of nine studies showed visual benefits at least one time point. Two studies showed better problem-solving ability at approximately 1 year of age, but no cognitive benefits were apparent at later time points. No benefits or disadvantages to growth were identified. Similarly, a review of 17 randomized trials (through December 2009) of formula supplemented with long chain PUFAs (in contrast to unsupplemented formula which contains precursor PUFAs) fed to relatively healthy and "older" premature infants did not show strong positive effects on visual acuity, cognitive development, or growth, though three of four studies showed an advantage on cognitive scores at one or more time points (Henriksen et al., 2008). The studies included in these reviews varied widely in terms of amount and type of supplementation and outcome measures, and did not consider maternal and infant baseline PUFA status in relation to outcome. It might be hypothesized that deficient individuals would benefit to a greater degree from supplementation. Other studies of "younger" premature infants supplemented with higher levels of DHA than those used in the formula studies, have shown positive developmental outcomes (Henriksen et al., 2008; Makrides et al., 2009)

Cognitive Effects in Older Adults

In the Framingham Heart Study, adults with the highest levels of DHA had significantly lower rates of all causes of dementia as well as Alzheimer's disease than those with the lowest levels (Schaefer et al., 2006). Some studies have shown slowing in the rate of cognitive decline in the more mildly involved subgroups of Alzheimer's patients with DHA/EPA (Freund-Levi et al., 2006) or DHA supplementation (Quinn et al., 2010). Studies of older individuals with milder age-related cognitive decline showed mixed results (Dangour et al., 2010; van de Rest et al., 2008; Yurko-Mauro et al., 2010). A meta-analysis of over 3000 older individuals who were cognitively healthy did not show an advantage to 6–24 month supplementation with omega-3 PUFAs in terms of number of new cases of dementia or measurable cognitive decline (Sydenham, Dangour, & Lim, 2012).

Effects on Mental Health Disorders

Research has suggested that abnormalities of neuronal membrane phospholipids and prostaglandins are associated with schizophrenia, although it is not clear if this is a cause or an effect of a different seminal abnormality. Several studies show reduced levels of red blood cell membrane DHA and AA in schizophrenics, leading to the hypothesis that supplementing with long chain PUFAs might be helpful in treatment. Case reports and/or open trials of omega-3, but not omega-6 supplementation suggested positive effects on residual symptoms in neuroleptic-treated patients, especially with EPA-enriched supplements (Fenton, Hibbeln, & Knable, 2000). Subsequent double-blind, placebo-controlled trials showed that omega-3 supplementation that included EPA may reduce the risk of progression from a prodromal state to first episode of psychosis, and reduce the level of antipsychotic medication required in the first episode of psychosis (Peet, 2008). Results in relapsing and chronic schizophrenia have been mixed (Irving, Mumby-Croft, & Joy, 2006; Peet, 2008). A longer, prospective, randomized, double-blind, placebo-controlled study of 12 weeks of omega-3 supplementation (EPA>DHA) followed by 40 weeks of follow-up in adolescents and young adults with sub-threshold psychosis showed significant positive effects. Not only did a smaller percentage of supplemented subjects progress to full-threshold psychosis (4.9 vs. 27.5 %), but there was a reduction in both positive and negative symptoms and improved functioning in the treated group (Amminger et al., 2010). This is a highly promising finding that requires replication.

There is also evidence for beneficial effects of omega-3 supplementation in depression and mixed, though promising, results in bipolar disorder. Multiple reviews and meta-analyses including over 15 randomized, controlled trials and over 1000 subjects indicate that omega-3 PUFA supplementation has positive effects in adults with depressive disorders (Grosso et al., 2014; Lin & Su, 2007; Sinclair, Begg, Mathai, & Weisinger, 2007). A closer look at the specific factors related to positive effects indicate that greater than 60 % of the supplement provided as EPA is a critical factor for successful treatment (Martins, 2009; Sublette, Ellis, Geant, & Mann, 2011). The omega-3 PUFAs provide benefit as adjunctive, not sole treatment agents. There is less clear evidence for a benefit from supplementation for post-partum depression (Grosso et al., 2014) and mixed results for depressive symptoms in those who are not diagnosed with major depressive disorder (Grosso et al., 2014; Sinn et al., 2012). The results in bipolar disorder are mixed, but also predominantly positive (Freeman & Rapoport, 2011; Lin & Su, 2007). The first positive randomized, double-blind, controlled trial in bipolar disorder employed high doses of omega-3 s (over 9 g/day, EPA>DHA; Stoll et al., 1999) and showed that supplemented subjects had longer periods of remission. A follow-up study, using the same protocol except for about ½ the dose of supplement (still well above the recommended daily intake), showed no benefit from the supplement (Murphy et al., 2012).

Autism Spectrum Disorders (ASD)

There have been inconsistent results among the studies that have looked at the PUFA levels of children with ASD. Both reduced (Bell et al., 2004; Vancassel et al., 2001) and elevated levels have been found (Sliwinski, Croonenberghs, Christophe, Deboutte, & Maes, 2006). The research regarding treatment effectiveness has been mixed as well. One open-label trial featured nine children with ASD who received EPA-rich fish oils, 18 children with ASD who did not receive fish oils, and 55 controls (Bell et al., 2004). This trial found that supplementation with omega-3 fish oils for at least 6 months in children with ASD led to improvements in sleep, cognitive skills, motor skills, concentration, eye contact, sociability, hyperactivity, aggression, and irritability. In contrast, a small randomized, double-blind placebo-controlled trial involving seven children and adolescents with ASD who received 1.3 g daily of omega-3 (EPA>DHA) and six matched controls found that there were no statistically significant differences between the two groups after 6 weeks (Amminger et al., 2007). A small decrease in hyperactivity and stereotypy was noted in the experimental group, and the study's small sample size and short duration are important limitations. A subsequent double-blind, placebo-controlled trial using a similar supplement ($N = 14$ supplemented; 13 controls) also found no significant differences after 12 weeks in 3- to 8-year-olds with autism, but all of the measured outcomes (irritability, social withdrawal, stereotypy, hyperactivity, and inappropriate speech) were improved in the supplemented group at the end of the study (Bent, Bertoglio, Ashwood, Bostrom, & Handren, 2011). The change in hyperactivity, though not statistically significantly different between groups, showed a small to moderate effect size, and improvement was correlated with increases in the percentage of omega-3 and reductions in the percentage of omega-9 free fatty acids in the supplemented group. When these two studies were combined in a meta-analysis, there remained no statistically significant differences (James, Montgomery, & Williams, 2011).

Attention Deficit Hyperactivity Disorder (ADHD)

Several research teams have identified deficiencies of DHA, EPA, GLA, and AA in children with ADHD (Brulotte et al., 2009). It is possible that these deficiencies are due to difficulties with fatty acid metabolism, since intake in children with ADHD versus controls does not differ. The degree of deficiency is correlated both with symptoms thought to be related to EFA deficiency (dry hair and skin, excessive thirst, polyuria) and with the degree of behavior problems (Burgess, Stevens, Zhang, & Peck, 2000; Colter, Cutler, & Meckling, 2008; Raz & Gabis, 2009). In spite of clear evidence for deficiencies, treatment studies have shown either negative or small positive effects. Two randomized, double-blind, placebo-controlled studies of DHA supplementation compared with placebo did not show any statistically significant improvement in ADHD symptoms of inattention and/or hyperactivity/impulsivity (Hirayama, Hamazaki, & Terasawa, 2004; Voigt et al., 2001). Likewise, studies of omega-6 supplementation alone do not show positive effects (Raz & Gabis, 2009). Other randomized controlled trials have shown that DHA and EPA in combination have a greater effect than placebo on measures of attention and behavior (Richardson & Puri, 2002; Sinn & Bryan, 2007; Stevens et al., 2003) and that combined omega-3 and omega-6 is effective when omega-3 alone is not (Gillies, Sinn, Lad, Leach, & Ross, 2012; Sinn & Bryan, 2007), especially EPA and GLA (Puri & Martins, 2014).

Phosphatidylserine is a phospholipid to which fatty acids attach in forming cell membranes. Recent studies, including a double-blind, placebo-controlled trial, suggest that phosphatidylserine alone and combined with omega-3 supplementation can also improve symptoms of ADHD but more research is needed (Manor et al., 2012).

Learning Disorders

Several studies of supplementation in children with ADHD indicated that improvements in academics, particularly reading, accompanied improvements in attention and hyperactivity

(Milte et al., 2012; Richardson & Montgomery, 2005; Richardson & Puri, 2002; Sinn & Bryan, 2007), but it can be difficult to separate secondary effects of improved attention versus directly improved reading ability. In an open study, in which children were selected for dyslexia (reading disorder), improvements were seen in decoding and reading speed after 20 weeks of supplementation with mixed DHA, EPA, AA, and GLA (Lindmark & Clough, 2007). In a double-blind, placebo-controlled study comparing children with dyslexia (matched at baseline for literacy skills and educational intervention) supplemented with EPA and carnosine for 90 days versus placebo, no differences were found in reading accuracy or speed, spelling, decoding fluency, arithmetic, language skills, attention, or behavior (Kairaluoma, Narhi, Ahonen, Westerholm, & Aro, 2009).

Multiple differences between studies complicate conclusions, including the dose of omega-3 fatty acids administered, symptom severity, and whether the individuals participating in the studies were on other medications (such as stimulants) during the trials.

Conclusions and Practice Recommendations

PUFAs, especially DHA and EPA, play an important role in neurodevelopment. The overall side effect profile of PUFA supplements is mild, although caution should be used in those at risk for bleeding disorders. Research provides mixed results as to the efficacy of these supplements, with single omega-3 s and omega-6 s alone more clearly ineffective. Mixed omega-3 s have some evidence for efficacy in mental health disorders and mixed omega-3 s with some omega-6 have been mildly effective in limited studies of ADHD and learning problems. Minimum treatment duration to observe effects is relatively long (at least 12 weeks). No studies have been done to evaluate the effectiveness of the supplements specifically in individuals with ID. It is possible that PUFA supplementation will provide some benefit in some individuals, but several questions remain as to how initial status might relate to selection of supplement and treatment response, dose, and role of other simultaneously needed nutrients.

Other Nutrients

While inadequate intakes of protein, iodine, and iron are most well-known for their adverse cognitive effects, subtler deficiencies of other nutrients may have adverse effects as well. In addition, it has been theorized in some cases that additional supplementation, in the absence of clinical or biochemical signs of deficiency, may provide cognitive advantage. In general, literature would suggest that broad nutritional supplementation has small, but positive effects on cognition (Schaevitz, Berger-Sweeney, & Ricceri, 2014), but this is most consistently found when deficiencies are present. One factor that impedes progress in understanding the role of nutrients is the difficulty in measuring "deficiency" in food-secure societies where deficiencies are likely subtle. Dietary intake does not uniformly reflect nutritional status, and serum or red blood cell measurements may not adequately reflect brain levels.

Vitamin B6 and Magnesium

Vitamin B6 (pyridoxine, active form pyridoxyl 5′-phosphate) is a water-soluble vitamin that is involved in fat and carbohydrate metabolism, and functions as an essential coenzyme in the conversion of homocysteine to cysteine. It plays an important role in the synthesis of the neurotransmitters serotonin, dopamine, norepinephrine, and gamma-aminobutyric acid (GABA). This relationship to neurotransmitter production has generated hypotheses regarding a role for vitamin B6 in neuropsychological disorders such as depression, Parkinson's disease, and Alzheimer's disease (Malouf & Grimley Evans, 2003).

Vitamin B6 is synthesized by microorganisms in the large intestine, and is found in dietary sources including liver, whole grain cereals, peanuts, and bananas. The recommended daily allowance for adults is 1.3–1.7 mg/day depending on age and gender. Individuals with vitamin B6 deficiency are at risk for seizures, peripheral neuropathy, sleeplessness, behavioral changes, and skin disorders including dermatitis, glossitis, cheilosis, and angular stomatitis (Truswell, 2012). Individuals who have had overexposure to vitamin B6 (at least 200 mg per day for several weeks) have been found to have peripheral sensory neuropathies as well (Malouf & Grimley Evans, 2003).

Negative side effects of large doses of vitamin B6, including irritability, hypersensitivity to sound, and enuresis, can be countered by administration of magnesium (Nye & Brice, 2005). In vivo research has shown an interaction between magnesium and vitamin B6 (Boylan & Spallholz, 1990). Magnesium functions as an NMDA receptor antagonist that blocks influx of calcium within neuronal ion channels (Nowak, Bregestovski, Ascher, Herbet, & Prochiantz, 1984). Magnesium's potential for impact on neuronal functioning has fueled research into its utility as a "calming" nutrient and in conditions such as perinatal asphyxia (Bhat et al., 2009). The recommended daily allowance of magnesium in adults is 310–420 mg/day, depending on age and gender. While higher doses of the water-soluble B vitamins are generally not problematic, exceeding daily needs of magnesium can be.

Research

Several studies have shown a correlation between cognitive function and serum levels of the B vitamins (Goodwin, Goodwin, & Garry, 1983; La Rue et al., 1997), including a study that showed that high serum vitamin B6 concentration correlated with improved performance on memorization tasks (Riggs, Spiro, & Rush, 1996). The most recent review of the use of vitamin B6 for cognition included two double-blind, randomized, placebo-controlled trials that had enrolled over 100 subjects (Malouf & Grimley Evans, 2003). None of the participants had intellectual disability or other cognitive impairments. The authors of the review concluded that, based on the available data, there is no evidence of benefit from vitamin B6 supplementation on mood or cognition of elderly individuals.

Vitamin B6 (with magnesium) supplementation has also been studied for its utility in ASDs. Speech and language improvement with vitamin B6 supplementation in children with ASD symptoms was initially reported in the 1960s (Bönisch, 1968). A later review assessed the efficacy of vitamin B6 and magnesium treatment to improve social and communication skills and to decrease behavioral stereotypies in individuals with ASD based on three randomized, controlled studies (Nye & Brice, 2005).

The earliest of these studies utilized a placebo-controlled, asymmetric crossover design and sought to measure changes in social skills, sensory responses, and language skills (Tolbert, Haigler, Waits, & Dennis, 1993). Twenty individuals between the ages of 6 and 18 who had ASD and intellectual disability participated in the study. Doses of 200 mg of vitamin B6 and 100 mg of magnesium were administered over a total of 20 weeks. Both placebo and treatment improved outcomes equally.

A second randomized, double-blind, placebo-controlled crossover study with 12 participants utilized daily doses of 30 mg/kg of vitamin B6 and 10 mg/kg of magnesium for a total of 8 weeks (Findling et al., 1997). Based on the absence of any statistically significant improvement in social interactions or communication skills with treatment, the authors concluded that the intervention was ineffective. Methodological concerns may limit the generalizability of this conclusion.

The third study was a randomized, placebo-controlled trial of vitamin B6 supplementation without concurrent administration of magnesium (Kuriyama et al., 2002). The authors hypothesized that vitamin B6 would improve IQ test scores in children with ASD. Eight children completed the study, took 100 mg per day of vitamin B6 for 2 weeks, and 100 mg twice per day for the following 2 weeks. A standardized IQ test was administered at baseline and after 4 weeks of treatment. The authors reported a statistically significant improvement in verbal IQ scores with vitamin B6 treatment as compared to placebo; however there were differences in IQ scores at baseline.

There were no significant adverse effects during any of these trials. There were several reports of upper respiratory infections, headaches, decreased appetite, and increase in nighttime enuresis. The authors concluded that, because of the small sample sizes, limited number of studies, and questionable methodologies of the studies, no recommendation could be given regarding the use of vitamin B6 and magnesium as a treatment for ASD (Nye & Brice, 2005).

Vitamin B12

Vitamin B12 (cobalamin, methycobalamin) is a water-soluble vitamin that is required for the methylation of homocysteine to methionine. The activated form of methionine is able to transfer methyl groups to myelin, neurotransmitters, and membrane phospholipids (Malouf & Areosa Sastre, 2003), indicating the importance of vitamin B12's role in the functioning of the nervous system. Vitamin B12 is also required for the conversion of methylmalonyl coenzyme A to succinyl coenzyme A in the Krebs cycle (Rasmussen, Fernhoff, & Scanlon, 2001).

Humans must obtain vitamin B12 from their diet, generally from animal protein. The recommended daily requirement is 2–5 μg, although the average adult (nonvegan and nonvegetarian) diet provides approximately 5–30 μg per day (Malouf & Areosa Sastre, 2003). Vitamin B12 is excreted in bile and reabsorbed in the terminal ileum with the aid of intrinsic factor, and up to 2–3 mg can be stored in the human liver (Lauer & Spector, 2012). Because of this active enterohepatic circulation and liver storage, several years of a vitamin B12-deficient diet may be required before an individual becomes functionally deficient (Rasmussen et al., 2001).

A deficiency in vitamin B12 leads to several negative effects including macrocytic anemia, leucopenia, thrombocytopenia, and pancytopenia (Lauer & Spector, 2012). Neurologic effects of B12 deficiency include hypotonia, seizures, paresthesias, ataxia, memory loss, developmental regression, irritability, weakness, and personality changes (Lauer & Spector, 2012). Elevated homocysteine levels may occur, which is a risk factor for vascular disease (Clarke et al., 1991) and dementia (Malouf & Grimley Evans, 2008). Children with vitamin B12 deficiency may also have anorexia, fatigue, glossitis, vomiting, diarrhea, and failure to thrive (Rasmussen et al., 2001). Several medications can interfere with absorption of vitamin B12, including certain antiepileptics, proton pump inhibitors, H_2 receptor antagonists, and potassium products.

Research

The impact of vitamin B12 on cognitive function in elderly patients with Alzheimer's disease and/or cognitive decline has been studied. One randomized, double-blind, placebo-controlled trial showed that a daily oral dose of 50 μg of vitamin B12 significantly increased the average serum levels of vitamin B12 in older individuals with B12 deficiency (Seal, Metz, Flicker, & Melny, 2002). This study did not include individuals with a history of intestinal malabsorption or known deficiencies of intrinsic factor. There was no evidence for improved cognition; however, cognition was not tested in detail, but rather with a brief mental status test.

Hvas, Juul, Lauritzen, Nexo, and Ellegaard (2004) examined the effects of vitamin B12 treatment on cognitive function and depression in patients with known vitamin B12 deficiency (determined by elevated plasma methylmalonic acid levels). One hundred and forty participants were randomly assigned to receive either a 1 mg vitamin B12 injection or a placebo injection weekly for 4 weeks. There was a higher rate of cognitive dysfunction and depression symptoms in this B12-deficient population than would be expected based on rates in the typical age-matched population. The patients were assessed at baseline and 3 months after completion of treatment. There was no statistically significant difference between the treatment and placebo group in the measurements of patient cognitive function or depressive symptoms. It was neither known how long the subjects had been vitamin

B12-deficient, nor how well the treatment corrected their deficiencies.

The role of vitamin B12 in the nervous system has also generated research into possible benefits for children with ASD. Subcutaneous injection of methylcobalamin has anecdotally been reported to improve ASD symptoms. One double-blind, placebo-controlled, crossover study examined the effects of methyl B12 in 30 children with ASD, ages 3–8 years. Doses of 64.5 μg/kg of B12 (or placebo) were injected every 3 days for 6 weeks, and then, without washout, the crossover portion of the trial took place for 6 weeks. Although nine subjects had a positive behavioral response, in the overall study population, there was no statistically significant improvement in behavioral symptoms of ASD (Bertoglio, James, Deprey, Brule, & Hendren, 2010).

Folate

Folate (B9) is a water-soluble B vitamin that, along with choline, is important in reactions that involve single-carbon metabolism. Single-carbon processes are necessary for the synthesis and maintenance of integrity of DNA, neurotransmitter synthesis, and methylation of DNA, RNA, proteins, polysaccharides, and phospholipids. Methylation of DNA is an epigenetic regulator of gene transcription. All of these molecules are involved in the proliferative and synaptic processes that result in cortical development and plasticity. Abnormal development of the cerebral cortex and reduced cortical plasticity are hallmarks of developmental disorders that result in intellectual disability, thus abnormalities in folate status may play a role (Schaevitz et al., 2014). Folate deficiency, which can occur due to inadequate intake, or individual genetic differences in folate usage/metabolism (such as methytetrahydrofolate reductase deficiency) is best known for causing megaloblastic anemia and neural tube defects. As with B12, folate deficiency can lead to an elevated homocysteine level, a risk factor for vascular disease and dementia. Folate occurs naturally in several fresh fruits and vegetables, but is added to foods or provided in most supplements in the form of folic acid, which must be reduced by dihydrofolate reductase and then tetrahydrofolate reductase to 5-methyltetrahydrofolate, the active form. Folinic acid, sometimes used as the supplement form in research, like folate, is biologically active once absorbed in the intestines.

Research

Although folic acid supplementation, with or without B12 supplementation, does not appear to benefit the cognitive function of healthy elderly individuals, the subgroup with high homocysteine levels does benefit on some measures of cognitive functioning (Malouf & Grimley Evans, 2003).

The role of folate has been studied in fragile X syndrome, a common and specific genetic cause of intellectual disability resulting from a greater than 200 triplet repeat expansion in the FMR1 gene on the X chromosome. The “fragile site” on the X chromosome was initially identified when cells were grown in folate-deficient culture media, leading to the theory that folate supplementation might have a stabilizing influence on the DNA of individuals with fragile X syndrome and, thereby, a positive impact on clinical status. However, it appears that individuals with fragile X do not have folate deficiency or any evidence for altered folate metabolism or single-carbon cycle abnormalities (Schaevitz et al., 2014) and placebo-controlled studies do not support improved function in individuals with fragile X supplemented with various doses of folate (Hall, 2009; Rueda, Ballesteros, Guillen, Tejada, & Solá, 2011).

Folate and choline supplementation have also been evaluated in Rett syndrome, Down syndrome, and ASD. Animal models typically indicate that oral supplementation can increase brain levels of these nutrients, but CSF studies in humans also indicate that central folate deficiency can occur when serum and red blood cell levels are normal. Cerebral folate deficiency occurs in some, but not the majority, of girls with Rett syndrome, at least according to research to date. This does not appear to be related to age or type of MECP2 mutation, but may be related to mitochondrial dysfunction, as transport of folate across the blood–brain barrier is an energy-demanding process. In some, but not all, open trials of folinic acid supplementation girls with Rett syndrome and cerebral folate deficiency, supplementation improved seizures, mobility, interest in surroundings, and social contact. Blinded, controlled trials will be needed to further assess this promising finding. Perinatal choline supplementation in mouse models appears to be beneficial in terms of neuronal health, glutamate cycling, and improved levels of acetylcholine and nerve growth factor, but no human studies have been completed (Schaevitz et al., 2014).

Among the over-expressed genes in trisomy 21 (Down syndrome), several are related to one-carbon metabolism in the folate-methionine cycle. Individuals with Down syndrome appear to have reductions in the production of homocysteine, S-adenosyl methionine, and methylation reactions as a result. Placebo-controlled trials of folinic acid supplementation in infants and children do not appear to improve cognitive or language development; however, positive effects were found in children who were also being treated for hypothyroidism. It is not clear whether this was the result of treatment of the hypothyroidism, or because hypothyroidism can also cause abnormalities in methionine cycle metabolism that respond to folinic acid (Blehaut et al., 2010). Perinatal treatment of rodents with choline appears to improve performance on spatial and attention tasks, but human studies are not yet available (Schaevitz et al., 2014).

Maternal folate status appears to be inversely related to risk for autism in children (Schaevitz & Berger-Sweeney, 2012), suggesting that folate supplementation may be beneficial prior to conception. A recent cohort study found that maternal supplementation with folic acid was associated with a lower risk for ASD (Suren et al., 2013). Choline status appears to be normal in most individuals, and in most areas of the brain, in individuals with ASD, though specific abnormalities have been found in some studies. There are no clinical studies of supplementation at this time (Schaevitz et al., 2014).

Conclusions and Practice Recommendations

The B vitamins, including folate, are important in brain development, cognition, and mood, and are generally safe, because of their water-solubility and ready excretion, though because of overlap in their absorption and utilization mechanisms, excessive doses of single B vitamins can lead to relative deficiencies in others by overwhelming absorptive capacity.

There is insufficient information in support of vitamin B6 supplementation with greater than RDA doses, with or without magnesium, for improving cognitive function in individuals with or without cognitive disabilities or ASD. Likewise, there is insufficient information in support of vitamin B12 supplementation with greater than RDA doses for improving cognitive function in a variety of patients groups, with or without B12 deficiency, though there may be a greater chance of benefit for some cognitive or depressive symptoms when a deficiency is present.

Adequacy of dietary intake in preconceptional, pregnant, and lactating women, and in infants and young children appears to offer the best chance of maximizing cognition, whereas supplementation in childhood, adolescence, and adulthood does not appear to alter functional status, at least as it has been measured to date. Neurotransmitter synthesis, and effects on attention and mood, may be more amenable to later change than cognitive status, which is largely determined by early brain development.

Individual differences in folate metabolic capacity, such as MTHFR deficiency, are not uncommon. An in depth discussion of this is beyond the scope of this chapter, but the reader is referred to http://ghr.nlm.nih.gov/MTHFR. In the setting of a family history of elevated homocysteine levels, homocystinuria, neural tube defects, thrombosis, or premature cardiovascular disease, measurement of homocysteine levels and genetic testing for MTHFR is indicated. The use of antiepileptic drugs may also interfere with folate metabolism, and should lead to consideration of monitoring folate levels and supplementation, especially during pregnancy. Red blood cell levels may be more accurate than serum levels for assessing cellular levels (Truswell, 2012).

Complementary and Alternative Treatments for Insomnia

The Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013) defined insomnia as "dissatisfaction with sleep quantity or quality with complaints of difficulty initiating or maintaining sleep." This definition includes sleep-onset insomnia, sleep maintenance insomnia, and late insomnia. Sleep-onset insomnia occurs when an individual consistently requires more than 20–30 min to fall asleep. Sleep maintenance insomnia indicates that an individual has nighttime awakenings that disrupt sleep quantity and/or quality. Late insomnia involves difficulties falling back asleep after early-morning awakenings.

Disorders of sleep are common. Recent estimates suggest that between 35 and 40 % of adults in the USA have difficulties falling asleep (Ferracioli-Oda, Qawasmi, & Bloch, 2013; Hossain & Shapiro, 2002), while it is estimated that between 15 and 25 % of the general pediatric population suffers from sleep difficulties (Shamseer & Vohra, 2009). In individuals with intellectual disability, research indicates that approximately 15 % of adults with intellectual disability have sleep problems (Gunning & Espie, 2003; Sajith & Clarke, 2007). For children with developmental disabilities, the prevalence is widely estimated to range from 25 to 86 % (Hollway & Aman, 2011). Several types of neurodevelopmental disabilities carry specific risk for sleep disturbances. For example, children who are blind or who have autism spectrum disorder are thought to have atypical circadian rhythms, which are the daily patterns that determine the regularity and intensity of wakefulness and drowsiness. Children with Williams syndrome are at risk for poor sleep due to periodic limb movement disorder. There are currently no medications approved by the Food and Drug Administration for the treatment of pediatric insomnia (Hollway & Aman, 2011; Owens et al., 2005).

The most commonly studied CAM treatments for insomnia in the general and disability populations are melatonin, valerian, and kava.

Melatonin

Melatonin is a hormone that is believed to help regulate the body's circadian rhythm. It is primarily produced in the pineal gland, which is the part of the brain connected by the suprachiasmatic nucleus to the retina. Small amounts of melatonin are also synthesized directly in the retina and gastrointestinal tract. Melatonin is synthesized from the dietary amino acid, tryptophan, with the neurotransmitter serotonin as one of the intermediate steps. Melatonin's production is directly related to perceptions of light and darkness within the environment. When perception of light is transferred from the retina to the pineal gland, melatonin is not produced. When perception of darkness is transferred, melatonin is synthesized. Melatonin is almost exclusively metabolized through the liver, with a small portion excreted in urine (Buscemi et al., 2004; Shamseer & Vohra, 2009).

Synthetic melatonin is a dietary supplement that has been used to help initiate sleep in individuals with disturbed sleep–wake cycles. Studies have shown that exogenous melatonin crosses the blood–brain barrier and requires 30–60 min to initiate sleep onset. Several theories exist regarding the mechanism by which exogenous melatonin exerts its effects. Exogenous melatonin may work by decreasing core body temperature, directly affecting the parts of the brain involved in sleep–wake cycles, and/or by phase-shifting the endogenous circadian pacemaker. The potential side effect profile of melatonin includes nausea, headache, dizziness, and fatigue (Buscemi et al., 2004; Hollway & Aman, 2011).

Research

A recent meta-analysis of the efficacy of melatonin included 16 studies in adults and three studies in children. This meta-analysis found that melatonin caused a statistically significant, although somewhat modest, reduction in sleep-onset latency, and increase in sleep quality, and total sleep time over the use of placebo. No significant adverse events were reported (Ferracioli-Oda et al., 2013).

To date, there have been several well-controlled trials of melatonin in children with sleep-onset insomnia and neurodevelopmental disabilities. One of the earliest studies showed that in a randomized, double-blind, placebo-controlled 6-week trial of melatonin in 20 children with developmental disabilities, there was statistically significant improvement in time to onset of sleep with melatonin versus baseline and placebo (Dodge & Wilson, 2001). In a recent meta-analysis of 13 controlled trials in children with developmental disabilities, it was found that melatonin significantly improved sleep in 424 children who had sleep-onset insomnia (Hollway & Aman, 2011). Melatonin doses ranged from 1 mg to 7.5 mg in these studies. Three of the studies included in this meta-analysis specifically included children and adolescents with intellectual disability. Other conditions included in the meta-analysis were ASD, ADHD, tuberous sclerosis, Rett syndrome, and Angelman syndrome. The sample sizes of the 13 studies ranged from 7 to 107 patients, and effect sizes ranged from 0.25 to 1.63 for onset of sleep and from 0.25 to 1 for total sleep time (Hollway & Aman, 2011). Side effects were mild and were not significant in comparison to placebo.

The authors of the meta-analysis acknowledge that one earlier study found exogenous melatonin to be ineffective in children with intellectual disability. Camfield, Gordon, Dooley, and Camfield (1996) conducted six “N of one” double-blind, placebo-controlled trials with melatonin. The researchers found that doses between 0.5 mg and 1 mg melatonin did not improve total sleep time or decrease the number of nighttime awakenings in these *N* of one trial. No data were reported regarding time to onset of sleep, and the dosages of melatonin used in the study were lower than that in subsequent studies. For these reasons, this study may not provide the most accurate assessment of melatonin’s efficacy in children with intellectual disability and sleep-onset insomnia.

The use of melatonin has also been examined specifically within an ASD population. Three randomized, double-blind, placebo-controlled trials demonstrated improvement in sleep onset in children and adolescents with ASD (Garstang & Wallis, 2006; Wirojanan et al., 2009; Wright et al., 2011). In addition to small sample sizes, which ranged from 7 to 16 patients, these studies all lacked an intent-to-treat analysis. Given that all three of the studies had a significant drop-out rate, the absence of such an analysis negatively impacts the ability to draw evidence-based conclusions from the work (Guénolé et al., 2011).

There are fewer studies of melatonin in adults with intellectual disability. Braam et al. performed a randomized, placebo-controlled study of melatonin that included 30 individuals with intellectual disability between ages 2 and 19 years, and 24 individuals with intellectual disability between ages 20 and 78 years. This study showed that melatonin treatment significantly improved time to onset of sleep and total sleep time (Braam, Didden, Smits, & Curfs, 2008).

Extended-release preparations of melatonin have recently been developed. These formulations are thought to help those with both sleep-onset insomnia and sleep maintenance insomnia. To date, there have been no clinical trials examining the safety or efficacy of extended-release preparations of melatonin in individuals with intellectual disability.

Valerian

Valerian is a herbal supplement composed of extracts from the roots of perennial plants in the genus *Valeriana*. The most common plant used in Western medicine is *Valeriana officinalis* (Wheatley, 2005). Other forms that may be used include *Valeriana edulis* (Mexican valerian) and *Valeriana wallichii* (Indian valerian). The most common method for preparing the extract is soaking the dried root and rhizome (the portion of the stem that is underground) in one of three possible solutions: water, ethanol and water, or methanol and water. The relationship between the type of extraction used and the degree of physiological effects of valerian is not thoroughly understood (Taibi, Landis, Petry, & Vitiello, 2007).

The exact mechanism of action of valerian is unknown, although it is thought to interact with the inhibitory neurotransmitter gamma amino butyric acid (GABA) (Francis & Dempster, 2002). The usual therapeutic dose of valerian is 600 mg per day (Wheatley, 2005). No significant side effects have been reported with use of valerian, including in patients who ingested 20 times the recommended dose (Willey, Mady, Cobaugh, & Wax, 1995).

Research

The most thorough and recent review of the safety and efficacy of valerian was an analysis of 29 controlled trials. The majority of the studies that were reviewed in this analysis found no significant differences between valerian and placebo, particularly in the trials that were the most methodologically rigorous. No significant adverse events occurred. The authors noted that there was wide variation in the preparations of valerian administered to patients (Taibi et al., 2007).

In a double-blind, cross-over study of the effects of valerian in children with intellectual disability, 500 mg was shown to significantly improve the time required to fall asleep and the total sleep time as compared to placebo. The study was limited by a small sample size of five children and by the finding of a positive placebo effect in parent-rated sleep quality measures (Francis & Dempster, 2002).

Kava

Kava, also sometimes referred to as kava-kava, is an extract from the plant *Piper methysticum.* It has been shown to decrease anxiety and increase sedation (Singh & Singh, 2002). The mechanism of action of kava is not fully understood, but it has been theorized to include blockade of voltage-gated sodium ion channels, enhanced binding to GABA type A receptors, reduced excitatory neurotransmitter release, and potentiation of anxiety-relieving neurotransmitters norepinephrine and serotonin (Grunze & Walden, 1999; Singh & Singh, 2002). The therapeutic dose of kava is 120 mg per day. Adverse effects of kava include hair loss, rashes, ataxia, jaundice, weight loss, difficulty breathing, vision loss, and hearing loss (Wheatley, 2005). One particularly dangerous potential side effect of kava is hepatotoxicity. Between 1990 and 2002, there were 39 reported cases in Germany of adverse hepatic reactions after ingestion of kava, including several cases of fulminant liver failure requiring liver transplantation and three deaths (Stickel et al., 2003).

Research

There are currently two studies that address the efficacy of kava in individuals with insomnia. One study examined 19 adults who initially received 120 mg kava per day and who subsequently received 600 mg of daily valerian (Wheatley, 2001). The results were reported as statistically significant improvement in insomnia with both kava and valerian. Methodological limitations may prevent this conclusion from being accepted with confidence. The other study was an internet-based, randomized, placebo-controlled trial of kava and valerian for anxiety and insomnia (Jacobs, Bent, Tice, Blackwell, & Cummings, 2005). In addition to difficulty proving that the study inclusion criteria were reliably met when one is using an anonymous, Internet-based sample, the results of this study showed that neither kava nor valerian significantly improved symptoms of insomnia in comparison to placebo. There have been no studies to date that specifically examine kava as a treatment for insomnia in individuals with intellectual disability.

Conclusions and Practice Recommendations

Given the existing literature, and in light of its minimal side effect profile, melatonin serves as a reasonable option for clinicians seeking to treat children, adolescents, and adults with intellectual disability who have sleep-onset insomnia. Research on the use of valerian in the general population suggests that it is most likely safe but ineffective, and there is limited data on the use of valerian in individuals with intellectual disability. As such, the existing evidence does not support valerian as a treatment for insomnia in individuals with intellectual disability. Due to the lack of evidence for effectiveness, and most importantly, the risk for significant side effects, kava cannot be recommended for use as a sleep aid in individuals with intellectual disability.

Physical and Training-Based Interventions

Sensory Integration Treatment

Sensory integration (SI) treatment is an approach to physical/occupational therapy practice that emerged in the 1970s in response to the observation that many children with developmental conditions show over- or under-sensitivity to sensory input from the environment. SI treatment is based on the theory that altered sensory sensitivity reflects inadequate processing of sensory information at lower brain levels, resulting in alterations in higher brain function that ultimately contribute to limitations in adaptive behavior and learning. It is further presumed that intervention that expose children to enriched sensory experiences in a controlled fashion provide practice integrating/organizing incoming sensory information, leading to improved higher brain function resulting in improved adaptive behavior and learning (Schaaf & Miller, 2005; Williams & Erdie-Lalena, 2009). The theoretical basis for SI practice was first developed by Ayers (1972) based on the following general principles: (1) sensorimotor development is an important prerequisite for learning, (2) the interaction of the developing child with the environment shapes brain development, (3) the young nervous system is "plastic," and (4) meaningful sensorimotor experience can therefore positively impact brain development. More specifically, she concluded that adequate integration of sensory input from vestibular, proprioceptive, auditory, and tactile systems at the brainstem level is important for optimal cortical function and learning. SI therapy typically incorporates activities with prominent tactile, vestibular, and proprioceptive components, using various items such as hammocks suspended from the ceiling, containers of textured material, ball bins, ramps, scooter boards, and various objects on which to spin or climb.

SI practice is based on a series of treatment principles: (1) The *just right challenge*—The therapist is to create playful activities at a level that challenges a child to a degree at which they can have a new experience but still be successful; (2) The adaptive response—The child *adapts* to the just right challenge using *new behavior/strategies* thereby advancing development; (3) Active engagement—The therapist creates enticing, play-based sensory activities so that the child is *actively engaged* to maximize processing and learning; and (4) Child-directed—The therapist observes, uses the child's cues, and *follows the child's lead* to create these play-based sensory activities.

Although the theoretical basis of SI therapy has not changed since Ayers (1972) developed it in the 1960s and 1970s, SI practice has evolved in several ways. First, although she developed SI treatment for children with learning disabilities, Ayres and others noted the presence of sensory differences in other populations as well, most notably children with autism, who have become the most commonly studied and treated population. Children and adults with intellectual disability or motor delay and children with ADHD or environmental deprivation are also included in some studies. Ayers first developed the practice of SI therapy based on a battery of tests (the Southern California Sensory Integration Tests, the Southern California Post-Rotatory Nystagmus Test, and the Sensory Integration and Praxis Tests) (Hoehn & Baumeister, 1994) which include measures of specific motor and sensory characteristics, postural reactions, eye–hand coordination, and nystagmus in response to body movement. The specific pattern of findings was used to determine the type of sensory integration dysfunction, which was linked to specific "learning disability" types including vestibular and bimanual integration problems, apraxia, tactile defensiveness, left hemisphere dysfunction, and right hemisphere dysfunction (Clark & Shuer, 1978).

Miller, Anzalone, Lane, Cermak, and Osten (2007) proposed a new classification system with sensory processing disorder divided into three subtypes: sensory modulation disorder, sensory discrimination disorder, and sensory-based motor disability. Sensory modulation disorder is further subdivided into overresponsive, underresponsive, and sensory-seeking/craving subtypes while sensory-based motor disability is divided into postural disorder and dyspraxia. The development of parent questionnaires for identifying symptoms and the book *The Out-Of-Sync Child* (Kranowitz, 1998) increased awareness of SI symptoms and therapy among clinicians and parents, but this also moved the field away from test-based assessments of symptoms and test result-based therapy plans. Since Ayers (1972) original description of theory and practice, a wide range of procedures have been used in studies, often not clearly described, or else a single preselected procedure is used on all subjects. Finally, although originally envisioned as an ongoing therapeutic process to modify brain function, some therapists use individual sessions of SI therapy to modify immediate subsequent behavior in the short term, a process which has received very little systematic study.

Research

The theoretical basis for SI therapy remains controversial. Although Ayers (1972) original four general principles are consistent with current understanding of experience-based brain plasticity, the more specific assumptions that stem from these principles are not necessarily supported by evidence. Hoehn and Baumeister (1994) challenged several of the assumptions on which SI therapy is based, including validity of the tests Ayers developed to assess sensory integration and classify learning disabilities, the meaning and measurement of post-rotatory nystagmus, and the relationship of vestibular function to learning. They concluded that there is insufficient validity of either the diagnostic procedures or the treatment programs based on SI theory.

Research in Children with Learning Disabilities

Two large-scale reviews focused on this group. Ottenbacher (1982) reviewed 49 studies of SI treatment and found 8 that met minimal standards of study design (two included children and adults with ID). These studies included a least two groups: an SI treatment group and a no-treatment control group. Dependent variables included motor or reflex measures, academic skills, and language. Overall, results suggested a positive effect of SI therapy, greater on motor than cognitive outcomes, and greater for individuals with LD than those with ID. However, design flaws in the original studies, as well as the way in which they were combined in this meta-analysis leave this conclusion open to criticism. Individual studies had deficiencies in subject sampling, group allocation, and blinding of those conducting treatment and assessments. The meta-analysis compared SI to no treatment, even though several studies included an alternate treatment control group that typically showed similar improvement to the SI group, raising the possibility that improved outcomes were related to some common factor shared by treatment groups rather than a unique effect of SI treatment.

A later meta-analysis conducted by Hoehn and Baumeister (1994) included seven subsequent studies. This meta-analysis included only studies of children with LD and a more careful statistical analysis of the results was undertaken, but not all studies included a no-treatment control group. Vestibular system functioning, as measured by duration of postrotatory nystagmus, was mixed among studies, with some subjects showing an increase and others showing no change or a decrease, however, subjects were not uniform in showing the expected (based on Ayers' [1972] theoretical framework) lower pretreatment duration of post-rotatory nystagmus. On other measures of sensorimotor, perceptual, and motor performance, there was an improvement in pretest to posttest performance, but no significant difference by treatment group. Likewise, on cognitive, language, and academic measures, there was no evidence for positive effects specific to SI treatment.

Miller, Coll, and Schoen (2007) studied 24 children with (primarily) ADHD and/or learning disabilities in a randomized, controlled pilot study that included no treatment and alternative (activity-based) treatment groups. Outcome measures, obtained before and after twice-weekly therapy for 10 weeks, included parent ratings of attention, social, cognitive, behavioral, and adaptive characteristics, progress toward goals and electrodermal skin conductance (a measure of sympathetic nervous system activity). Improvements were greater overall in the SI vs alternative treatment control group and in this group compared with the no treatment group, though there were few statistically significant findings. Lack of blinding of parents and providers was a significant weakness of this study. The authors calculated the need for 64 individuals per group in order to detect an improvement of 0.5 standard deviations. To date, we are aware of no studies of this size.

Research in Children with Intellectual Disabilities

Although not widely studied in this population, Pothier and Cheek (1984) found that 24 % of directors of motor programming services in 625 facilities serving developmentally delayed infants and children reported having a theoretical framework that was consistent with SI treatment, suggesting that, in spite of limited study, it is widely used in this population. A position paper on behalf of the American Occupational Therapy Association (Hinojosa, Anderson, Goldstein, & Becker-Lewin, 1982) stated that there was evidence to support this type of treatment in children with learning disabilities and autism, which likely contributed to increased use in these and additional populations. In the ID population, it has also been used in an attempt to reduce self-injurious and stereotypic behavior, in addition to improving motor function and adaptive skill development.

The early studies of individuals with ID also tended to be limited by methodological flaws such as small numbers, the absence of good control groups or blinding of those who did the assessments (Clark, Miller, Thomas, Kucherawy, & Azen, 1978; DePauw, 1978; Kantner, Clark, Allen, & Chase, 1976; Morrison & Pothier, 1972). In single case studies, changes in behavior in the period right after treatment and deterioration in behavior after withdrawal of treatment were interpreted as support for the effect of SI treatment, but this contradicts the theoretical framework of increased neural organization as a result of therapy, which would not be expected to lead to immediate positive changes or rapid reversals in behavior (Kantner et al., 1976; Sandler & Coren, 1980; Wells & Smith, 1983). Studies with comparison groups (usually receiving another type of motor or operant behavior therapy) typically showed improvement that was similar to that of the group receiving SI therapy (Clark et al., 1978; Jenkins, Fewell, & Harris, 1983). In addition, there tended to be similar improvement across all outcomes within a study (motor, social, or language) (Clark et al., 1978; Jenkins et al., 1983). Some studies did find SI therapy to be superior to more traditional motor approaches even when social attention and interaction with a trained provider were controlled for (Montgomery & Richter, 1977; Morrison & Pothier, 1972), but the absence of blinded before- and after-treatment assessments remains a significant concern.

A meta-analysis by Vargas and Camilli (1999) included studies of SI treatment published between 1972 and 1994 in patients with LD, ID, minor brain dysfunction, aphasia, motor delay, adult psychiatric patients, and other patients with developmental risk. The majority of studies assessed effects on children with learning disabilities. Case studies, single group studies, and laboratory simulation studies were excluded. There were a total of 16 studies comparing SI with no treatment ($N = 341$ subjects, 237 controls) and a total of 16 studies comparing SI with alternative treatment ($N = 250$ subjects, 191 controls). Outcomes were coded as psychoeducational, motor, behavior, language, or sensorimotor. More careful statistical analysis was undertaken with type and quantification of outcome measures encoded for comparison across studies, variables related to quality of treatment and study design accounted for, and effect sizes calculated and adjusted for sample size. The average effect size for SI treatment compared with no treatment was 0.29, but when divided into earlier (1972–1982) and later (1982–1994) studies, the effect sizes were 0.6 and 0.03, respectively. The greatest effects in the earlier studies were seen on psychoeducational and motor variables. The average effect size for SI vs another treatment was 0.09, this did not show heterogeneity across time, and all outcome measures improved similarly. This is similar to findings in the meta-analysis of studies specifically evaluating studies of SI treatment in individuals with ID.

Given methodological limitations, the fact that most studies did find positive results with SI therapy, though not unique to SI therapy, lead Arendt, MacLean, and Baumeister (1988) to assert that some other factor(s) related to therapy might be responsible, such as maturation, placebo, Hawthorne, or positive reinforcement effects. In summary, some evidence supports SI treatment leading to positive change in motor function in some children with ID, but the positive effects are not specific to SI therapy, and do not appear to differ from those of other therapies, and thus it is most likely that some shared characteristics of therapy, not SI-induced reorganization of the nervous system, leads to these positive results.

Research in Children with Autism/Autism Spectrum Disorder

ASD is perhaps the most common diagnosis associated with sensory integration deficits. SI symptoms have been added to the Diagnostic and Statistical Manual (American Psychiatric Association, 2013) as one of four categories of restricted or repetitive behaviors of which at least two must be present in order to make the diagnosis. Studies and reports published prior to and including 1999 were reviewed by Dawson and Watling (2000) who found only four studies that specifically evaluated outcome after SI therapy. These included small numbers (the total *N* for four studies was 26) leading to difficulty drawing conclusions, though some had positive outcomes in socialization and language use. The authors noted that they did not find any studies that evaluated the effects of standard occupational therapy in children with ASD.

A meta-analysis by Lang et al. (2012) included 25 studies and 217 participants aged 2–12 years with ASD. Information about intellectual status was not provided in most studies, but a substantial number had ID in those that included this information. All studies involved some form of SI treatment designed to address identified outcome variables; however, most had small numbers and inadequate controls. Evidence was deemed suggestive, preponderant, or conclusive. Overall, three studies were deemed to show suggestive positive effects, eight had mixed results, and 14 showed negative results, leading the authors to conclude that there was no consistent positive effect of SI treatment in children with ASD.

A highly rigorous research program in this area, developed in a stepwise fashion over several years has resulted in a randomized, controlled trial of sensory integration treatment that is both manualized and individualized, and which shows positive results in comparison to usual care controls after 30 sessions of therapy over 10 weeks (Schaaf et al., 2014) in 32 4- to 7-year-old children with autism. “Gold standard” assessments for autism and cognitive level, clear descriptions of sensory processing symptoms using standardized methods, sample size determination, establishment of group equality at outset, data collection about “usual care” intervention, highly skilled and blinded assessors, careful randomization procedures, and intervention fidelity checks make this the most rigorously conducted study to date. The primary outcome measure, change in Goal Attainment Scales, used parent-identified goals that were quantitatively defined in a standardized manner, allowing both sensitivity to individual outcomes and comparison between groups. Additional outcome measures included a variety of parent rating scales measuring mobility, social function, independence, autism-related behaviors, and adaptive skills. SI treatment was significantly better than usual care on goal attainment, independence, social function. There was better, though not significantly better, improvement on the sensory-perceptual subscale of the autism-related behavior measure and the adaptive skill measure in the treatment group. The main weakness of this study was dependence on unblinded parent ratings for outcome measures. It should also be noted, based on mean and range IQ scores, that at most a small minority of these subjects have ID.

Conclusions and Practice Recommendations

While many children with a variety of disabilities, including intellectual disability, show differences in sensory processing, there continues to be concerns about the validity of the specifics of SI theory and the measurement of SI "ability." Adaptive human behavior is assumed to be evidence of good sensory integration while maladaptive behavior is assumed to be evidence of poor sensory integration, while there are no tests that clearly discriminate sensory integration from adaptive behavior (Hoehn & Baumeister, 1994). The manualized type of intervention that best lends itself to research contradicts the individually determined therapy espoused by the core principles of SI treatment. No treatment controls are particularly difficult to establish over an extended period, especially in childhood when brain plasticity is an accepted principle and therapies exist with better-documented efficacy for certain outcomes that SI therapy is proposed to treat (such as operant behavior therapy and speech-language therapy). The vast majority of studies of individuals with the variety of developmental diagnoses are plagued by small numbers, limited controls, and inadequate blinding. Nonetheless, some studies suggest at least equal benefit, especially for motor symptoms. SI research is most active and advanced in children with ASD.

We recommend that parents and caregivers consider the following four recommendations. (1) Consider any safety concerns. SI treatment can provide intense stimulation to sensory systems. Individuals with medical conditions that may make them vulnerable to complications of tachycardia, orthostatic symptoms, excessive sweating, increased intracranial pressure, etc. should be carefully monitored. (2) Clear outcome goals should be established, anticipated progress toward goals and treatment duration should be discussed in advance, and periodic monitoring of progress should be reviewed. (3) When other therapies have better-documented effectiveness for particular outcome targets, care should be taken not to lose the opportunity to participate in these therapies as a result of participating in SI treatment. (4) The American Academy of Pediatrics suggests that SI disorder not be considered a specific disorder until so proven, but that the additional disorders it typically accompanies (ASD, ADHD, motor and deprivation conditions) be sought and remediated with evidence-based therapies (American Academy of Pediatrics, Section on Complementary and Integrative Medicine and Council on Children with Disabilities, 2012).

Therapeutic Horseback Riding and Hippotherapy

Reports of the use of animals in the therapeutic process extend back for centuries and horses have been used in the therapeutic process for individuals with disabilities for over 30 years. There are three different types of practices and two of these will be discussed in this section. Therapeutic horseback riding (THR) refers to instruction in recreational horseback riding by trained instructors that provides individuals with disabilities a variety of sensory-motor, perceptual-motor, and gross motor experiences with the goal of improving skills. Hippotherapy refers to the use of horseback riding by physical and occupational therapists to produce specific physical movements in response to the horse's movements with the goal of improved balance, posture, mobility, and functional skills. Studies of these two types of horseback riding are often included together in meta-analyses and reviews. The third use of horses in therapy is equine-assisted psychotherapy alternately referred to as equine-facilitated therapy. This involves the use of horses (gaining the trust of, caring for, learning to manage) in the psychotherapeutic process, and has most commonly been used in individuals with anxiety, depression, post-traumatic stress disorder, and autism. Since psychotherapeutic practice is beyond the scope of this chapter, this type of therapy involving horses will not be discussed but reviews are available (Masini, 2011; O'Haire, 2013).

Research

THR/Hippotherapy in Individuals with Cerebral Palsy

THR/hippotherapy has most often been studied in children with cerebral palsy. The rider experiences passive movements in three dimensions that mimic the pelvic movements required for walking, gaining experience with the trunk stability, posture, and pelvic mobility required for ambulation. Thus, there is a sensible rationale for consideration of this type of therapy for children with challenges to ambulation. Several reviews and meta-analyses of THR/hippotherapy (Snider, Korner-Bitensky, Kammann, Warner, & Saleh, 2007; Sterba, 2007; Tseng, Chen, & Tam, 2013; Whalen & Case-Smith, 2012; Zadnikar & Kastrin, 2011) have been completed, and some of the included studies overlap. When performed at least weekly over several weeks, this type of therapy can improve muscle tone and activity and postural control, but may (Snider et al., 2007; Sterba, 2007; Whalen & Case-Smith 2012) or may not (Tseng et al., 2013) improve functional gross motor outcomes, specifically ambulation. When compared with other forms of physiotherapy, it is not consistently superior (Zadnikar & Kastrin, 2011). When therapy is withdrawn, gains are likely to be lost (Snider et al., 2007).

Several individual studies provide some detail. For example, Sterba, Rogers, France, and Vokes (2002) studied school-aged children with various distributions of spastic cerebral palsy in a 6-week pre-riding control period, 18 weeks of 1 h weekly THR, and 6 weeks after completion. Each child served as his own control, and assessors were blinded to the riding condition. The Gross Motor Function Measure (GMFM) includes 88 items grouped into five dimensions: Lying/Rolling, Sitting, Crawling and Kneeling, Standing, and Walking/Running/Jumping. No improvement occurred during the pre-riding period. Improvements of approximately 8 % occurred in the overall GMFM and in the Walking dimension at 12–18 weeks, but these gains were substantially lost by 6 weeks post-treatment. Kwon et al. (2011) found improvements in pelvic and hip kinematics as well as ambulation parameters and the GMFM in children with spastic cerebral palsy who received 8 weeks of hippotherapy plus conventional physiotherapy versus a control group who received conventional physiotherapy alone; however, the experimental group received twice as much time in therapy. Silkwood-Sherer, Killian, Long, and Martin (2012) noted improved balance compared with baseline after 6 weeks of hippotherapy (45 min twice weekly) on the Pediatric Balance Scale in a group of 16 5- to 15-year-olds with a variety of diagnoses including cerebral palsy, ASDs, Down syndrome, and other neurologic conditions. There was also a statistical improvement on a measure of participation in daily activities, though to a smaller and more variable degree. This was the first study to report on improved functional outcomes beyond ambulation. Others have also noted improvements in pelvic positioning in children with a variety of neurologic conditions, assessed by changes in gait analysis pre- and post-treatment (Encheff, Armstrong, Masterson, Fox, & Gribble, 2012).

Overall, although the current level of evidence remains limited by small numbers, quality of research design, especially lack of control groups and blinding, and limited knowledge about the relationship of the pretreatment level of gross motor function to likelihood of improvement, it appears that 8–10 weeks of at least weekly THR/hippotherapy is likely to improve the range of motion, postural control, and coordination that are precursors for improved functional motor skills (Whalen & Case-Smith, 2012). The studies that reassessed after a final no-treatment period suggest that gains are not maintained when therapy is discontinued, so it will be important in future research to confirm findings with more rigorous research designs and determine who improves and how to sustain initial improvements.

THR/Hippotherapy in Individuals with Autism

The use of animals in the therapeutic process for individuals with autism has resulted in studies of language, social, and adaptive outcomes in addition to the primarily motor outcomes studied in individuals with cerebral palsy. Most of these studies are limited by small numbers, single-case (pre–post) design lacking adequate controls, and inadequate or no blinding of the raters. Outside therapies typically continue and with little to no accounting for their variety or intensity. There is typically little information about the baseline abilities of the subjects, including intellectual ability. Thus, though uniformly suggesting positive outcomes, lack of methodological rigor makes these conclusions tenuous.

An extensive review of the wide range of animal-assisted interventions for individuals with ASD resulted in 14 articles in English from peer-reviewed journals that included original, empirical data in individuals with autism, Asperger's disorder, or pervasive developmental disorder-NOS of all ages, though the vast majority were children and adolescents (O'Haire, 2013). This author's overall conclusion was that despite unanimously positive outcomes (using various measures of communication and social interaction), methodological weaknesses limited conclusions. She also noted that standardized outcome measures were rarely used and none of the measures were used more than once to replicate results across studies.

Some individual studies are notable for their unique contributions. The focus of a small, single case (pre–post) design pilot study by Ajzenman, Standeven, and Shurtleff (2013) was on adaptive behavior and child participation in daily activities as rated by parents. Due to lack of controls and blinding, the positive results of parent ratings are not proof of treatment effectiveness; however, a pre–post motor assessment of pelvic motion using force plates and video motion analysis provides a unique method of quantitatively evaluating changes in pelvic motion. Kern et al. (2011) studied the effects of a riding program on autism severity based on a standardized parent questionnaire obtained by a blinded interviewer. This was also a single-case (pre–post) design, but it included the advantage of a no-treatment "wait" period and multiple assessments—upon enrollment, after a 3–6 month wait period to assess the effects of no intervention, and after 3 months and 6 months of intervention. Kent et al. concluded that there was no improvement in autism symptoms during the wait period, but there was improvement after 3 months and 6 months of treatment. However, careful review of the data suggests that inadequate power to detect change in the ratings during the wait period, or to determine whether any further positive change occurred from 3 to 6 months of treatment may mitigate the positive conclusion.

THR/Hippotherapy in Individuals with Intellectual Disability

There is little information available about this therapy in individuals specifically with ID; however, the higher rate of inactivity, reduced physical fitness, poor balance, and risk of falls resulting in injury in this population makes the study of treatment options important (Giagazoglou, Arabatzi, Dipla, Liga, & Kellis, 2012). Case reports of two young children with Down syndrome suggest improved postural control and gross motor function (Champagne & Dugas, 2010) and a 7-week treatment with pre/post measures of gross motor function in seven children with developmental delay showed improvement that remained for an additional 7 weeks after treatment ended (Winchester, Kendall, Peters, Sears, & Winkley, 2002). Giagazoglou et al. (2012) performed a randomized, controlled trial of 10 weeks of twice weekly hippotherapy in 19 adolescents ($N = 10$ experimental and nine controls) with moderate ID. Measures of balance and strength improved, but functional gross motor activities were not assessed. Borrioni et al. (2012) studied physical and psychosocial outcomes in adults with ID before and every 3 months during 12 months of equestrian therapy. Effects on measures of autonomy and social integration improved to a greater degree than motor-praxis function, with maximal improvements at 6 months for most measures and rapid declines in motor, but not other functions, after discontinuation. Though not controlled or blinded, this study is unique in its focus on adults, functional orientation, and in the combination of motor and psychosocial outcomes assessed.

"Simulated" THR/Hippotherapy

Simulated hippotherapy uses a mechanical "horse" to provide the motor-equivalent of horseback riding in what may be a more convenient, less expensive and labor-intensive environment. These studies, one in children with cerebral palsy (Herrero et al., 2012) and one in children with autism (Wuang, Wang, Huang, & Su, 2010) lessen the "human factor" of the involvement of a trainer and parents, and the experience of participating in an outdoor experience with others participating in the same activity. They are also more methodologically rigorous. Herrero et al. (2012) studied the therapeutic effects of a 10 week (15 min per weekly session) simulated hippotherapy program and a single-blind, randomized, controlled design in 4- to 18-year-old individuals with cerebral palsy. They found positive effects on sitting balance/postural control, but not on overall gross motor function. The improvement in balance/postural control was not maintained 12 weeks after completion of the intervention.

Wuang et al. (2010) studied sensorimotor outcomes in 60 6- to 8-year-old children with autism. Half received simulated therapy twice weekly (for 1 h per session) plus their regular occupational therapy for 20 weeks while the other half received their regular occupational therapy alone. The treatments were reversed for the subsequent 20 weeks. Assessors were blinded, fidelity of treatment was insured, and the two groups did not differ at the outset. Treated children showed improved scores on gross and fine motor skills and on an overall measure of multiple symptoms considered to reflect sensory integration. Gains made by the first group after therapy were sustained for the subsequent 20 weeks. This program of therapy followed a specific sequence of developmental skills that was individualized based on the child's skills at the outset, and included warm up exercises on the floor, followed by exercises on the "horse," followed by game-like activities on the "horse" that involved interaction with the therapist and adjustment to his/her movements. This was clearly a more intensive treatment than most.

Conclusions and Practice Recommendations

The level of evidence needed to be confident that this treatment is evidence-based does not exist, but available evidence is promising, primarily in terms of motor function. The role of this treatment in improving the broader range of social, communicative, activities of daily living, and quality of life measures is more difficult to document; however, it may have the advantage of improving quality of life by providing therapy in the context of participation with non-disabled peers. In addition, it has been suggested that some individuals with ASD may have a unique affinity for interaction with animals that may make animal-assisted therapy a particularly promising approach for them (O'Haire, 2013).

If this treatment is pursued, a certified riding program for individuals with disabilities should be sought in order to insure optimally safe procedures and knowledgeable staff. Given the high risk for loss of gains when therapy is discontinued, it seems important to (1) identify specific, attainable goals and (2) identify mechanisms for engaging in regular activities that support the maintenance of gains.

Hyperbaric Oxygen Therapy

Oxygen is both necessary for cellular survival and toxic in excess. The application of oxygen, either at concentrations higher than 21 %, or at higher than atmospheric pressure (hyperbaric oxygen therapy, HBOT), or both, has been used to improve nervous system function in several conditions. These include ischemic stroke, traumatic brain injury, carbon monoxide poisoning, near drowning, radiation encephalopathy, status migrainosus, and air embolism. There is evidence that increasing the concentration of oxygen to the lungs at increased pressures does increase brain tissue levels of oxygen, and when applied within 2 h of an acute brain insult, it can decrease the severity of brain damage (Nemoto & Betterman, 2007). The question of whether these treatments can improve cognitive function in chronic static encephalopathy is a different question and one that remains largely unanswered.

Research

Breathing increased concentrations of oxygen increases blood O2 saturation and appears to improve immediate and delayed word recall, and measures of attention and vigilance in healthy young adults (Moss, Scholey, & Wesnes, 1998), visual-spatial task performance and brain activation by fMRI in young male adults (Chung et al., 2004), and decreases reaction time, (but not accuracy), on a continuous performance task in children with ADHD (Kim et al., 2012). Oxygen applied just before, during, or just after the task appears to enhance memory formation for up to 24 h, but has no effect when applied 10 min before or after the task or just before or after the test (Moss & Scholey, 1996; Scholey, Moss, & Wesnes, 1998). These experiments demonstrate an effect on memory formation but not retrieval, and they do not measure whether there is sustained improvement in tested skills.

HBOT has been shown to attenuate acute damage to the CNS (Nemoto & Betterman, 2007; Rockswold, Rockswold, Zaun, & Liu, 2013; Singhal, 2007) and attenuate radiation toxicity (Kuffler, 2012). A prospective, randomized, phase II clinical trial of prompt, brief treatment with HBOT alternating with increased inspired O2 concentration at normal pressures in patients with TBI resulted in improved markers of oxidative metabolism in areas bordering the injured area, decreased intracranial hypertension, and improved morbidity and mortality (Rockswold et al., 2013). In addition, it may decrease inflammation (Rossignol & Rossignol, 2006). In a randomized, prospective, controlled (though not blinded) trial of late HBOT treatment 6–36 months after a stroke, clinical improvement in neurologic function, ADLs, and quality of life was demonstrated after treatment, but not after a control wait period. Improvement was correlated with increased activation on SPECT scans of brain regions shown at baseline to have intact structure by CT scan, but low activity by SPECT (Efrati et al., 2013). This suggests that HBOT may be inducing neuroplasticity long after the injury.

In a rat model of neonatal hypoxic-ischemic injury, HBOT resulted in less apoptosis and brain atrophy, and better sensorimotor function 5 weeks after the injury (Calvert et al., 2002). Thus, there is some evidence that HBOT, with or without increased O2, can improve brain physiology and clinical function following an acute insult, and there is some evidence that it can induce beneficial neuroplasticity in brain regions that are underactive as a result of previous injury. Finally, there is some evidence that breathing an elevated concentration of O2 can improve some measures of cognitive performance.

Research in Developmental Disabilities

Compared with TBI and stroke, there has been relatively little research about oxygen therapy in children with developmental disabilities. A blinded, randomized, controlled trial of 111 children with cerebral palsy demonstrated no difference between children receiving 40 treatments of 1.3 atmospheres (atm) of air (controls) and those treated with 1.75 atm of 100 % O_2. Both groups improved on measures of cognition, communication, memory, and gross motor skills over the course of the study suggesting that Hawthorne or other treatment effects were responsible (Collet et al., 2001; Hardy et al., 2002).

Given recent evidence for oxidative stress, neuroinflammation, and areas of under-active cerebral cortex in individuals with ASD, there have been several investigations of variable experimental rigor in children with ASD. These studies either showed improvement of questionable clinical significance, equal improvement in control and treatment groups, or no improvement (Lerman et al., 2008; Rossignol et al., 2009; Rossignol, Rossignol, James, Melnyk, & Mumper, 2007). A recent randomized, double-blind, placebo-controlled study of HBOT (80 sessions over not more than 15 weeks) in 34 children with ASD was designed with matching for other treatment, intent to treat analysis, and a variety of parent, clinician, and direct assessment outcome measures. There was no difference on any outcome measure between those treated with 1.3 atm of 24 % O2 ($N = 18$) and those treated with air at 1 atm ($N = 16$) (Granpeesheh et al., 2010). Intellectual ability was not reported in any of the studies of children with cerebral palsy or autism.

Kim et al. (2013) treated adults with ID (aged 30 ± 6 years) with 92 % vs. 21 % O2 at normal pressure and found decreased reaction time, but no significant increase in accuracy on a simple matching task during the oxygen administration. Given previous studies, the relevant question would be whether HBOT or increased inspired O_2, at a level that activates areas of under-active cortex can be safely administered, and whether this leads to a meaningful improvement in function that persists over time, after treatment had ceased. Safety considerations include barotrauma to the sinuses or middle ear (which may be able to be avoided with attention to acclimatization and monitoring), increased free radical production, and rare reports of seizures (Doherty & Hampson, 2005).

Conclusions and Practice Recommendations

Oxygen therapy has not been shown to be efficacious for improving cognition or skills post-treatment in the setting of chronic disability, in part due to negative data and in part because the most relevant questions in this population have not yet been investigated. HBOT side effects may be significant for some individuals, therefore, it cannot be recommended at this time.

Working Memory Training

The use of computerized programs that present verbal and visual working memory tasks of increasing length and complexity, and that reinforce the participant for persistent practice and increasing success, have been developed and used with the goal of improving working memory. Such tasks have been used primarily with the elderly to ameliorate declines in working memory and with children and adolescents with ADHD. In ADHD, working memory is thought to be a key factor underlying academic underachievement and working memory weaknesses may persist even when behavioral intervention and medication have been used to improve behavior and attention. Although some research groups have developed their own computerized battery of activities, the most commonly researched program was developed by Klingberg et al. (2005) and is commercially available under the name "Cog-Med." In addition to non-disabled individuals across the age spectrum and individuals with ADHD, this program has been used in individuals with brain injury, learning disabilities, Down syndrome, hearing loss, and formerly premature infants.

Research

Research in ADHD

Klingberg et al. (2005) studied 53 medication-free children with ADHD ages 7–12 who were randomly assigned to receive either 5 weeks of progressive computerized working memory training or a comparison program that did not increase in difficulty as the child progressed. A visuospatial task was administered at the beginning of training, at the end of training, and 3 months later as the main outcome measure. There were significant improvements not only in visual working memory as measured by the task, but also in verbal working memory, response inhibition, and complex reasoning. Gains were maintained at the 3 month follow-up. A similar study in children with learning disabilities, many of whom also had ADHD showed a similar response in 52 seven to 17-year-olds, half of whom were wait list controls (Beck, Hanson, Puffenberger, Benninger, & Benninger, 2010). The program was equally effective in students on or not on medication for ADHD, and improvements were sustained at the 4 month follow-up assessment, but the outcome measures in this study were parent and teacher ratings of ADHD symptoms, working memory, planning, organization, and initiating tasks. Parent, but not teacher, ratings reached significance, but parents were not blinded. Several additional studies showed positive responses in school-aged children, but the specific type of outcome measure that did or did not show a benefit (neuropsychological measures, parent and teacher behavior ratings, reading and math performance) was not consistent across studies for reasons that remained unclear (Chacko et al., 2013). They concluded that this treatment is possibly efficacious for youth with ADHD. A subsequent randomized, controlled trial (wait list controls, not blinded) showed a significant improvement in processing speed that was maintained at 8-month follow up, as well as improved reading and math scores (Egeland, Aarlien, & Saunes, 2013). Results of a comprehensive meta-analysis that took into account more complex models of working memory (Rapport, Orban, Kofler, & Friedman, 2013) suggest that what was actually improved in these studies was short-term memory, one component of working memory, and not the "central executive" aspect which includes control of attention and mental manipulation of information, and that blinded behavior ratings and transfer of training gains to academic achievement was, in fact, minimal in the most rigorous research designs.

Studies investigating the biological underpinnings of response to training show increased activation of the prefrontal and parietal cortices, regions of the brain known to be involved in working memory (Olesen, Westerberg, & Klingberg, 2003), accompanied by increased D1 dopamine receptor density in the same regions (McNab et al., 2009). In one study, two single nucleotide polymorphisms located near and in the dopamine type 2 receptor gene were significantly associated with degree of improvement during training (Söderqvist, Matsson, Peyrard-Janvid, Kere, & Klingberg, 2014).

Research in Other Developmental Disabilities

In a non-randomized group of children with ADHD, who were receiving special education intervention for mathematics, the working memory-trained group improved in math performance compared with peers who were not trained, but the improvement was not sustained at follow up approximately 7 months later (Dahlin, 2013). One study indicated that adolescents who were born at extremely low birth weight responded positively to working memory training to a similar degree as term-born controls, and both groups improved in trained and non-trained verbal and executive memory tasks with sustained improvements at 6 month follow-up, whereas non-trained controls did not improve at the end of treatment or 6 weeks later (Löhaugen et al., 2011). One study in formerly very low birthweight preschoolers showed a positive response to working memory training on trained and untrained working memory tasks, auditory attention phonological awareness, visual memory for faces, narrative memory, and sentence repetition (Grunewaldt, Löhaugen, Austeng, Brubakk, & Skranes, 2013). Given the important role of working memory deficits in the academic risks of prematurity, these authors suggested that further prospective studies in formerly premature preschoolers be undertaken to determine whether working memory training can prevent or ameliorate their academic risks. A double-blind, placebo-controlled, randomized controlled trial with follow-up up to 2 years is currently underway, although subjects will be studied at 7 years of age rather than as preschoolers (Pascoe et al., 2013).

Research in Individuals with Intellectual Disability

Van der Molen, Van Luit, Van der Molen, Klugkist, and Jongmans (2010) developed a computerized working memory program analogous to CWMT for adolescents with IQs from 55 to 85 and performed a randomized, single-blind, controlled trial. Ninety-five adolescents aged 13–16 years were studied after 15 sessions lasting 6 min each over 5 weeks of either adaptive (increasing challenge with improvement) or nonadaptive (remains at the easy, beginning level) working memory training or control computer activity (a similar matching activity that did not require memory). Coexisting diagnoses of ADHD, ASD or previous head injury were exclusionary criteria. Visual and verbal short-term memory, verbal and visuospatial working memory, immediate and delayed recall, response inhibition, fluid intelligence and academic testing was carried out prior to the treatment, at the end of treatment, and 10 weeks later. Several measures, including verbal short term memory, improved similarly in both of the trained groups compared with the control group, and this improvement was maintained at follow-up. The group that underwent adaptive training also improved on visual short-term memory. Both trained groups showed additional improvements at follow-up on visual short-term memory, story recall, and mathematics. Increased effects at follow-up, also reported in other studies (Holmes, Gathercole, & Dunning, 2009; Klingberg et al., 2005), were theorized to result from time needed for the increased cognitive support for learning to translate into new learning.

In another study, 41 children ages 6–12 with IQs less than 70, 20 with a variety of additional diagnoses (autism and severe sensory and motor disorders excluded) were studied in a double-blind fashion for their response to CWMT (Söderqvist, Nutley, Ottersen, Grill, & Klingberg, 2012). They were pseudo-randomized to insure matching at baseline to either adaptive (increasing difficulty) or nonadaptive (remaining at the easiest level) training. They received 5 weeks of training, five sessions per week for approximately 20 min per session. Testing, including verbal and visuospatial working memory tasks, and measures of nonverbal reasoning, verbal short-term memory, sustained attention, and language functioning, was completed before and after training, and 1 year later. Different versions of tests were used when available. Due to wide interindividual results (some individuals showed no improvement), very limited effects of adaptive versus nonadaptive treatment was evident at the end of the treatment period. This analysis indicated that female gender, absence of a coexisting diagnosis, and higher baseline performance on verbal short-term memory and working memory tasks were predictors of improvement during training.

Individuals with Down syndrome are thought to have more severe deficits in verbal than visual short-term memory, though both are impaired compared with age-matched peers. Bennett, Holmes, and Buckley (2013) studied 24 children with Down syndrome, ages 7–12 with the junior version of CWMT (visuospatial working memory tasks only) because a pilot trial indicated that they were not able to effectively complete the standard CWMT for school-aged children. IQ screening indicated mental ages from 4 to 7 years. Subjects were randomly assigned to intervention or wait-list. Treatment occurred in the school setting approximately three times per week for approximately 25 min per session over 10–12 weeks. Testing occurred at baseline, after treatment, and 4 months later, and included an automated working memory assessment (one test each of verbal short-term memory, verbal working memory, visual short-term memory, and visuospatial working memory) and parent completion of a rating scale of executive function. There were no significant differences at baseline. Children in the treatment group showed gains in the training tasks as well as on both untrained visual memory tasks that were sustained at follow-up while controls showed no improvement, but did once trained. No improvements in verbal tasks were seen in this group, though cross-domain improvements have been seen in typically developing children. The lack of improvement in this study may have been due to the more significant verbal memory deficits characteristic of this group. Parent ratings improved to a greater degree in the treatment group, but their lack of blinding prevents a strong conclusion from this information.

Conclusions and Practice Recommendations

There is accumulating evidence of benefit from CWMT and related programs in typically developing children, though questions about transfer of benefit to complex daily skill demands, as well as maintenance of gains remain. Among individuals with intellectual disability, modifications from age-based to mental age-based training protocols may be needed, and gains may be more modest, perhaps due to limitations in capacity for CNS plasticity. Specific etiologies for intellectual disability may also result in specific cognitive profiles that will influence the effects of training. More study is clearly needed before this can be convincingly recommended in this population, and the cost in time and money is a consideration, however, the lack of alternatives for targeting working memory, and the safety of the procedures involved may make this acceptable at an individual level, in spite of limited data.

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Cognitive Behavioral Therapy

11

Paul Willner and William R. Lindsay

Introduction

Cognitive behavior therapy (CBT) was developed in the 1960s and over the subsequent half century emerged as the predominant approach to evidenced-based psychological therapy and the treatment of choice for many psychological disorders (Roth & Fonagy, 2004). The basic assumptions of CBT are: that people's emotions and behavior are influenced by their perceptions of events (that is, that thoughts, images, and other cognitive mediating processes affect behavior); that psychological disorders are characterized by distorted or dysfunctional thinking; and therefore, that mood and behavior can be improved by working with the patient to modify thinking in the direction of more realistic evaluations of events.

Until relatively recently, the psychological problems of people with intellectual and developmental disabilities (IDD) were treated almost exclusively by hospitalization, psychopharmacology, and/or behavioral interventions based on manipulation of the person's environment. These interventions were implemented via third parties such as nursing or care staff, often without the client's consent. A climate of "therapeutic disdain" prevailed (Bender, 1993) under which it was assumed that people with IDD were incapable of taking responsibility for their own mental health or collaborating in their psychological treatment.

This situation began to change in the 1990s when, particularly in the UK, clinical psychologists started to challenge the assumption that people with IDD could not engage with psychological therapies. A 1999 survey of British clinical psychologists reported that while behavioral and organizational interventions remained the mainstay of psychological support to people with IDD, 35 % of those surveyed reported "frequent" or "very frequent" use of cognitive-behavioral methods, with almost as many (31 %) "frequently" or "very frequently" using humanistic or person-centered interventions, and a significant minority (17 %) experimenting with psychodynamic approaches (Nagel & Leiper, 1999). Around the same time there appeared an influential compendium of pioneering explorations into the application of CBT to people with IDD (Stenfert Kroese, Dagnan, & Loumidis, 1997). This stimulated a concentration of further research and clinical work in this area, leading to the development of an evidence base that for the first time included controlled trials.

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Although small, and for the most part methodologically weak, the controlled trials of CBT interventions for people with IDD were important in contradicting a widely held belief that controlled trials with this population were just too difficult to undertake (Oliver et al., 2002). As a consequence, controlled trials of other psychological interventions for people with IDD have now begun to appear, recapitulating the seminal role of CBT trials in the development of controlled evaluation of psychological therapies for the general population. This chapter summarizes the current status of CBT for people with IDD.

Cognitive Behavior Therapy

The roots of CBT can be found in the writings of the stoic philosophers. For example, Epictetus wrote that "Men are disturbed not by things, but by the view they take of them." This idea, that how people feel is determined by the way in which they construe situations rather than by the situations per se, was familiar to Shakespeare, who had Polonius tell Hamlet "There is nothing either good or bad but thinking makes it so." From this starting point, a number of approaches have been developed by therapists working within a broad CBT framework, the two most influential being Cognitive Therapy (CT; Beck, 1967) and Rational Emotional Behavior Therapy (REBT; Ellis, 1962). Others include Schema-Focused Therapy, Dialectical Behavior Therapy, and more recent mindfulness-based approaches such as Mindfulness-Based Cognitive Therapy (MBCT) and Acceptance and Commitment Therapy (ACT). The common feature of all of these approaches to psychological therapy is that treatment is based on a cognitive-behavioral formulation that (1) seeks to explain the symptoms displayed, and (2) guides the choice of therapeutic activities.

Formulation

Table 11.1 Some examples of cognitive distortions (after Beck, 1967)

All or nothing thinking—*seeing things as black or white*
Over-generalization—*of negative events*
Mental filter/bias—*dwell on the negatives, ignore the positives*
Jumping to conclusions—*e.g., Fortune telling (assuming that things will turn out badly); Mind reading (assuming people are reacting negatively in the absence of supporting evidence)*
Magnification and minimization—*no sense of proportion*
Emotional reasoning—*e.g., 'I feel stupid so I must be stupid'*
Labelling—*Identifying with your shortcomings*
Personalization—*"It's all my fault"*

Beck's basic insight was that people may be subject to habitual cognitive distortions (Table 11.1) and that the therapist's job is to identify the distortions that color clients' views of themselves and the world around them and help the client to perceive the world more accurately. (This can be problematic when the client is in an adverse situation that is perceived accurately (Alloy & Abramson, 1988; Moloney & Kelley, 2004), and was the starting point for the later development of therapies such as MBCT and ACT that help the client to accept their own experience rather than attempting to change it.) Psychological problems are said to arise when, as a result of adverse early experiences, people develop dysfunctional assumptions and a set of negative core beliefs, the classic example being the "depressive triad" of negative beliefs about the self, other people and the world. These form a cognitive schema, which may lie dormant but can be activated by critical incidents. When the schema is activated, the mind is flooded by negative automatic thoughts, which generate negative emotions and behavior and have negative consequences, creating a positive feedback system from which it is difficult to escape. Figure 11.1 shows an example of a CT formulation of client's challenging behavior that illustrates these concepts.

REBT is based on the assumption that each person holds a unique set of assumptions that guide reactions to situations encountered, and that these may be irrational. People assume, for example, that they are failures if they are not loved by everyone they know, that they have no control over their happiness, that they need to

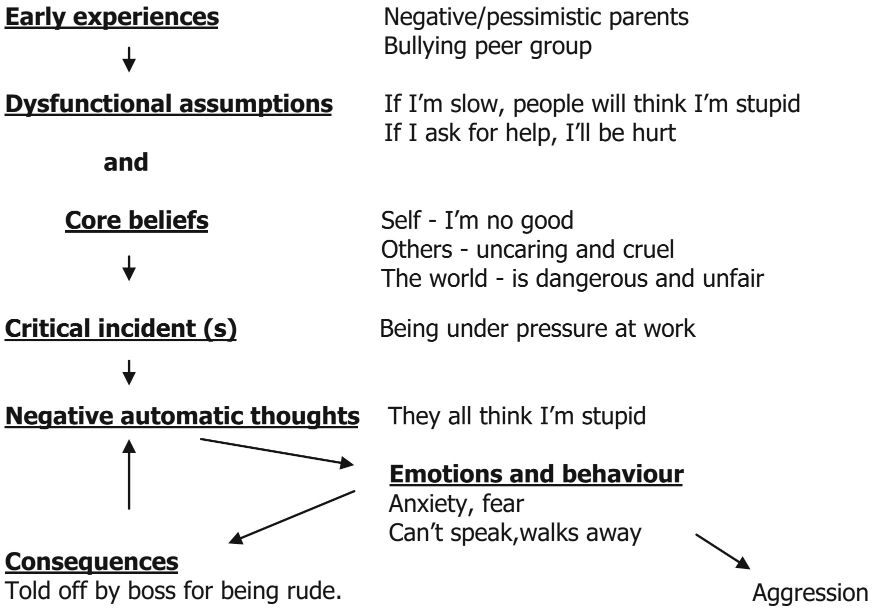

Fig. 11.1 An example of a CBT formulation of challenging behavior, illustrating the early development of a depressive schema and the interplay of negative automatic thoughts, emotions, and consequences following a critical incident

depend on someone stronger than themselves, or that there is a perfect solution to human problems and it is a disaster not to find it. REBT to some extent avoids the problem that the client's perceptions of a hostile world might be uncomfortably accurate by placing the emphasis on the choices that people can exercise over their appraisals of events. This is revealed through A–B–C analysis of the Antecedents (or activating event), Beliefs (thoughts that occur in that situation) and Consequences (the feelings that ensue). The classic example is the thought experiment "You are lying in bed and hear a noise downstairs: what do you think? what do you feel? what do you do?" If the thought is "I am being burgled" the feeling is likely to be fear and the resulting behavior would be to hide or to confront the intruder. Whereas, if the thought is "My partner has come home and bumped into something in the dark" a range of alternative feelings could ensue, but fear would probably not be among them. REBT therefore encourages clients to choose appraisals of uncertain events that work better for them.

These concepts apply equally when creating a CBT formulation of a member of the general public or a person with an IDD. However, an IDD by definition confers some cognitive limitations, and these also contribute to the formulation. A useful distinction is between cognitive distortions, which are inaccuracies in the contents of thoughts, assumptions and beliefs, and cognitive deficits, which are deficiencies in the processes by which information is acquired and processed (Dagnan & Lindsay, 2004; Kendall, 1985; Willner, 2006). A client with an IDD may have cognitive deficiencies in areas such as language, memory, emotional literacy, and executive functioning, all of which would influence the accessibility or effectiveness of a CBT intervention. Therefore, the formulation should include an assessment of a client's cognitive deficiencies (attained through formal or, more usually, informal assessment) and an account of how the cognitive deficiencies interact with other factors to influence the problem presented for therapy.

Practical Aspects of CBT

In addition to the conceptual tools outlined above, CBT also involves a tool-box of practical techniques. CBT is typically time-limited (though this may be relaxed for a client with an intellectual and developmental disability [IDD]), meaning that the therapist needs to plan out and structure the intervention so as to bring it to a conclusion within the time available. CBT is problem oriented and has a primary focus on present difficulties: it will often be necessary to delve into historical factors such as childhood difficulties, and these may be prominent in the formulation (as in Fig. 11.1), but the aim is to change the way in which the client responds to current circumstances. The therapy is seen as a learning process in which the client plays an active and collaborative role, for example, in setting the agenda for a session. The therapist makes extensive use of Socratic questioning, designed to guide clients step by step to discover answers for themselves, and behavioral experiments, in which clients try out different ways of interacting with the world and observe their own and other people's reactions. A particular importance is placed on homework, often involving behavioral experiments, which deepens the intensity of the intervention by extending it outside the therapy session. A typical therapy session could include: reviewing a client's state of mind; setting an agenda for the session; reviewing homework; setting session targets; and at the end of the session setting homework and eliciting feedback on the session.

The basic methods of cognitive therapy, as outlined by Beck, Rush, Shaw, and Emery (1979), include guided discovery, identification of cognitive schemas, and developing and sharing the formulation as a collaborative exercise between client and therapist. The collaborative relationship between therapist and client is considered to be a central feature of CBT (e.g., Alford & Beck, 1998): they work together to develop the formulation, organize the program of treatment around the client's needs, and progress towards therapeutic goals. In CBT, as in other structured psychotherapies, the nature of the therapeutic relationship is a positive source for change that accounts for a large proportion of the variance in therapeutic outcomes (Power, 2010). Indeed, it has been reported that CBT therapists were more successful than psychodynamic therapists in establishing and maintaining good collaborative relationship and agreeing therapeutic goals with the client (Keijsers, Schaap, & Hoogduin 2000). The CBT therapist's aim at the outset is to help clients to understand and become familiar with the CBT model so that they can then engage actively with the therapeutic process. This joint working, based on the Socratic process and guided discovery has been termed "collaborative empiricism" (Beck et al., 1979).

One study has examined the extent to which the principles of CBT are followed when the client is a person with an IDD. Jahoda et al. (2009) conducted a detailed analysis of transcripts of two sessions from each of 15 clients receiving CBT for problems of depression, anxiety, and anger. They found that power was equally distributed between client and therapist, indicating a good collaborative relationship, and the therapists made good use of Socratic questioning. There were high levels of adherence to CBT structures and processes, including setting an agenda, employing appropriate feedback, conveying understanding towards the client, interpersonal effectiveness, collaboration, guided discovery, focussing on key cognitions, choosing appropriate interventions, and employing homework. From the point of view of the therapeutic process, understanding clients' needs, interpersonal effectiveness and employment of the collaborative process are the most relevant components. These processes were present in well over 90 % of ratings, indicating a high level indeed of effective therapist-client relationships in a technically difficult area.

Increasingly, CBT interventions are manualized. There is evidence that where therapy manuals have been developed, departure from the manual is associated with a decrease in the efficacy of the intervention (Bellg et al., 2004; Eames et al., 2009; Saini, 2009), albeit that in practice, therapists who claim to deliver evidence-based interventions may do so to a very limited extent (Santa Ana et al., 2008; Waller, Stringer, & Meyer, 2012). Two of the instruments that have been developed to measure the fidelity of delivery of manualized interventions, the Cognitive Therapy Scale and the Cognitive Therapy Scale for Psychosis have been applied to individual interventions for people with IDD (Hassiotis et al., 2013; Jahoda et al., 2009). There is also an instrument that was developed specifically to measure the fidelity of delivery of manualized group-based interventions to people with IDD. A study using this instrument to evaluate the fidelity of delivery of an anger intervention found high levels of interpersonal effectiveness and good adherence to the principles of CBT, but that the behavioral elements of the intervention were delivered more effectively than the cognitive elements, perhaps unsurprisingly considering that the therapists in this study were support workers who had received minimal training to act as "lay therapists" (Jahoda et al., 2013).

Back to Basics

While the CBT toolkit is of proven importance, it is also important to distinguish between the toolkit and the therapeutic principle underlying CBT: that psychological distress can be decreased by counteracting dysfunctional cognitions. This objective can sometimes be achieved much more simply than by deploying the full CBT toolkit. For example, Willner (2006) described two cases where significant therapeutic improvements were achieved in people with IDD simply by correcting false beliefs (e.g., that breathing the air in a toilet causes illness). Imagery Rehearsal Therapy (IRT) is a simple approach to cognitive change that has been used to deal with recurrent nightmares associated with post-traumatic stress disorder (PTSD), by helping the client to change the nightmare story to a version that has a more acceptable ending, and then to rehearse the new story before going to sleep. The benefit of this approach has been demonstrated in a controlled trial in the general population (Krakow et al., 2001), and there are five case studies reporting impressive effects in people with IDD (Bradshaw, 1991; Lindsay, Willner, & Sturmey, 2013; Stenfert Kroese & Thomas, 2006; Willner, 2004). These cases used almost none of the CBT tools, but demonstrate the underlying principle: replacing a dysfunctional cognition with one that works better to promote psychological health.

Adapting CBT for People with IDD

Why Is It Necessary to Adapt CBT for People with IDD?

In order to work effectively with a person with an intellectual disability, a conscious effort is needed to adjust the style of presentation to take account of the client's limited information processing abilities. The major adaptation is the use of simple words and short sentences; there is also a greater use of nonverbal techniques such as gesture and pictorial materials: for example, estimations of the intensity of experiences or the importance of events would typically be elicited using either gestures (e.g., hand separation) or a visual scale made up of 3–5 shapes of increasing size (see for example Marshall & Willoughby-Booth, 2010). The need for these adaptations is obvious, albeit that experience may be needed to implement them consistently.

However, difficulties also arise from specific cognitive deficits, which, if not recognized and addressed, are equally detrimental to engagement with CBT. The severe problems that cognitive deficits can create in therapy, if ignored, go far wider than a simple focus on IQ. Table 11.2 (from Lindsay, Jahoda, Willner, & Taylor, 2013) summarizes deficits that may be encountered in four domains of cognition: intellect, emotional literacy, memory and executive functioning. The table also lists some of the potential solutions to the problems that these deficits cause. The case formulation for a person with an IDD is likely to include intellectual limitations as a predisposing factor, but other cognitive deficits also be need to be identified and included in the formulation (see Willner & Goodey, 2006). These are important issues to consider during the assessment phase, because they are likely to have a damaging effect

Table 11.2 Cognitive deficits that can cause difficulty in CBT if not addressed

Cognitive domains	Specific processes	Implications for therapy
Intellect	Verbal understanding and reasoning	Simple words and short sentences
	Nonverbal understanding and reasoning	Use of nonverbal techniques and materials
Emotional literacy	Emotional vocabulary	Psycho-education
	"CBT skills"	Psycho-education and provision of ideas
Memory	Assimilation	Frequent repetition and more sessions
	Recall of experiences	Involvement of carers
	Prospective memory	Use of reminders and involvement of carers
Executive functioning	Working memory	Chunking of information
	Behavioral inhibition	Greater use of behavioral self-control techniques
	Initiative	Provision of ideas

on the course of therapy if appropriate adaptations are not implemented.

There has been extensive discussion of emotional literacy in relation to people with IDD. Many people with IDD have a limited emotional vocabulary (Joyce, Globe, & Moodey, 2006; Reed & Clements, 1989), resulting in difficulty in expressing feelings verbally, or a poor understanding of the difference between the verbal labels for different emotions, for example, conflating "sad" and "angry," and this may require some preliminary psycho-educational input before attempting to work on emotional problems (McKenzie, Matheson, McKaskie, Hamilton, & Murray, 2000). Less obviously, people with IDD are generally poor at recognizing the central role of cognitions as mediating between situations and emotions. Indeed, while the majority of people with mild IDD are able to recognize the relationship between antecedents and emotional consequences, a minority have difficulty in making this discrimination even without considering the role of mediating cognitions (Dagnan, Chadwick, & Proudlove, 2000; Reed & Clements, 1989). The ability to recognize the mediating role of cognitions varies greatly within the general population (Safran, Vallis, Segal, & Shaw, 1986), and the majority of people with IDD have difficulty in doing this reliably (Dagnan et al., 2000; Dagnan & Chadwick, 1997; Joyce et al., 2006; Oathamshaw & Haddock, 2006; Sams, Collins, & Reynolds, 2006). All of the cited studies reported significant relationships between "cognitive therapy skills" and measures of language ability. However, even high levels of correlation leave much of the variance between individuals unexplained, so there is no simple way to infer emotional literacy from IQ scores.

If a client cannot demonstrate an understanding of the mediating role of cognitions, then it would sometimes be appropriate to offer simpler form of therapy, such as self-instructional training (Dagnan & Chadwick, 1997). Socratic questioning is certainly more difficult in these circumstances, with frequent blocks when the client can only answer, "Don't know." However, the inability to articulate thoughts can often be circumvented by the therapist suggesting answers for the client to consider (e.g., "In a situation like this, some people might be thinking …"). This represents a dilution of the "guided exploration" component of cognitive therapies, but has the merit of enabling the therapeutic conversation to continue (Willner & Goodey, 2006).

People with IDD are also likely to have memory deficits, relative to more intellectually able people. As with emotional literacy, scores on memory tests tend to correlate positively with scores on tests of verbal ability, but again, this relationship accounts for only 40–50 % of the variance in memory scores (e.g., Willner, Bailey, Parry, & Dymond, 2010), so there is a great deal of individual variability. Memory problems interfere with CBT in several different ways.

Most obviously, problems in assimilating new material mean that there is a need for frequent repetition and recapitulation, both within and between sessions. This means that progress is likely to be much slower than for a more intellectually able client, and therefore that more sessions may be needed to achieve a comparable outcome. As a result people with IDD need flexibility over the number of sessions that are available, rather than the fixed session lengths provided by some brief intervention services. A second problem is that people with IDD may have great difficulty in remembering and recounting their experiences, both remote and recent, which form the foundations on which a CBT session is built. In order to address this problem it may be helpful to involve a carer to discuss the events with the client so as to aid recall. This could involve a preliminary discussion after which the carer withdraws from the session, or, with the client's consent, the carer might even be present throughout the session (see Willner & Goodey, 2006). Thirdly, people with IDD have problems with prospective memory—remembering to do things: specifically, homework. Research has shown that completion of homework assignments is an important component of effective CBT, but one with which even intellectually able people have difficulty (Rees, McEvoy, & Nathan, 2005). Providing memory aids, such as reminder notes or calendars, can support homework. However, for people with IDD, carers can provide an additional resource to support homework assignments, and in this respect people with IDD are potentially at an advantage over other clients. This typically works by inviting the carer to join the final part of the session when homework is being discussed. But involving carers is not entirely straightforward. While they can provide invaluable assistance, carers, like clients, can vary in their ability and willingness to take on the tasks they are allocated (Willner, 2006); careful assessment and delicate handling are needed when engaging their support.

Impairments of executive functioning are highly prevalent in people with diagnoses of IDD, and unlike emotional and memory deficits, the severity of executive functioning deficits is largely unrelated to verbal ability, across the mild learning disability range (Willner et al., 2010). Executive functioning is a complex area that includes three broad sets of skills: monitoring of one's own behavior using working memory, inhibition of impulsive responding, and initiative: initiating actions or changing strategies under internal control (Miyake et al., 2000). Problems in the first of these areas present as a short attention span, which means that particular care is needed to keep ideas simple and short, so that they are presented in easily assimilated chunks. Problems with impulsiveness can mean that a far greater proportion of therapy time is taken up with teaching behavioral self-control skills to prevent the occurrence of crises. (For example, if an angry client commits an act of physical aggression, this preempts the use of cognitive strategies aimed at avoiding such outbursts, so the priority must be to help the client to maintain self-control.)

Finally, a problem with the initiation of self-directed behavior can mean, again, that the client has difficulty in generating the ideas around which a Socratic dialogue is built. Just as when this problem arises from a limitation of emotional literacy, the solution is for the therapist to provide active support by suggesting ideas for the client to consider. This can easily lead to a situation in which CBT for people with IDD appears more directive and less collaborative than standard CBT, with the therapist appearing more in the role of teacher and less in the role of guide. Therapists find this an uncomfortable position to adopt but may accept it as inevitable in cases where the alternative would be to accept defeat and try a different approach.

The cognitive deficits that we have discussed differ from person to person, so the adaptations needed to enable individuals with lower intellectual functioning to engage in CBT need to be calibrated to the individual client. However, when making the necessary adaptations, two fundamental requirements need to be respected. The first is that effective communication is an essential requirement for any interpersonal process including therapeutic interactions. If a person with IDD misunderstands the therapeutic process, this invalidates the whole exercise. Therefore the process must be adapted so as to ensure that the client understands and engages with it. The second requirement is that the adaptations that are introduced do not undermine the collaborative cognitive-behavioral approach, in relation to, for example guided discovery and cognitive mediation. Therefore, we need to ensure that while the therapist's style and approach are modified to allow for the cognitive constraints presented by the client, the integrity of the therapeutic process is maintained. In the following sections, we describe adaptations of CBT processes that are used to achieve these outcomes, expanding on the brief outline shown in Table 11.2 in the context of specific CBT techniques.

Communication and Engagement

While simplifying adaptations often promote better understanding, this is not always the case. For example, simplified outline drawings of facial affects can be ambiguous and difficult to follow, while richer, dynamic, and contextual cues can be easier to grasp (Matheson & Jahoda, 2005). It can, therefore, be helpful to provide additional contextual cues, albeit that the context for the facial expression would usually already be under discussion. However, it would invariably be appropriate to use simple language.

Simplifying one's language is not a natural or easy process; it requires constant adjustment of vocabulary and syntax, in addition to continuing self-monitoring to avoid the significant danger of becoming patronizing or even dismissive. There are a number of fairly basic recommendations, which, if followed, will allow for clear unambiguous communication in order to help the person with IDD to engage in the process. The first is to try to use short sentences that contain a single concept. The second is what we might call "the three-syllable rule": the therapist should attempt to use words of fewer than three syllables. Constant self-monitoring of one's utterances is difficult but necessary. Whenever therapists hear themselves using a word of three or more syllables, they should automatically review the sentence for its linguistic and syntactical complexity. Although this may sound straightforward, some professionals with many years of experience continue to use complex syntactical structures and words while presenting didactic explanations of therapeutic and other concepts. When a client is not understanding information fully or engaging with the process this will usually be fairly obvious. However, and importantly, clients may appear to be participating because they have had many years of learning how to mask their lack of understanding in order to mix with normally able peers. It is therefore good practice to ask clients to summarize previous sections of a session in order to assess their understanding and retention.

Lengthy presentations of information are likely to become boring and tedious, and to overload the client with too much information. This can be especially true if therapists feel they should work to a timetabled and time-limited program. It is preferable to be reasonably flexible in the amount of time taken for each section of any program and as far as possible to avoid didactic methods. The use of Socratic or inductive methods, as discussed below, is helpful in guiding the therapist to avoid didactic and lengthy explanations. The Socratic dialogue allows the therapist to develop a series of questions that will lead patients to appropriate information. This may not always be possible when introducing entirely new concepts, but in such instances, a small amount of introductory information can often be sufficient to begin the inductive process.

A problem that can arise when using this approach is that clients may expect to be told what to do or say because they may have had repeated experience of directed interactions. They may also be worrying about "giving the wrong answer" as a result of experiencing repeated failure and negative self-evaluation. Therefore, the therapist should be aware of the temptation to lead the session or provide the answers and information. Clients should be enabled to review their own evidence in the development of arguments, and so gain an understanding through their own cognitive processes rather than attempting to grasp information presented by someone else. A significant drawback of this process (as with all processes in psychological therapy for people with IDD) is that it is much slower than providing the person with information. However, the therapist can have greater confidence that the client has understood the concepts and will retain them better. By helping to generate the information themselves through guided discovery, the clients are more likely to consider that they have ownership of the content of the session. A further method to promote ownership is to encourage clients to record the information themselves.

Setting an Agenda

Although setting an agenda for sessions is generally considered to be a CBT technique, it is a method that can be helpful for any form of psychotherapy, by enabling a relatively complex process to become more predictable and controlled. However, once established, the agenda may become be repetitive, and simply be assumed in later sessions. In the study of Jahoda et al. (2009) that analyzed the process of CBT process for people with IDD, setting the agenda was the method to which therapists adhered least frequently. The same was true of an analysis of group-based CBT delivered by care staff (Jahoda et al., 2013). A typical agenda might include the following elements: monitor current emotional state; review of the past week; review of homework; analysis of one particular incident: cognition, behavior, emotion, and arousal; review implications for future and other settings; exercises or psycho-education; and setting homework tasks.

The Socratic Process/Guided Discovery

The basic principle of collaborative empiricism (Beck et al., 1979) is that rather than using didactic methods, therapists should Socratic methods of guided discovery to elicit information from participants. The rationale for this approach is that clients who generate the appropriate information themselves are more likely to retain it, and to reach adaptive conclusions that challenge cognitive distortions and maladaptive schemata. But for clients with IDD, this approach can be extremely difficult at first because they may expect therapists to outline the procedures and methods, and to provide answers. Clients may feel that the therapist is an expert and will have the answers to their difficulties. They are likely to have had years of acquiescence and compliance in an effort to mask their learning disability by feigning understanding.

Some clients may be worried about making mistakes, “giving the wrong answer,” “doing the wrong thing,” or “making a fool of themselves.” While responding to these fears in a supportive manner, therapists should try to resist the urge to conform to expectations that they will lead or direct sessions: rather than resorting to the use of didactic methods to tell clients exactly what the problem is and what they need to do, it is important to persevere with the use of guided discovery and exploration, even though this may be challenging for the therapist. Clients are unlikely to have clearly defined the problem they are experiencing, and the guided discovery method allows them to explore various aspects of their difficulties. Inductive methods encourage participants to follow through the arguments themselves, develop their own evidence, and review pieces of information available to them. In this way, clients develop information that may challenge their dysfunctional cognitions and more basic dysfunctional schemas.

Socratic questioning can be difficult to follow for some people with IDD, but it is possible to help “scaffold” this approach when people are stuck. For example, it is legitimate for therapists to suggest alternative possible interpretations of situations, such as “Some people, in that situation, might say ….” If the client says that a member of the staff has been deliberately nasty when asking him or her to do household chores, the therapist may not be able to come up with an alternative explanation, but could ask, “What if you thought the staff member was trying to help you rather than being nasty?" The therapist would then follow up with questions about how it might be possible to interpret a staff member's behavior as helpful and how that would make the client feel. Once this alternative interpretation has been established with the accompanying alternative responses from the client, treatment can continue with a discussion on how he or she would respond. This can also be role-played.

Therapists should also be aware that Socratic questioning can be difficult when the client with IDD is stuck on an antecedent-to-consequences manner of thinking. In the earlier example, the client perceives the staff member as being nasty and the response is maladaptive. The therapist could suggest different possible more charitable interpretations for the staff member's actions, but the client could continue to express anger toward the staff member and to believe that the staff member was being nasty. In this case, a different role-playing approach could be considered, in which the client is asked to take the part of the staff member while the therapist takes the part of the client. Role reversal is a useful technique that is commonly employed in CBT with people with IDD. Through this perspective-taking exercise, the client as the staff member might suggest that he or she was simply asking the other person to remember to carry out the tasks. With two alternative interpretations on the table, the way is open for a REBT-style discussion of which interpretation would leave the client feeling better about the situation.

Monitoring Thoughts and Feelings

A formal, weekly assessment of progress has been recommended by several authors, including Beck et al. (1979), and this approach has been adopted in the UK Increasing Access to Psychological Therapies program, a national roll-out of CBT for common mental health problems delivered in primary care settings (Department of Health, 2011). There is a developing technology for the valid and reliable assessment of thoughts and feelings for clients with IDD. Formal instruments include adapted versions of standard scales and instruments developed and validated specifically for the IDD population, such as the Glasgow Anxiety and Depression Scales (Cuthill, Espie, & Cooper, 2003; Mindham & Espie, 2003). Many people with IDD require assistance to complete such inventories, and the process could take up a substantial portion of a 1-h session. Therefore, formal assessment is typically conducted less frequently than in mainstream services.

More usefully, pictorial materials can be used to take summary ratings of how the client has felt over the previous week, for example by using four-point scales that can be presented repeatedly during the course of treatment (and indeed, within sessions). Such scales often include pictorial representations of the four scale points, or of the two ends, which clients might draw themselves (Lindsay, Jahoda, et al., 2013). Regular use of such instruments illustrates the course of therapy not only to the therapist but also to the client. This simple method of regular, weekly review of treatment progress is well established in CBT for people with IDD (Dagnan & Lindsay, 2004).

Identifying Automatic Thoughts and Testing Their Accuracy

It can often be easy to identify negative self-statements in clients with IDD (even without the use of guided discovery methods), and straightforward interviewing is one of the most important methods for eliciting them. For example, a case study discussed by Willner et al. (2013a) reports the client making the negative self-statement. "What do you want to talk to me for? The idea that "Nobody wants to talk to me" provides a powerful disincentive for engaging with others and is likely to evoke strong feelings of stigmatization. Negative self-statements can sometimes be so straightforward that there is a danger of missing them. In one or two quick sentences, clients will sometimes reveal several negative automatic thoughts, which if used repeatedly, can be quite debilitating to the individual's everyday life. Therapists need to carefully isolate negative self-statements and make them explicit as they are revealed. They can be analyzed later for their accuracy, the way in which they evoke negative emotions and the way in which they activate underlying assumptions or schemas. A quote from the case study presented by Lindsay, Jahoda et al. (2013) shows how automatic thoughts can come tumbling out from the client's description of events: "… I saw her and I know she doesn't like me because we had an argument two weeks ago and she was accusing me of being drunk and she would say I was drunk again and she's got friends and her friends are always talking about people behind their back." In this single statement, the following thoughts have been established: (1) She doesn't like me; (2) She will talk to others (negatively); (3) She spreads rumors about me being drunk; and (4) She may say I was drunk before and I am drunk now.

And, given that the client had a history of depression and of feelings of stigmatization, the therapist might probe for the presence of related thoughts that might continue to undermine her emotion and promote feelings of stigmatization, such as: (1) Other people will start talking about me while I am here; (2) Lots of people at this party will be saying bad things about me; (3) They might start laughing at me; and (4) They will all be looking at me to see if I am drunk. This illustrates how the therapist will have a number of hypotheses based on knowledge of the client and her history. The questions posed by the therapist are, therefore, deliberately "guiding."

While dealing with "hot cognitions" related to recent situations is thought to be a critical aspect of CBT, the emotional element contained in the client's experience is especially important in working with people with IDD. This is because it can be difficult to talk about the personal meaning of events in the absence of the emotion. The emotion can be discussed in a more immediate fashion, making it easier to find out what the person thinks and the nature of his or her reaction. In other words, it may be easier to begin by talking about feelings about an event, with the prospect of subsequently moving on to cognitions about the event and about the client's response.

Another effective method for eliciting negative automatic thoughts is through role play in which the therapist and client reenact some of the difficult situations that have taken place in the client's recent past. (However, it may be difficult to employ role-play with some clients who may be reluctant to engage because they feel embarrassed and self-conscious.) For example, Lindsay, Jahoda, and Willner (2013) described a client who had difficulty in describing his feelings, but when role playing speaking to a member of his day center staff his thoughts emerged in a simple uncluttered fashion, with statements such as "He's going to see me as a criminal," "He's going to think I am a bad person," and "People are never going to believe me now and he doesn't believe me." Another technique that can be used to elicit automatic thoughts is role reversal, where client and therapist reverse roles and the client, as therapist, has to ask what "the patient" is thinking (Lindsay, Howells, & Pitcaithly, 1993). The client, as therapist, may ask a very leading question of the "patient," such as "Do you worry that everyone is watching you when you go out of your house?" or "Do you think you are a bad person?" In this way, clients can either reveal very clearly the nature of thoughts that they consider being important in their own lives or confirming thoughts that have been elicited previously during interview. This illustrates a more general technique in which clients are asked to review their circumstances from the point of view either of the therapist or of a dispassionate observer such as a friend.

Occasionally, clients will say that they are unable to identify any thoughts, only that they feel bad. This could arise because self-statements can become enmeshed into emotions and do not reach the level of conscious thought, because clients do not have the language to express their emotional state, or because there really is no negative thought associated with "feeling bad." However, mediated self-statements are possible and can be inserted into the chain of responses if spontaneous self-statements are absent, or used to promote more adaptive self-statements if they are present. In his development of the theoretical framework for self-statements, Meichenbaum (1977) wrote that it is unlikely that clients actively talk to themselves prior to treatment. Nevertheless, he recommended the use of self-statements as a proactive treatment procedure to challenge a client's elicited self-statements and increase their importance to a level where clients may be able to use them to good effect.

Once elicited, self-statements can be tested, initially through a review of the direct evidence gathered through Socratic questioning. It may be convenient to use a flip chart at this stage to list the evidence for and against the self-statements, as a basis for challenging the accuracy of the client's cognitions. Another common method for challenging the accuracy of cognitions is to employ reattribution methods using role reversal or by asking clients to imagine themselves as independent or dispassionate observers. An exercise that is often used is for the therapist to ask the client to make an appraisal of an individual who has exactly the same characteristics and circumstances. This is likely to uncover positive cognitions that clients have not, up to this point, applied to themselves. There can be two results from this exercise; clients may accept the challenges to their cognitions or offer further justification for them. In the latter case, this can be added to the list of automatic thoughts and negative cognitions that might lead to underlying assumptions and schemas that can be dealt with later in treatment. In general, this method of reattribution can be an effective means of reviewing the outcomes for negative self-statements or developing a clearer picture of the client's matrix of negative cognitions.

Eliciting and Testing Underlying Schemas and Assumptions About Self

Many psychological therapies rely heavily on the concept of schemas and underlying assumptions. These are thought patterns that develop early in life and become filters that organize and process incoming information. Schemas or "world views" have been employed to explain the way in which individuals approach interpersonal situations, solve personal problems, and generally deal with events. For example, Palmer (2003) used the concept of egocentric self-schemas and a "hostile world" schema to explain criminal behavior in young men, and Trower and Chadwick (1995) proposed an understanding of persecutory beliefs and depression in term of paranoid "poor me" and self-blaming "bad me" schemas.

In the field of IDD, studies of negative self-image and stigma (Dagnan & Sandhu, 1999; Dagnan & Waring, 2004), the relationship between social development and depression (Payne & Jahoda, 2004), and the relationship between social support and depression (Benson, Reiss, Smith, & Laman, 1985; Richards et al., 2001) indicate that these schemas can be of primary importance for this client group. Young, Beck, and Weinberger (1993) have outlined a number of maladaptive schema domains several of which seem particularly relevant to people with IDD. Instability and disconnection refer to the expectations that one's basic needs for nurturance and safety may not be met by one's social support network, which leads to schemas involving abandonment, mistrust, and emotional deprivation. The domain of impaired autonomy refers to a perception that one cannot function independently and adequately within society, which is associated with schematic concepts of dependence, personal vulnerability, and under development. The domain of undesirability indicates negative social comparisons with others across a range of features including social skills, achievement, socioeconomic background, and physical and personal attractiveness, leading to schemas involved feelings of shame, defectiveness, social undesirability, and failure.

In order to identify underlying schemas, it is important to identify themes emerging from the therapeutic process that are common to problematic self-statements, avoidant actions, and emotionality. As therapy progresses, it usually becomes apparent that there are certain representations or underlying assumptions that underpin the way in which clients interact with their world. From this point onwards, the major aim of the therapy is to recall information from previous sessions and gather further information that will challenge the client's maladaptive schemas. For example, Lindsay, Jahoda, and Willner (2013) described a client who had strong underlying beliefs that she was unlikeable and that others were hostile to her. These schemas were challenged through evidence of her interaction with others, including evidence supplied by her care staff about various successful interactions and events in which she had participated, which contrasted with her own evaluation of those events. This illustrates a valuable feature of CBT as applied to people with IDD: that, relative to therapy with a person who is more intellectually able, the therapist working with a person with IDD is more likely to have access to valuable third-party information from support workers or family members.

Homework

Homework is an integral part of CBT and is usually set at the end of each session. Homework can be difficult for people with IDD, and tasks should be kept as simple and clear as possible. Tasks can range from a piece of behavioral rehearsal, through interaction with others, to rehearsal of thoughts and attitudes considered during the treatment session. A functional analysis of a therapy-relevant event occurring between sessions, in which clients identify the antecedent circumstances, describe the event and reflect on their consequent thoughts, feelings and behavior can be a particularly fruitful exercise (Willner et al., 2013a, 2013b). The important point about homework is that it should have been discussed or practiced during the session in order to help the client develop some skills for use in the real-life setting. Behavioral rehearsal might be to approach an individual with whom the person has had difficulty in the past and engage in a piece of interaction that has been practiced during role-play sessions.

Clients should be encouraged to think about homework tasks between sessions as part of treatment rather than an optional task or a burden. However, therapists should be careful to ensure that clients are not made to feel guilty for not completing homework tasks because people with IDD may find it difficult to remember the homework or to consider it during critical periods where it might be used: it is difficult to focus on an abstract task decided a few days ago when faced the demands of the present situation. Having said this, we encourage clients to learn effective ways of dealing with present situations both in terms of behavior and thought, and when homework assignments are effective they can be one of the most important elements of treatment. They encourage the client to consider the positive effects of treatment, because of the potential successes inherent in carrying out homework tasks, and they also provide a great deal of reflective information for the following sessions. The way in which homework tasks have been carried out, and the relative success of the incident, can be used to structure future sessions and to reflect on the importance of the material being dealt with during treatment. If clients are able to self-monitor, using a form that can be adapted during treatment sessions, then the feedback from the self-monitoring tasks is invaluable.

Homework tasks are a continuation of the collaborative empiricism central to CBT. The reason for carrying out each task should be clear and the methods for carrying out tasks should be specific and rehearsed. Because of the collaborative nature of treatment, therapist and client will develop these tasks together and clients will see them as directly relevant to their situation, which also enhances motivation because the reason for the task is linked to the reason for therapy. It is important to keep homework straightforward: for example, a single behavioral or interactional task or one particular way of thinking in a familiar situation. Because the therapeutic techniques outlined are accessible and uncluttered, they can be much more powerful in their implementation. Clients should not, for example, be faced with a number of conditions or caveats to tasks, such as “If this happens then this is how you should behave but only when these circumstances are in the situation and only when you are in this place.” Such an instruction would be difficult for many of us; for a person with IDD, who might have difficulty remembering the demands of the homework task in the first place, its nature should be kept as clear and accessible as possible.

Although it can be difficult to support the completion of homework tasks, it is essential to make the effort, not only because this is a way of generalizing treatment gains, but also because engagement in homework helps people make the links between what has been talked about during sessions and its relevance to their daily lives. Some practical steps can be taken to increase the possibility that clients will complete self-monitoring and homework tasks between sessions. Clients can be given visual timetables to put on their kitchen wall, or telephone prompts can be given between sessions. Where clients lack literacy skills, other means of recording what they have done can be helpful: for example, they can be given voice recorders or digital cameras to take photographs of activities they have carried out (or a significant other could have a camera to take photographs at crucial times). These ways of recording give clients an active role in the monitoring process, and listening to their recordings, or viewing their photographs, enables the therapist to access far more information during sessions than would be the case if the clients were only to give verbal feedback or to rely on their memory of events.

Involving significant others in treatment can make a considerable difference to the completion of homework tasks. If carers or family members are involved and knowledgeable about the progress of treatment, their help can be enlisted at key points to encourage clients to act, interact, and think in specific ways, and to support them in the successful implementation of behavioral and cognitive techniques in their general lives. Clients may lack the autonomy or ability to carry out homework tasks on their own, and may need help to complete monitoring forms or someone to accompany them to an activity. A carer or relative may be able to support clients to employ cognitive thinking styles that have been developed during treatment so that they are able to challenge maladaptive styles of thinking when they arise in everyday life. The extent of a client's need for support with homework may be an important consideration when deciding whether to include significant others in therapy sessions.

Relapse Prevention: Employing Carers and Significant Others

The process of generalizing treatment gains from the individual therapy session into the wider aspects of the person's life can present significant challenges to the clinician. This is because not only is it expected that the client's own views will change or become more adaptive, but there is also an underlying implicit assumption that the person will implement the new skills and world view developed in therapy in the real world, and that the other people in the client's life will begin to reflect the different perspective that the client is presenting. However, for people with IDD, the degree of control that is typically exerted over them within their service and social structures may either stop them acting in different ways or mean that their actions have limited impact. So when discussing the importance of tackling issues such as stigma or social exclusion, while the therapist can work to improve the client's confidence or resilience, it may not be possible to stop others calling them names in the street or to make other people friendlier. In community settings, the therapist can have little influence over the client's living environment. However, by working alongside significant others in the person's life, it might be possible to begin to look at ways of reducing someone's isolation and increasing protection against, for example, name calling. There is evidence that those clients who are accompanied to treatment by a carer make better progress than those who are not (Rose, Loftus, Flint, & Carey, 2005; Willner, Jones, Tams, & Green, 2002). The mechanism for this finding is presumably that carers are able to support clients in developing their skills and cognitions, in identifying target situations, and in practicing the techniques developed during treatment.

Where carers and relatives are involved, target situations can be identified and practical strategies worked out to support clients to engage with homework. However, consistency is essential because the carer must work within the same principles and the same strategies as have been worked out during treatment sessions. If the support worker were to deviate significantly from the agreed strategy, the client would simply become confused by the competing messages. It is therefore necessary to assess whether the carer or family member has understood the strategy, and crucially, agrees with it and with their role in supporting the client to implement it. It may require work with the carer to reach this point (Willner, 2006). It can sometimes become clear from feedback from carers that the agreed strategies are very difficult for clients to implement because of unforeseen demands of the situation. This is extremely helpful information to feed back into the therapy session so that the strategies can be adjusted to become more effective and relevant.

It should be remembered that involving carers and family members in therapy creates difficulties over confidentiality. Carers will be in sessions with the agreement of the client and need to understand that they are subject to the same conventions of confidentiality as the therapist. A therapist should also be very mindful that a carer who accompanies the client may have been allocated to that person irrespective of choice or preference. One way to overcoming this difficulty is to have clients nominate an individual whom they would wish support them in treatment. This can be discussed with the client as the sessions progress and can be arranged in advance so that an individual of the person's choice (assuming the client wishes to be accompanied) can be asked to contribute.

Relapse Prevention: Resilience

Resilience should be built into each session and it should be part of routine procedure for the therapist and the client to consider what might happen should predicted response not occur. Therefore, the therapist might review with clients how they would deal with a range of responses when they practice a new skill or employ a new approach to situations. These responses would vary from a good outcome through a neutral outcome to an unexpectedly bad outcome. Clients can be encouraged to develop personal resilience in the face of negative outcomes, by practicing self-appraisal in response to a negative outcome during a therapy session. This is an important aspect of treatment, one purpose of which is to equip clients with a repertoire of self-appraisal skills for a range of positive and negative outcomes that will serve them in their future life after therapy has ended. Another element of this part of treatment is to consider what the client would do if a completely unexpected and unpredictable outcome occurred. While some such events can be suggested, by their very nature, it is difficult to either discuss them or rehearse them during treatment sessions. The important aspect is to review the way in which the client would appraise the situation, and emphasize the importance of maintaining self-concept and self-esteem in unpredictable situations.

Where significant others are involved, relapse prevention can be reviewed in the context of the social network. Practically, a number of potential scenarios will be reviewed and rehearsed with both the client and the significant other. These can be based both on previous experiences and upon speculation about the kinds of situations that might arise in the future. The final few sessions of treatment can be used to discuss, rehearse, and possibly role-play some of these potential situations. In addition, the effect of changing circumstances might be considered. For example, if difficult interpersonal encounters were to occur while the client was on holiday rather than in usual settings, how would that affect the outcome? Here, we are altering the setting characteristics for a familiar difficulty, emphasizing that even predicted situations can occur in settings that may present additional unsettling variables.

Another method to promote resilience and maintain improvements is to employ routine follow-up or booster sessions. In cases where the person continues to cope successfully with people and events, these sessions can be a routine review with encouragement to maintain these adaptive procedures. In other cases, there may have been deterioration or setbacks. In these instances, the client and the therapist can revisit the methods that have been used in treatment in order to reestablish coping strategies. In extreme cases, another course of treatment can be initiated, which would probably be shorter than the original because the client is already familiar with the structure, process and content of CBT.

Effectiveness of CBT Interventions for People with IDD

There are many barriers that limit access to psychological therapies for people with IDD, including social restrictions, communication problems, challenging behaviors, a failure of general practitioners to recognize mental health problems, and exclusion criteria operated by specialist mental health services (IAPT, 2009; Leyin, 2011). However, a further problem is that the necessary research on effectiveness of psychological therapies for this population is still at a rudimentary stage. There is a relatively large case-based literature describing successful outcomes for CBT in small numbers of cases of people with mild to moderate learning disabilities presenting with a variety of mental disorders, including anxiety, depression, anger, post-traumatic stress disorder, obsessive compulsive disorder, sexual offending, and psychosis (Hatton, 2002; Lindsay, 1999; Taylor, Lindsay, Hastings, & Hatton, 2013; Willner, 2005). However, the evidence from controlled trials is sparse. There have been few such trials, and these have been limited to two indications, anger (the majority) and depression.

A recent meta-analysis of controlled studies involving at least two independent groups identified a total of 22 such studies, of which 18 were identified as CBT-based. After excluding some studies for methodological reasons, 14 studies were entered into the meta-analysis (Vereenooghe & Langdon, 2013), which included a total of 663 patients, and found a significant intervention effect, with a moderate to large effect size (0.68 [95 % CI: 0.38–0.99]. As is typically the case, the effect size was larger for non-randomized trials (0.85, $N=275$) than for randomized trials (0.56, $N=388$). Across all studies, the effect size for individual therapy (0.78) was a little greater than that for group-based interventions (0.56). Moderate and large effect sizes, respectively, were reported for depression (0.74) and anger (0.83); all of these studies involved CBT interventions. No overall improvement was found in two small studies of interpersonal functioning (Matson & Senatore, 1981; McGaw et al., 2002), albeit improvements on some measures were reported in both of those studies.

Anger

The literature in this area includes two types of intervention: anger management and anger treatment. A literature search identified 11 studies of anger management and three studies of anger treatment, which are summarized in Table 11.3. Nine of these 14 studies were included in the Vereenooghe and Langdon (2013) meta-analysis.

The anger treatment studies were all conducted by the same group and include partially overlapping populations of participants (Taylor, Novaco, Gillmer, Robertson, & Thorne, 2005; Taylor, Novaco, Gillmer, & Thorne, 2002, 2004; Taylor, Novaco, Guinan, & Street, 2004). All used a standard 18-session individual-treatment format. These studies differ from the anger management studies in that they were conducted in forensic, rather than community, settings, and included an equal mix of participants with mild ($IQ<70$) and borderline (IQ 70–79) IDD. They followed essentially the program described in detail in the previous section of this chapter.

Five of the 11 anger management trials were led by the same investigator. Rose, West, and Clifford (2000) and Rose (2010) administered an anger management program modelled closely on the intervention devised by Benson, Rice, and Miranti (1986), involving either a 16-week program of 2-h sessions delivered in a group format (Rose, 2010; Rose et al., 2000, 2005; Rose, O'Brien, & Rose, 2009), or 14–18 individual 30–60 min sessions (Rose et al., 2009; Rose, Dodd, & Rose, 2008, 2009). These interventions were delivered by qualified clinical psychologists or experienced assistant psychologists. Willner et al. (2002, 2005) delivered a group-based intervention that was adapted from the same session

Table 11.3 Anger management and anger treatment studies

Study	Date	N^a	Format	Sessions (h)	Duration (h)	Rater	Follow-up
Taylor et al	2002	20	Individual	18 × 1	18	Self	None
	2004	17	Individual	18 × 1	18	Self	None
	2005	36	Individual	18 × 1	18	Self/carer	4 m
Rose et al.	2000	25	Group	16 × 2	32	Self	12 m
Willner et al.	2002	16	Group	9 × 2	18	Self/carer	3 m
Lindsay et al.	2004	47	Group	40 × 1	40	Self/carer	3–30 m
Willner et al.	2005	17	Group	12 × 2	24	Self/carer	6 m
Rose et al.	2005	86	Group	16 × 2	32	Self	3–6 m
Hagiliassis et al.	2005	29	Group	12 × 2	24	Self	4 m
Rose et al.	2008	41	Individual	$16 \times ¾^b$	12	Self	None
Rose et al.	2009	64	Group	16 × 2	32	Self	None
			Individual	$16 \times ¾^b$	12		
Rose	2010	56	Group	16 × 2	32	Carer	None
Collado-Castillo[c]	2010	36	Group	??	??	Self	None
Willner et al.	2013a, 2013b	179	Group	12 × 2	24	Self/carer	6 m

[a] The numbers listed are the total number of participants in the study; they may not have been equally distributed between conditions

[b] Participants in the study by Rose et al. (2008, 2009) received 14–18 sessions of 30–60 min duration. The figures in the table provide a rough average

[c] The study by Collado-Castillo (2010) was published in abstract only; few details are available

plan used by Rose et al. (2000) but was a little shorter. The first study involved nine 2-h sessions delivered by two clinical psychologists and the second study involved 12 sessions that were delivered by day service staff, who were trained and closely supervised by a clinical psychologist. The participants in all of these studies were adults with mild to moderate IDD. As almost all of these studies used a group format, they inevitably were able to devote less attention to individuals' cognitive processes, and focussed rather on helping participants to understand better the situations in which they experienced anger and acquire a repertoire of coping skills to deploy when those situations arose.

The study by Lindsay et al. (2004) used a very similar intervention that was delivered to a similar client group, but at a slower pace (40 sessions of 40–60 min), commencing with relaxation and making extensive use of role-play in later sessions. The study by Hagiliassis, Gulbenkoglu, Di Marco, Young, and Hudson (2005) also used an intervention very similar in content and pace to that of Willner, Brace, and Phillips (2005), but varied from other studies in including some participants with more severe disabilities. Clinical psychologists delivered both of these interventions. The study by Collado-Castillo (2010), which was published in abstract only, reported positive results for two interventions, cognitive reappraisal and problem solving, but few further details are available.

In reviewing these studies, a number of methodological issues that potentially bias the outcomes were identified:

1. The anger treatment studies were conducted in a forensic setting and the results may therefore not generalize to community settings.
2. Only three studies used randomized allocation to groups (Hagiliassis et al., 2005; Taylor et al., 2002; Willner et al., 2002) and one of these was extremely small (Willner et al., 2002).
3. In some studies the groups were not well matched at baseline (Lindsay et al., 2004; Willner et al., 2005).

4. There was some overlap between groups or samples: for example, in some studies, participants in the control group were later added to the intervention group.
5. The relatively small size of most studies meant that they involved few centers and few therapists, and where a group format was used, very few groups.
6. Several studies, including some of the largest did not include a long-term follow-up (Rose, 2010; Rose et al., 2009) and, with few exceptions (Hagiliassis et al., 2005; Taylor et al., 2005; Willner et al., 2005), studies that did include long-term follow-up only followed up the intervention group, not the controls.
7. One study was conducted over a period of more than 10 years, during which time the characteristics of the population changed (Lindsay et al., 2004).
8. One study only used third-party (carer) ratings to assess anger (Rose, 2010). All other studies included first-person reports from service users, but only four studies included both of these sources of information (Lindsay et al., 2004; Taylor et al., 2005; Willner et al., 2002, 2005).
9. Some of the interventions were manualized (Hagiliassis et al., 2005; Taylor et al., 2002, 2004, 2005; Willner et al., 2005), but most were not.
10. In those studies where the intervention was manualized, no assessment of fidelity to the manual was reported.
11. In all studies, the authors themselves or close colleagues delivered the therapy, raising the possibility of therapist allegiance effects (Chambless & Hollon, 1998; Luborsky et al., 1993, 1999; Luborsky, Diguer, Luborsky, & Schmidt, 1999).

The study by Willner et al. (2013a,b) was designed to address these issues. It was a large ($N = 179$), community-based, phase-3 study involving multiple groups of adults with mild to moderate intellectual disabilities (14 groups in each arm of the trial), with post-intervention and long-term (6-months post-intervention) follow up. All groups had different therapists, allocation to treatment or waiting list arms was random, the intervention was manualized and fidelity-checked, and multiple raters participated (service users, key-workers, and home carers). The intervention was based on those implemented previously by Willner and Rose (both of whom were investigators on this study), and fidelity to the manual was relatively good, though the quality of delivery varied considerably across groups (range 40–86 %, with the exception of one group rated at 19 %). The intervention was delivered within day services. Following Willner et al. (2005), the therapists were not psychologists (as in all of the other anger studies), but members of staff in the services that the participants attended, who were trained and supervised by clinical psychologists, but had no previous experience of CBT.

Table 11.4 lists the outcomes of all of these studies, and shows that all studies reported significantly better outcomes in the treated group relative to waiting-list control groups. These improvements were maintained at 3- to 30-month follow-up in all of the studies that included a follow-up assessment. Considering only the anger management studies and outcomes on measures of anger disposition (AI, PI, or DPI in Table 11.4), so as to compare like with like), similar large average effect sizes were found for group ($n = 10$ studies; $d = 1.15$) and individual ($n = 2$ studies; $d = 1.38$) formats, and for self-ratings ($n = 9$ studies, $d = 1.13$) and carer ratings ($n = 3$ studies, $d = 1.38$). Overall, anger ratings decreased by around 17 % in the intervention groups, whereas they increased by around 7 % in the control groups.

The outcomes for the phase 3 study were somewhat smaller than expected on the basis of earlier trials (Willner et al., 2013a, 2013b). One potential explanation is that the intervention was delivered by lay therapists, rather than psychologists, which would be consistent with a report that assistant psychologists achieved smaller effects on the expression of anger by people with IDD than qualified psychologists (Rose, 2013). Also relevant is that the majority of the anger management techniques included in the intervention were aimed at changing the situation

Table 11.4 Outcomes of controlled studies of anger interventions for people with intellectual disabilities[a]

Study	Date	Format	Rater	Instrument[b]	Control		Intervention		Effect size[c,d]
					Mean	SD	Mean	SD	
Individual anger treatment in forensic settings									
Taylor et al.	2002	Individual	Self	PI	108.3	17.8	77.4	19.8	1.61**
			Staff	WARS	109.0	84.6	63.8	49.3	0.61
Taylor et al.	2004	Individual	Self	IPT	107.8	13.1	67.5	23.2	2.24**
Taylor et al.	2005	Individual	Self	NAS	93.7	13.4	91.7	12.2	0.15*
			Self	PI	92.5	21.3	84.7	21.8	0.34
			Self	STAXI	106.8	26.2	85.7	33.3	0.71
			Staff	WARS	79.4	75.5	59.1	50.8	0.29
Group or individual anger management in community settings									
Rose et al.	2000	Group	Self	AI	102.5	10.4	88.5	11.8	1.27***
Willner et al.	2002	Group	Self	AI/PI	116.4	17.2	86.3	28.8	1.31**
			Carer	AI/PI	102.2	15.6	83.7	15.9	1.17*
Lindsay et al.	2004	Group	Self	DPI	100.0	31.0	69.5	40.6	0.89*
				diary	94.2	12.0	43.9	23.9	2.84***
Willner et al.	2005	Group	Self	PI	111.6	32.2	86.7	40.7	0.68
			Carer	PI	119.5	40.6	55.8	23.8	1.82***
			Carer	PACS	91.8	38.4	219.8	52.8	2.33***
Rose et al.	2005	Group	Self	AI	103.0	12.7	90.3	11.7	1.06***
Hagiliassis et al.	2005	Group	Self	NAS[e]	101.4	23.6	120.5	26.3	0.77**
Rose et al.	2008	Individual	Self	AI	104.2	14.3	86.7	14.9	1.20***
Rose et al.	2009	Group	Self	AI	104.2	10.0	88.0	11.4	1.52***
		Individual	Self	AI	104.2	10.0	85.4	14.0	1.57**
Rose	2010	Group	Carer	AI	102.4	9.5	90.3	14.9	0.99**

(continued)

Table 11.4 (continued)

Study	Date	Format	Rater	Instrument[b]	Control		Intervention		Effect size[c,d]
					Mean	SD	Mean	SD	
Willner et al.	2013a, 2013b	Group		*Anger disposition*					
			Self	PI	108.4	33.6	96.5	67.7	0.24 (0.20)
			Self	PACS-IPT	107.7	34.2	84.5	44.1	0.60**
			Key-worker	PI	114.9	60.1	96.0	63.2	0.31 (0.27)*
			Home carer	PI	114.5	54.2	104.0	48.3	0.20 (0.13)
				Challenging behavior					
			Key-worker	ABC-H	125.7	101.0	69.9	68.1	0.67 (0.45)***
			Key-worker	ABC-I	118.3	102.0	68.2	70.9	0.60 (0.37)***
			Key-worker	MOAS	74.8	109.0	67.6	100.0	0.15 (0.11)
			Home carer	ABC-H	118.6	118.0	78.8	82.2	0.41 (0.32)*
			Home carer	ABC-I	100.0	77.4	68.9	80.7	0.41 (0.22)
			Home carer	MOAS	89.4	104.0	58.4	122.8	0.28 (0.11)
				Use of anger coping skills					
			Self	PACS	99.0	81.4	147.5	97.3	0.51 (0.51)***
			Key-worker	PACS	117.9	84.1	179.9	136.6	0.53 (0.53)***
			Home carer	PACS	117.1	83.6	251.0	190.6	0.50 (0.18)

[a] In order to present data on a standardized scale across studies and measures, all data are reported as percentage of the pre-treatment mean. Where the relevant data were missing from the published paper, they were requested from the author. For studies that employed more than one anger-related outcome measure and more than one rater, outcomes are listed for all measures and all raters

[b] *ABC* aberrant behavior checklist (*H* hyperactivity scale, *I* irritability scale); *AI* anger inventory, *DPI* Dundee Provocation Inventory, *IPT* imaginal provocation test, *MOAS* Modified Overt Anger Scale, *NAS* Novaco Anger Scale PACS: Profile of Anger Coping Skills (an increase on this scale indicates better coping); *PI* provocation inventory, *STAXI* State-Trait Anger Expression Inventory, WARS ward anger rating scale. See the actual studies for further details

[c] Effect sizes were estimated by Cohen's d (Cohen, 1988), calculated as the difference of intervention and control group raw scores post-treatment, divided by the mean of the two standard deviations. Conventionally, small > 0.2; medium > 0.5; large > 0.8. $^{**}p<0.01$; $^{*}p<0.05$ for the difference between intervention and control groups

[d] Differences in baseline scores were generally very small but in one case (Willner et al., 2005: carer ratings) intervention group scores were 25 % lower than control group scores at baseline. In order to correct for this difference, pre-treatment means were subtracted from post-treatment means before calculating d. Because a standardized methodology has been applied to all studies, reported effect sizes are not always identical to published values. For the study of Willner et al. (2013a, 2013b) the figures in parentheses are the published effect sizes, which were calculated using a regression model with baseline scores as a covariate

[e] In this study, an increased score on the NAS corresponds to a decrease in anger

(e.g., walking away, help-seeking) rather than the person. These techniques represent responses to anger-provoking situations that can be effective in limiting the build-up of anger, particularly if they become automatic and habitual (Hayes et al., 1989), but behavioral techniques leave intact the potential of situations to trigger anger if habitual strategies cannot be implemented (e.g., a small space that prevents walking away or the absence of anyone available to provide help). Cognitive restructuring techniques have the potential to prevent trigger situations being perceived as anger provoking, and so decrease the potential for anger, but in this study, cognitive techniques were introduced late in the program, with little opportunity for service users to assimilate them. Consequently, and given their lack of professional training, lay therapists were observed to overlook opportunities to work cognitively with service users: the therapy manual did not ask them to do so until late in the program, and the training they had received did not prepare them to recognize these situations as opportunities for therapeutic input (Willner et al., 2013b). More experienced therapists might have been more ready to take advantage of these opportunities.

Interestingly, particularly large effect sizes (>2) were reported for three measures that were not included in any of several meta-analyses of this area: anger expression as assessed using the Imaginal Provocation Test (IPT: Taylor et al., 2004) or a diary measure (Lindsay et al., 2004), and anger coping as assessed using the Profile of Anger Coping Skills (PACS: Willner et al., 2005). The common feature of these measures is that, relative to standard measures, they increase the salience of the situation about which a report is being made, by requiring reflection on either a detailed scenario (IPT) or on recent personal experience rather than hypothetical events (diary and PACS). This raises the possibility that the standard measures of anger expression underestimate the extent to which these interventions change behavior in real life situations.

There have been several meta-analyses of CBT for anger in the intellectually able population. For example, De Guiseppe and Tafrate (2003) reported an overall effect size of 0.86, based on 57 studies of offenders ($N=1841$), while Del Vecchio and O'Leary (2004) reported an overall effect size of 0.76, based on a partially overlapping sample of 23 studies of non-institutionalized participants ($N=1340$). A recent meta-analysis of comparable studies of adults with IDD reported a very similar outcome: an overall effect size of 0.88, based on within-group pre–post changes reported in nine studies ($N=168$), with similar effect sizes for group and individual interventions (Nicoll, Beail, & Saxon, 2013). This result is almost identical to that reported by Vereenooghe and Langdon (2013) for between-group comparisons of treatment with control groups of adults with IDD (0.83). Overall, it appears that the effects of CBT on anger outcomes for people with IDD are similar to those seen in the general population of intellectually able people.

Depression

Two small controlled trials in depression (McCabe, McGillivray, & Newton, 2006; McGillivray, McCabe, & Kershaw, 2008) have reported that, in people with relatively mild (but clinical) levels of depression, a brief group-based intervention caused significant decreases in both depression scores and the occurrence of negative automatic thoughts, confirming that the intervention engendered cognitive change (in addition to clinical improvement). Interestingly, in terms of the change in depression scores, the intervention was as effective when delivered by support staff using a treatment manual (McGillivray et al., 2008) as when delivered by trained therapists (McCabe et al., 2006), albeit that the staff-delivered intervention was longer than the therapist-delivered intervention (12 vs. 5 2-h sessions, respectively) and produced a substantially larger effect size (because within-group variability was smaller). In both studies, the changes were maintained at 3-month follow-up.

A more recent small, randomized controlled trial did not support these findings. Hassiotis et al. (2013) found no significant effect of a

16-session (1 h/week) cognitive behavioral intervention for anxiety and depression, on either outcome. The description of the intervention is consistent with the principles outlined in this chapter, based on a simplified version of cognitive therapy using behavioral experiments to challenge unhelpful thinking styles. The manual for the study also contained psycho-educational materials, including chapters on the symptoms and presentation of mood disorders, relaxation, clinical vignettes, and a leaflet about how carers could support the therapy (Hassiotis et al., 2013). However, it is arguable that the study may have been too ambitious in targeting two separate clinical disorders that have different formulations, and so may require different interventions (Vereenooghe & Langdon, 2013). Also, it is unclear how well participants were able to engage with the intervention. Perhaps the most significant factor to consider is that the therapists who were recruited to the trial appear not to have had any prior experience of working with people with IDD and adapting CBT to address their cognitive limitations. This is the only controlled trial of CBT for common mental health problems that failed to report a significant effect and given the problems with the study, it should perhaps be considered as an understandable anomaly.

Practice Recommendations

We conclude with some practice recommendations that flow from the literature we have reviewed, and from clinical experience of working with people with IDD within a CBT framework.

Screening

We recommend against the use of psychometric tests when deciding how to proceed with a newly referred client. While psychometrics are of undoubted value in helping to understand a client's intellectual limitations they cannot support the conclusion that an individual client would be unable to engage with a CBT-based intervention. Indeed, striking clinical outcomes are possible with some clients who would have failed any conceivable screening test (e.g., Willner, 2004). In our view, the best way to determine whether a client is able to engage with an adapted CBT program is to try it out.

Features of Intellectual Disability

When constructing a formulation, it is important to take into account that IDD itself has a number of features that, while not inevitable for any individual client, should at least be considered. The first is that cognitive limitations might be a feature of the formulation. Any situation that has the potential for provoking anxiety requires understanding, assimilation and response. This will involve emotional, cognitive, physiological, and behavioral reactions and it is one purpose of CBT to analyze misunderstandings, errors in interpretation, distortions in immediate reaction, and problematic responses. It is also likely that a person with IDD will require more time to assimilate novel and anxiety provoking situations. The cognitive limitations themselves may be a factor in the confusion or misunderstanding in any given situation and therefore should be considered as part of the formulation.

It is also the case that CBT for certain problems requires perspective taking. There is often an assumption that people will be able to take the perspective of others and in doing so will generate an empathic remorseful response. Therefore, during anger treatment, we may expect that the client understands that other people may have felt threatened or frightened in specific situations that are discussed during treatment. The available evidence would suggest that empathic responses are related to intelligence (Jolliffe & Farrington, 2004). Empathic responses are predicated on perspective taking, which varies with developmental level. With a client group who have intellectual and developmental delay, there is certain to be corresponding delay in the ability to take the perspective of other people and as a consequence, to experience empathy, and as a consequence, a corresponding difficulty in experiencing remorse. In these cases, the therapist must understand that cognitive deficits and developmental delay may be preventing the client from generating a truly empathic response, or at least, contributing to the difficulties in doing so. This does not prevent the client from benefiting from CBT but does alert the therapist to the possibility that certain targets may not be readily achievable.

Issues Related to Intellectual Disability

There are issues related to IDD that should automatically be reviewed to assess whether or not they are contributing to the person's difficulties. By its very nature, IDD may involve a degree of dependency. Therapists should bear in mind that for many clients this dependency may be placed on a statutory footing by a Guardianship Order which allows others to make decisions for them in the areas of their personal welfare, financial arrangements or housing. Therefore, a dependency on others should not be considered in any way pathological when legal arrangements are in place that will essentially hinder individuals from making their own decisions.

Another related issue is that difficulties with stigma and negative social comparison have been shown to be a developmental feature of many individuals with IDD (Dagnan & Waring, 2004). The experience of repeated failure, the experience of stigma at school or other daily activities and the experience of repeated negative social comparison should at the very least be considered automatically when constructing a formulation. We are not suggesting that these issues will be incorporated inevitably into the formulation. Rather, we are prompting therapists to consider issues that have emerged from the bodies of research into important developmental issues for people with IDD that may or may not be important to include in the formulation.

Motivation

In outpatient work with the general population, the therapist is unlikely to consider whether or not the patient is motivated, even to attend sessions. When a patient is referred by their general practitioner, psychiatrist, or physician, it can be assumed that the individual is motivated because of their difficulties. This is not the case in a referral of a person with IDD. That is not to say that clients do not have motivation, which they often have in abundance, but the locus of their concern may not be shared by those around them, family or carers. They may see the source of the difficulties as interference from neighbors, restrictions on their spending, problems arising from family requests to conform with family or residential regimes, or other outside influences. Alternatively, the individual may understand that they are experiencing difficulties that arise from intra-psychic problems but lack a wish to do anything about it. Because of this, it is important to consider how to motivate participants from the outset of treatment.

This issue is integrally linked to that of communication in that it relates to the engagement of clients in the therapeutic process. Treatment should be set up in a way that is not only accessible to clients with IDD but also interesting and even "fun." Exercises relevant to the issues involved should be planned for individual sessions. These exercises can promote curiosity, interest, and humor. For example, Lindsay et al. (2011) incorporated some physical exercise into treatment in order to illustrate the way in which physiological responses are related to behavioral activity, thereby linking the physiological and behavioral channels of emotion. In group situations, a quiz can be introduced, specifically on the topic that has been dealt with during treatment, to review the extent to which individuals have retained information presented during sessions. In this way, treatment can be kept lively and interesting.

A range of skills is required to engage and maintain individuals with IDD in CBT. Although a basic requirement, it is insufficient to understand the principles and procedures of CBT. It is also important for a therapist to develop a range of personal skills in order to promote the therapeutic relationship. Unlike other client groups, a therapist may need to develop skills to engage the individual at the outset. The therapist will then have to adapt the approach considerably to ensure that the person with IDD understands the requirements of treatment. It is also helpful if the therapist is able to keep treatment interesting through humor or other engaging "tricks" to initiate and maintain motivation for continued attendance.

Engagement

When conducting psychological treatment with members of the general public it is assumed that clients will understand the requirements and processes of treatment. Where there might be some difficulties in the technical aspects of treatment, it is again assumed that clients will have the capacity to understand explanations of procedures. For clients attending outpatient clinics in mainstream services there is little doubt of their capacity to engage with the process. Such an assumption cannot be the case in CBT for people with IDD. The most important aspect of any psychological treatment is that the patient understands what we (the therapists) are trying to do. Given that all of our clients have de facto limitations in cognitive functioning this will give rise to corresponding limitations in communication. Put simply, if the client is not clear about the requirements and processes of treatment, it is unlikely to lead to a successful outcome.

We have already explained some procedures that therapists can undertake when adapting treatment for the better engagement of clients. It should be emphasized that this is not a simple process because ensuring engagement should not diminish the various components of CBT. Therapists who are accustomed to treatment with intellectually able clients may be at a loss as to how to explain the procedures in a straightforward fashion with no use of technical terms and jargon. This will often require preparation and planning on the part of the therapist, who needs to ask "How will I explain the term negative self statements?" "What term will I use for schema?" "How will I am sure that the client understands me?" and so on.

Clients with IDD have spent a lifetime in a linguistic world that is relatively complex, and may have learned extremely effective techniques to cover for the lack of understanding. This may involve simple acquiescence, such as, answering "Yes," with a nod of the head for emphasis, when asked if he or she understands. Alternatively, it can involve a relatively complex response incorporating humor to divert attention from a general lack of understanding, such as "Oh … my head is out the window today can you tell me again," and following up a repeat explanation by saying "I get it this time." It can be difficult for a therapist to ensure understanding without being patronizing or disrespectful. In these cases, role-playing with a colleague who is knowledgeable about the client group can be particularly helpful. It is also a good habit to review sections of treatment in the client's own words (for example: "That's great that you've got it. So let's go over it again – you tell me this time what we've been talking about"). If areas of misunderstanding arise it is important to deal with them in a positive fashion ("That's good. Now there's just one thing I'd like to go over again – let's talk about this bit again").

The Pace of Treatment

Given the problem of acquiescence, a therapist must avoid making a series of explanations with which the client continually agrees. The strength of CBT for people with IDD is that the Socratic method is a central procedure. If the therapist persists with the Socratic method, the inductive process supports clients to develop their own understanding of targets of treatment and the way in which they can move towards those targets, and to develop their own lexicon of treatment that incorporates a personal vocabulary. However, this may in turn generate another difficulty unfamiliar to those who have dealt with other client groups: using inductive reasoning to develop the content of treatment for people with IDD can be very slow. (When trainees first observe treatment sessions, they invariably find the slow pace surprising.) The therapist may have prepared material to cover during the session and it may become clear that the Socratic process is slowing progress to such an extent that this material will not be completed. The therapist should be comfortable that the material can wait until the next session: there is no point in rushing if there is any possibility that the client will not understand fully, and this holds true even when the therapist feels there is a pressure either of time or attendance (a fear that the client may not return for another session). To emphasize, it is better that the therapist feels uncomfortable that treatment has not been completed than that treatment be completed but the client has insufficient comprehension.

Conclusion

An important therapeutic skill in CBT for people with IDD is to ensure engagement while adhering to the procedures and principles of CBT. We have provided a number of illustrations of how each phase of CBT can be adapted to enable the therapist to incorporate the stages of treatment in a way that is meaningful for the client. It is all too easy to stray from the normal processes when attempting to ensure engagement. The therapist should attend to each phase of treatment in an orderly fashion with regular reference to a CBT manual and clinical supervision.

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Mindfulness

12

Yoon-Suk Hwang and Nirbhay N. Singh

Introduction

People with intellectual and developmental disabilities (IDDs) are at increased risk of health problems (Cooper, Smiley, Morrison, Williamson, & Allan, 2007; Dykens, 2000; Emerson, 2007). Children and young people with IDDs are over seven times more likely to have a diagnosed psychiatric disorder than their peers without IDDs (Emerson, 2003) and are more likely to receive mental health treatment for more severe mental health disorders, such as psychosis and personality disorders (Howlett, Florio, Xu, & Trollor, 2015). Adults with IDDs are also exposed to elevated risks of mental ill-health, along with problem behavior (Cooper et al., 2007). Problem behavior occurs in about 10 % of individuals with IDDs (Lowe et al., 2007), and this places significant hardship on caregivers (Beer, Ward, & Moar, 2013; Hastings & Brown, 2002). Problem behavior is also a major contributor to the overrepresentation of individuals with IDDs in criminal systems (Carson et al., 2010).

Mindfulness-based practice has been used to address behavioral, physical, and psychological problems in individuals with IDDs (Singh et al. 2011c, 2013a). Singh, Wahler, Adkins, and Myers (2003) introduced mindfulness-based practice to the field of IDDs in an intervention in which an adult with IDDs and mental illness who was about to lose his community living arrangement because of his uncontrolled aggressive behavior was trained in mindfulness over a period of 5 days. His mindfulness practice continued for 12 months. The results included reductions in aggressive behavior and maintenance of community placement. Follow-up studies investigated the effects of mindfulness training for individuals with IDDs, including family and professional caregivers (Myers, Winton, Lancioni, & Singh, 2014). Recent mindfulness-based interventions have extended their objectives to include the behavioral, physical, and psychological well-being of individuals with IDDs and have diversified their research design to include randomized trials for investigating intervention effects.

Our aim in this chapter is to present mindfulness and mindfulness-based intervention studies involving individuals with IDDs in such a way as to allow practitioners in the field of IDDs to understand and make good use of mindfulness practices. We introduce mindfulness in its contemporary and traditional contexts. We then

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discuss why and how mindfulness-based interventions have been used for individuals with IDDs. We review mindfulness studies involving individuals with IDDs according to their intervention and research design and their methods. Finally, we present recommendations to strengthen the applications of mindfulness as an evidence-based practice.

What Is Mindfulness?

Mindfulness within Its Contemporary Context

Mindfulness meditation is a form of attention and awareness training. It has been used in the fields of health and social science as an evidence-based practice, where it has demonstrated positive changes in mental and physical well-being. These changes include stress reduction (Baer, Carmody, & Hunsinger, 2012), anxiety reduction (Kabat-Zinn et al., 1992), depression relapse prevention (Deyo, Wilson, Ong, & Koopman, 2009; Segal, Williams, & Teasdale, 2002), and increased psychological well-being (Carmody & Baer, 2008). The clinical application of mindfulness began in the late 1970s with the Mindfulness-Based Stress Reduction (MBSR) program for people with chronic health problems (Kabat-Zinn, 1980). Initially, Kabat-Zinn (2011) presented the meditation practice in MBSR to a medical audience using the concept of attention self-regulation. He subsequently introduced the term "mindfulness" to describe his approach to meditation practice, which he located in the teachings of the Buddha as practiced in both the Theravada and Mahayana traditions, as well as within Yogic traditions.

Considering his visionary contribution to incorporating Eastern meditation practices into modern health science, it is not surprising that the most frequently cited definition of mindfulness comes from Kabat-Zinn (2003, p. 145), where he described it as "the awareness that emerges through paying attention on purpose, in the present moment, and nonjudgmentally to the unfolding of experience moment by moment." This was presented as an operational, as opposed to a theoretical, definition of mindfulness and describes how mindfulness functions in the specific context within which he applied it. Despite subsequent attempts to introduce greater precision into the definition of mindfulness (e.g., Bishop et al., 2004; Brown, Ryan, & Creswell, 2007), contemporary mindfulness literature continues to echo this early understanding (e.g., Baer, 2003; Harnett & Dawe, 2012) as it is applied in various forms of psychotherapy, such as Mindfulness-Based Cognitive Therapy (MBCT; Segal et al., 2002).

Contemporary applications of mindfulness find their origins in the teachings of Gautama Buddha, an Indian teacher who flourished sometime between the sixth and the fourth centuries BCE. The adaptation of mindfulness practice to its contemporary context may be facilitated by an exploration of its historical and philosophical origins. It is important to note here that a turn toward the Buddha does not represent a turn away from secular modernity toward traditional religion. In part, this is because the very idea of "religion" that permeates the European tradition is itself an invention of European thought (King, 1999). The Buddha taught dharma, and dharma is an Indian cultural category that is not isomorphic with any specific European cultural category, whether religion, psychology, or philosophy, although the Buddha's dharma has been approached as all these. In the context of modernity, the Buddha can be seen as teaching a kind of practical phenomenology (Kalupahana, 1992) undertaken to cultivate human flourishing (Gowans, 2003) and, as such, a possible source of data for any contemporary attempt to study and understand the human condition (see Shonin, Van Gordon, & Singh, 2015).

Mindfulness within Its Traditional Context

The word mindfulness has its origins in the Pali word *sati*, which literally means memory (Gunaratana, 1980, 1991). Bodhi (2000) pointed out that *sati* as a mental factor "signifies presence of mind, attentiveness to the present, rather than the faculty of memory regarding the past" (p. 86).

Sati keeps the present in mind, an activity that could be described as remembering the present or remembering to be present. The task of mindfulness meditation is simply to note whatever comes up as it arises, so that one is anchored onto the present experience, here and now, without getting distracted from it (Bodhi, 1994). For example, if an unwholesome mental state (e.g., anger) arises, a meditator notes it without thinking further about it or interfering with it. If she does think further about it and becomes swept away by angry thoughts, she simply notes this experience and in doing so returns to the present. This noninterfering quality of *sati* enables a meditator to clearly observe the nature of anger, for example, and its underlying motives (Anālayo, 2006). Underlying this activity is the process of remembering to keep the present in mind (Gethin, 2001).

Mindfulness is cultivated through the four applications of mindfulness (*satipatthana*), the mindful contemplations of body (i.e., breath), of feelings (i.e., hedonic tones such as pleasant and unpleasant), of states of mind (i.e., desire and aversion), and of phenomena (i.e., any objects of the senses that arise during contemplation) (Anālayo, 2006, 2015). In each instance, mindfulness anchors the mind in the present (Bodhi, 1994). While mindfulness can be conceptually isolated as a unique mental factor, however, it never works alone but always in partnership with other factors such as clear understanding (*sampajanna*). Clear understanding facilitates the development of wisdom (Gunaratana, 1980). When the mind remains anchored in present experience, we may learn to notice our habitual behavioral or thought patterns and, when this noticing is maintained over time, an understanding of these patterns can arise. It is therefore important to understand that if we are to understand how mindfulness is meant to work, we must see it as it operates within its practical context, that of the eightfold path. The eightfold path constitutes a practical system of training aimed at the development of wisdom and the eradication of human suffering.

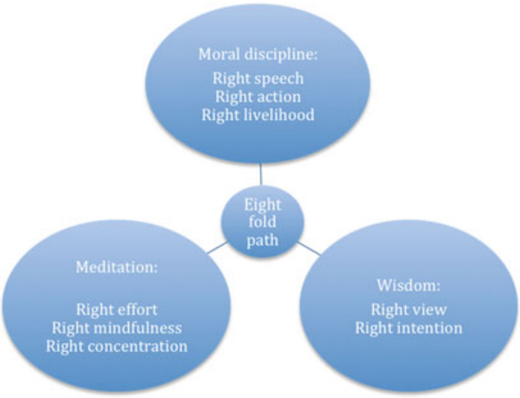

Fig. 12.1 Three training groups of the eightfold path

The eight factors that together constitute the path are distributed into three training groups, those of moral discipline, meditation, and wisdom (Fig. 12.1). Right speech, right action, and right livelihood comprise the moral discipline group. Moral discipline is not a "prescribed guide to action" (Bodhi, 1994, p. 43) but ameans of training oneself in activities that are both intrinsically fulfilling and, in turn, lead to an authentic and psychologically healthy way of life. The meditation group is made up of right effort, right mindfulness, and right concentration. Right view and right intention constitute the wisdom group. All these factors are modified by the word "right" to indicate that they are meant to be practiced in such a way that they lead toward the reduction of suffering rather than its cultivation. The relationships among the three training groups can be seen as constituting a linear as well as a nonlinear system. The linear progression begins with training in moral discipline, which provides the foundation for meditation practices, which in turn give rise to the growth of wisdom. Wisdom, finally, is expressed in the ethical life of the practitioner (Bodhi, 1994).

The path is also characterized by dynamic nonlinear relationships. For example, the practice of moral discipline encourages a social and psychological peace that supports the practice of meditation. The factors of the wisdom group assist the learning of the craft of meditation and how to extend the lessons of that craft into everyday life—that is, back into the realm of moral discipline. And, the cultivation of the mind through meditation encourages the growth of wisdom.

As well as across the groups, these nonlinear relationships are also evident within any given training group. For example, the three factors of the meditation group, right effort, right mindfulness, and right concentration, mutually support each other, and progress in the training requires maintaining an ongoing balance among them (Bodhi, 1994). Right effort represents the active, purposive aspect of the practice. Right concentration indicates the unification of mind, which allows awareness to remain still and undivided (Pandita, 1993), and it represents the receptive aspect of the practice. Right mindfulness creates a felt continuity of awareness by its activity of remembering awareness and its object, and this allows a balance to emerge between the active and receptive aspects of the practice.

The various ways in which mindfulness practice is explained within the contemporary literature can be reframed in terms of the path factors outlined above. For example, Bishop et al. (2004, p. 232) described mindfulness practice as: “The client maintains an upright sitting posture, either in a chair or cross-legged on the floor and attempts to maintain attention on a particular focus, most commonly the somatic sensations of his or her own breathing. Whenever attention wanders from the breath to inevitable thoughts and feelings that arise, the client will simply take notice of them and then let them go as attention is returned to the breath. This process is repeated each time that attention wanders away from the breath.”

Mindfulness here is the practitioner’s activity of remembering (awareness of) the breath, as well as remembering the experience of distraction each time it is noticed. Concentration is the mind’s resting upon the breath. The work of effort is also evident in the continued commitment of returning again and again to one’s present experience of the breath. Another aspect of effort, not specifically mentioned in this passage but axiomatic to it, is the initial determination to engage in mindfulness practice, a decision that cannot be externally forced. The importance of teaching mindfulness as supported by concentration and effort is acknowledged in recent mindfulness intervention studies for individuals with IDDs (e.g., Singh et al., 2014).

Individuals with IDDs: Elated Risks of Mental and Behavioral Ill-Health

Children and adults with IDDs are at increased risk of health problems (Emerson, 2007; Howlett et al., 2015), which presents as a strong potential to impede the quality of life of those with IDDs and their caregivers. The majority of prevalence studies have consistently reported elevated psychiatric and behavioral problems in individuals with IDDs. For example, Emerson (2003) compared the prevalence of psychiatric disorders among children and adolescents with IDDs and their peers without IDDs. This population-based study revealed that children and young people with IDDs were over seven times more likely to have a diagnosed psychiatric disorder than their peers without IDDs (e.g., 39 % for IDD group versus 8.1 % for non-IDD group). Conduct disorder, anxiety disorder, and pervasive developmental disorder, in particular, were more prevalent in children and adolescents with IDDs than those without IDDs. A longitudinal study following the psychiatric conditions of 582 young people with IDDs (aged 4–19 years) for over 4 years also revealed that psychological problems in young people with IDDs were 3–4 times more prevalent than their counterparts without IDDs, yet less than 10 % of these young people received specialist services (Tonge & Einfeld, 2000).

Adults with IDDs also present heightened mental health support needs. After conducting comprehensive health checks on 1023 adults with IDDs, another population-based prevalence study reported point prevalence of mental ill-health of 40.9 % in adults with IDDs (Cooper et al., 2007). Problem behaviors were identified as the most prevalent type of mental ill-health. These results were consistent with those of previous studies that called for the development of improved health-care interventions and services, supporting individuals with IDDs to manage potentially stressful life events (e.g., Cooper & Bailey, 2001; Cooper, Melville, & Morrison, 2004).

A recent Australian study using ambulatory mental health data revealed that the need for the provision of mental health services to children and young people with IDDs remains unchanged

(Howlett et al., 2015). The analysis of a community mental health service data set over a 6-year period showed that children and adolescents with IDDs were more likely to receive ambulatory mental health treatment for more severe mental health disorders, such as psychosis and personality disorders. They were more than twice as likely to have an unknown diagnosis than their peers without IDDs. Service use profile also showed that individuals with IDDs had 1.6 times more face-to-face contacts and 2.5 times longer face-to-face contact time than their counterparts without IDDs. These results together clearly indicate that people with IDDs have not only more frequent but also more complex service needs in comparison to those without IDDs.

Adults with IDDs are significantly overrepresented in the criminal justice systems (Hayes, Shackell, Mottram, & Lancaster, 2007; Søndenaa, Rasmussen, Palmstierna, & Nøttestad, 2008) and mental ill-health and unmet health needs are also of major concerns for them. A cross-sectional study conducted between 2008 and 2010 with a sample of 1279 adult prisoners suggested that almost one in ten adult prisoners (i.e., 9 %) had IDDs and, of these, more than half had a lifetime mental disorder (Dias, Ware, Kinner, & Lennox, 2013). Prisoners with IDDs and coexisting mental health issues are also more likely to reoffend than those with IDDs alone. They are also significantly more likely to have a current diagnosis of depression and to use antipsychotic medication than their peers without IDDs.

Psychiatric disorders in individuals with IDDs often include problem behaviors. Problem behaviors, in fact, were identified as the most prevalent type of mental ill-health problem among adults with IDDs (Cooper et al., 2007). Holden and Gitlesen (2009) raised a concern about explaining problem behaviors mainly by a way of psychiatric symptomatology. They noted that this approach could potentially oversimplify the complex and dynamic relationships between psychiatric symptomatology and problem behaviors. Problem behaviors might be an atypical presentation of underlying psychiatric symptoms, or they might be a secondary feature of psychiatric symptoms. Examination of different approaches to the relationships between problem behaviors and psychiatric symptomatology is beyond the scope of this chapter. Nevertheless, problem behaviors of individuals with IDDs warrant careful attention.

Problem behaviors occur in about 10 % of individuals with IDDs (Lowe et al., 2007). Emerson (1995) defined challenging (problem) behavior as that which would threaten the physical safety of the person or of others or result in that person's denial of access to community facilities. It includes aggressive behavior, self-injurious behavior, and stereotypic behavior. Whether behavior is viewed as challenging (problematic) or not depends upon the cultural context within which that behavior occurs. Owen et al. (2004) found that individuals with IDDs who were exposed to greater negative life events were rated as having more frequent problem behaviors, especially aggressive behavior. Aggressive behavior is of a particular concern for individuals with IDDs. It has been seen as a major reason leading them to criminal pathways. For example, from a case record analysis of over 450 offenders with IDDs, Carson et al. (2010) identified physical aggression and a history of problem behaviors as major predictors for community services or secure provision.

Researchers have endeavored to discover associated factors for an elevated risk of mental ill-health, including problem behaviors, in people with IDDs. Dykens (2000) suggested multiple mediating factors for the manifestation of psychopathology in people with IDDs. These include psychological (e.g., self-image fueled by learned helplessness and depression), familial (e.g., family stress), social (e.g., social stigma and abuse), and biological (e.g., epilepsy) factors.

In their population-based studies of children, adolescents, and adults with IDDs, Emerson (2003) and Cooper et al. (2007) undertook a series of bivariate and multivariate analyses to identify factors associated with an increased risk of psychological and behavioral issues in individuals with IDDs. Age-specific associated factors were found. Punitive child management strategies were found to be moderately associated with the assessed mental health status of the children and adolescents with IDDs (Emerson, 2003) and smoking with adults with IDDs (Cooper et al., 2007). For children and adolescents with IDDs, boys were more likely than girls to have a diagnosed psychiatric disorder, such as conduct disorder (Emerson, 2003). For adults with IDDs, however, females were more likely to have mental ill-health (Cooper et al., 2007). Children living in lower-income households, living with single parents, and living in detrimental family environments were more likely to have a diagnosed disorder (Emerson, 2003). For adults with IDDs, those living with paid caregivers were more likely to suffer mental ill-health (Cooper et al., 2007). Individuals with IDDs, regardless of age, who underwent a greater number of stressful life events were more likely to have mental health problems (Cooper et al., 2007; Emerson, 2003). A recent longitudinal study of adults with IDDs living in residential environments confirmed that negative life event exposure is an associated factor for psychological problems, including anger and aggression (Hulbert-Williams et al., 2014).

Close examination of the associated factors for an elevated risk of mental ill-health can assist in explaining how individuals with IDDs are more vulnerable to mental health problems and provide implications for interventions addressing mental health problems in them. Recent intervention studies have used mindfulness as a preventative and nonintrusive approach to addressing psychological and behavioral problems in individuals with IDDs (e.g., Singh et al., 2013a). Mindfulness intervention studies have also addressed some associated factors of mental ill-health, such as smoking and quality of care. In doing so they demonstrated a potential to equip individuals with IDDs with skills necessary to enable them to undergo inevitable life events with fewer reactions.

Caregivers of Individuals with IDDs: Connected Hardship

While caring for individuals with IDDs is rewarding and empowering, it can lead to family conflict, stress, exhaustion, resentment, and fear of what the future may be like (Willingham-Storr, 2014). Poverty is often associated with the life of people living with IDDs (Emerson, 2007). The overlap between IDDs and mental ill-health has been an ongoing concern because of its adverse impact not only on people with IDDs themselves but also their caregivers. Caregivers can undergo significant hardship that may expose them to increased risks of mental and physical problems (Noone & Hastings, 2010).

Managing the challenging behavior of their care recipients with IDDs is a particular concern for caregivers (James, 2013). It generates stress and burnout in caregivers and adversely affects the relationships among care providers and care recipients. This, in turn, increases the likelihood of challenging behavior in the care recipients (Hastings, 2005; McGrath, 2013). A close relationship exists between the levels of challenging behavior in people with IDDs and the severity of stress and burnout in their family and professional caregivers (Hastings & Brown, 2002; James, 2013). Preventative approaches are needed to reduce health and social inequalities (Emerson, 2007).

Mindfulness Interventions: Self-Help Skills for Individuals with IDDs

Two general approaches to mindfulness interventions have been used in the field of IDDs. One approach is training individuals with IDDs in mindfulness so they can address their own behavioral and/or psychological issues. The other approach is training caregivers of individuals with IDDs in mindfulness to promote the caregivers' well-being, thus providing possibilities for enhancing the quality of life for individuals with IDDs. The first approach (i.e., mindfulness training for individuals with IDDs) can be classified according to the theoretical framework that guides the practice of mindfulness: (1) providing mindfulness-based interventions (MBIs) with mindfulness as the sole or principal component of training and (2) providing mindfulness-incorporated interventions (MIIs) with mindfulness functioning as one part of a multicomponent intervention.

Mindfulness-Based Stress Reduction (MBSR), Mindfulness-Based Cognitive Therapy (MBCT), and Meditation on the Soles of the Feet (SoF) are MBIs dedicated to cultivating mindfulness as the sole or principle component of training. Acceptance and Commitment Therapy (ACT) and Dialectical Behavior Therapy (DBT) are MIIs in the form of psychotherapy programs within which mindfulness functions as one of a number of core skills. The majority of MBIs and MIIs were initially developed to address medical and mental health problems (e.g., chronic pain, depression, borderline personality disorder) of individuals without IDDs. Hence the content and instruction methods of these programs had to be modified to accommodate the learning requirements of individuals with IDDs. However, no modification process was required for the Meditation on SoF, which was developed specifically for individuals with IDDs.

Singh et al. (2003) introduced mindfulness meditation to the field of IDDs. They aimed to address problem behaviors and developed the specific steps of the SoF procedure. The practice was taught to a 27-year-old young man with dual disability, mild IDDs, and psychotic disorder, who was in danger of losing his community living arrangement because of his uncontrolled aggressive behavior. Meditation on SoF was composed of four major stages: (1) establishment of posture, (2) application of attention, (3) setting up an arousal state, and (4) tranquilization. The practitioner begins by sitting or standing and grounding his feet on the floor. He then pays attention to breathing. He subsequently reminds herself of angry thoughts and feelings. Upon feeling any disturbance, he directs his attention to the soles of the feet and sustains it there until his mind and body calm down. The young man practiced Meditation on SoF for 12 months and demonstrated the effects through zero incidences of aggressive behavior and his ability to remain in his community living arrangement.

The significance of this study is threefold. The results were very positive and are philosophically significant as they shed light on the ability rather than the disability of a person with IDDs, in terms of his ability to both practice mindfulness and regulate his own problem behavior through this practice. Hence, this study strongly suggests the potential for mindfulness training to function as a self-management strategy that can regulate emotionally arousing behavior of individuals with IDDs. The SoF meditation is simple to the degree that a practitioner with mild IDDs learned it within 5 days and was able to continue independently thereafter. The Meditation on SoF also promotes serenity. By grounding himself on the felt contact with the floor, the practitioner finds a clear, firm, and stable reference point, which over time can stabilize a mentally and/or physically aroused state.

A wide range of follow-up studies confirmed the behavioral and psychological effects of practicing Meditation on SoF (e.g., Adkins, Singh, Winton, McKeegan, & Singh, 2010; Myers et al., 2014; Singh et al., 2007a). Since these studies predominately adopted a multiple-baseline single-subject design and were conducted by the same research group, a diversification of research methods was recommended for future studies (Chapman et al., 2013; Hwang & Kearney, 2013; Miodrag, Lense, & Dykens, 2013). More recently, a randomized control trial of the SoF meditation with individuals with mild IDDs confirmed earlier findings (Singh 2013a). Furthermore, at least three independent research teams (e.g., Felver, Frank, & McEachern, 2014; Shababi-Shad, 2014; Wilson, Kasson, Gratz, & Guercio, 2015) have confirmed the effectiveness of the SoF meditation with different populations.

Subsequently, other MBIs have been developed. MBSR, for example, was adapted to improve the physiological and mental well-being of individuals with IDDs. Miodrag et al. (2013) provided a modified MBSR program to 24 adolescents and adults with Williams syndrome at a residential music camp. Simplified MBSR activities were taught and practiced in small group settings for 20 minutes a day over 5 days. Hands-on support was provided. The results indicated reductions in stress-related physiological (e.g., cortisol level) and psychological (e.g., anxiety) symptoms after each mindfulness session.

Mindfulness practice has also been incorporated into mindfulness-integrated interventions (MIIs) such as DBT and ACT. DBT was initially developed to support people with borderline personality disorder to manage their overwhelmingly negative and intense emotions. Mindfulness was one of four key skill sets, along with distress tolerance, emotion regulation, and interpersonal effectiveness (Linehan, 1993). Mindfulness in DBT is seen as comprising "what" skills (i.e., observing, describing, participating) and "how" skills (i.e., taking a nonjudgmental stance, focusing on one thing in the moment, being effective). These categories describe *what* needs to be cultivated to practice mindfulness and *how* it can be done.

Sakdalan, Shaw, and Collier (2010) provided a modified DBT Coping Skills training program for 13 weeks (1.5 h) to six forensic clients with IDDs. They used simple language, concrete examples and visual aids, and reported decreased risks of reoffending as a training effect. Each session began with a mindfulness exercise. However, it is difficult to distinguish how much the positive results of the program can be accounted for by mindfulness practice as such. The same difficulty applies to other studies using psychotherapy programs that incorporate mindfulness as one of a number of core skill sets, such as ACT.

The theoretical framework of ACT comes from relational frame theory (RFT), a psychological theory of human language within which human suffering is viewed as emerging from the way the human mind relies upon language and concept for its sense of reality (Hayes, Strosahl, & Wilson, 2012). ACT aims to increase psychological flexibility through working on six core processes: defusion, acceptance, flexible attention to the present moment, self-as-context, values, and committed action (Harris, 2009). Of particular importance to ACT are the cultivation of flexible attention to the present moment and a sense of self-as-context. These constitute not only acceptance and mindfulness processes but also commitment and behavioral activation processes, these being the two wings of ACT practice that lead to the promotion of psychological health. Flexible attention to the present moment requires "attending to what is present in a focused, voluntary, and flexible fashion" (Hayes et al., 2012, p. 78), and self-as-context denotes an understanding that one's sense of self emerges out of a web of integrated relationships (e.g., I/you, now/then, we/they). However, we stress that the mindfulness processes in ACT are based on cognitive strategies bereft of meditation. Thus, comparing the mindfulness in ACT to the Buddhist tradition of mindfulness would be a category error.

Brown and Hooper (2009) taught body and thought awareness along with ACT to a female adolescent with moderate/severe IDDs and neuropsychiatric disorder, in order to reduce anxiety and obsessive thoughts. They provided 17 individual training sessions over 6 months, teaching body and mind awareness and conducting activity-based ACT exercises. The authors noted how the intervention process was slowed by her struggle to maintain attention and her need for high levels of prompts to stay on task. The results indicated that the practitioner was less avoidant of cognition, emotions, and motives. Her parents also noticed her being less affected by obsessive thoughts and she was calmer than before. Since mindfulness constitutes one aspect of a wider group of core psychological flexibility processes, the results of this study present the same dilemma; to what extent can its effects be accounted for by the practice of mindfulness? The authors of this study raised a more fundamental question; to what degree and in what ways should language-based interventions, including mindfulness interventions, be adapted to enable people with IDDs to benefit from them?

Mindful Caring: A New Approach to Supporting Individuals with IDDs

Mindful caring is the other approach applying mindfulness to support individuals with IDDs. Several studies provided mindfulness training to family and professional caregivers of individuals with IDDs and investigated the training results. Bazzano et al. (2015) trained 66 family and professional caregivers of individuals with DD, including those with IDDs, in an adapted MBSR program over 8 weeks and reported post-intervention effects of reductions in perceived parenting stress and increases in mindfulness and self-compassion.

Noone and Hastings (2009, 2010) provided 1.5-day ACT workshops, which included mindfulness exercises, to professional caregivers of adults with IDDs. Self-reported general well-being and work stress in professional caregivers of adults with IDDs were compared before and after the workshops. Noone and Hastings reported reduced psychological distress after the workshops and suggested that mindfulness-incorporated ACT training has the potential to improve the psychological well-being of professional caregivers of adults with IDDs.

Bethay, Wilson, Schnetzer, Nassar, and Bordieri (2013) confirmed the potential of ACT training to address the psychological distress of professional caregivers of adults with IDDs. They compared the effects of two training programs, one composed of ACT and applied behavior analysis, and the other of applied behavior analysis only. Both training programs were offered for 3 hours, once a week, over 3 weeks. The results suggested reductions in psychological distress among those who reported that they had been practicing the ACT techniques.

Some mindfulness intervention studies for caregivers of individuals with IDDs suggested positive effects not only for the caregivers who received mindfulness training but also for those individuals with IDDs who received care from them. Singh et al. (2004) introduced mindfulness training to caregivers of individuals with IDDs, and they raised the possibility of supporting individuals with IDDs through supporting their caregivers. In an intervention study of six caregivers of three male adults with profound IDDs, Singh et al. (2004) provided three caregivers with mindfulness training and three with behavioral training. The quality of the interactions among care recipients and caregivers was studied in order to investigate the effects of the mindfulness training. Upon the completion of mindfulness and behavioral staff training, the physical happiness indicators of three care recipients were remarkably increased in their interaction with the three caregivers trained in mindfulness, while they remained unchanged among those whose caregivers underwent behavioral training. The results are significant as they opened up a potential way to benefit individuals with profound/multiple disabilities who may not be able to practice mindfulness, by training their caregivers in mindfulness.

The follow-up studies (e.g., Singh et al., 2006a, 2009, 2015) confirmed the possibility of reducing problem behaviors of care recipients through the provision of mindfulness training to their professional caregivers. The change in the behavior of care recipients with IDDs was explained in terms of the cultivation of nonjudgmental acceptance of their behavior on the part of their caregivers, along with increased attentiveness to their individual needs (Singh et al., 2006a). These results, however, did not go into the specifics of how mindfulness training affected the caregivers nor exactly how and in what ways their views of and behavior toward care recipients changed. The precise nature of the interconnections between mindfulness training and behavioral changes remained unknown.

Mindfulness training was also provided to family caregivers of children with IDDs. Singh et al. (2007b) individually provided mindfulness training to four mothers of young children with developmental delay (DD) and aggression. During a 12-week mindfulness parent training program and a year of mindfulness practice, the authors examined the direct effects on mothers who practiced mindfulness and the indirect effects on their child. The direct effects for mothers included increased satisfaction with parenting, increased parent–child interactions, and increased use of mindfulness, along with decreased parenting stress. The indirect effects for the children were incrementally decreased aggression at home and incrementally increased social interactions at their day care center. This was despite the fact that the parent mindfulness program did not target changes in child behavior.

A recent study by Neece (2014) reported similar results, where 46 parents of young children with IDDs participated in the standard MBSR program. This program does not have any components specifically addressing mindful parenting. At the end of the training, the parents demonstrated statistically significant reductions in self-reported parenting stress and depression and significantly increased satisfaction with life. These parents also reported for their child with IDDs, who did not learn mindfulness, significant reductions in ADHD symptoms and marginally significant reductions in attention problems. The results of these mindfulness intervention studies for parents of children with IDDs confirmed the interconnectivity found between professional caregivers and their care recipients with IDDs. In addition, they shed light on both the direct and indirect effects of mindfulness interventions for family caregivers.

Exploring the nature of the interconnectivity between caregivers and their care recipients could enhance our capacity to support individuals with IDDs. A description that may explain some of the nature of this interconnectivity came from Singh et al. (2009). Following up on their previous study of training three professional caregivers of three male adults with profound IDDs (Singh et al., 2004), Singh et al. investigated whether the increased mindfulness of the three caregivers would transfer to interactions with their own children without IDDs. In informal interviews, the caregivers reported meditation-related experiences of being light and calm, which lasted throughout the day. As mindfulness practice progressed they noticed instances of pausing prior to responding to others, with responses that were less habitual in manner and more aligned with their mindfulness training. Alongside this, caregivers saw their interpersonal interactions with family members becoming more mindful and positive. Their family members also noticed this change.

The caregivers' descriptions illustrate how automatic interpersonal behavior can be noticed and modified on the basis of being firmly grounded in the present. Automatized behavior is performed out of habit with little or no conscious awareness and is therefore highly resistant to change. This often characterizes the family relationships of children with disruptive/problem behaviors, along with a lack of sensitivity and responsiveness in interpersonal interactions (Dumas, 2005). The positive interpersonal interactions characterized by mindfulness, and noticed by practitioners and their family members, indicate the effects of loosening automaticity. Within these psychological environments, care recipients may demonstrate more signs of physical happiness or less aggressive behavior.

A bidirectional relationship between stress in caregivers and the problem behaviors of individuals with IDDs may provide another possible explanation for the interconnectivity between caregivers and care recipients in the context of mindfulness practice. Problem behaviors contribute to generating stress and burnout in caregivers (Hastings & Brown, 2002) and adversely affecting relationships between caregivers and care recipients. This, in turn, increases the likelihood of problem behaviors (Hastings, 2005). Children with IDDs are more likely to have family environments with high levels of stress (Emerson, 2003), and caregivers identify management of the problem behavior of children with IDDs as a major area in which they need to be supported (James, 2013). A recent longitudinal study (Neece, Green, & Baker, 2012) examined the relationship between parenting/caring stress and child problem behavior with a sample of 237 children aged under 10 years, both typically developing children (144) and children with DD (93). Analysis of data collected at seven time points indicated that for both groups of children, heightened parenting stress is an environmental risk factor leading to increases in child problem behaviors over time, and elevated child problem behaviors lead to increases in parenting stress over time.

According to the results of mindfulness intervention studies that examined both direct and indirect training effects (Neece, 2014; Singh 2007b) reductions in parenting stress and reductions in child problem behavior occurred concurrently, from which a close relationship can be inferred. It is possible that mindfulness practice supported caregivers to notice and lessen the grip of automaticity in their interpersonal interactions and this may have created environments leading to reductions in child problem behaviors over time. A deepened understanding of the nature of this interconnectivity is yet to be developed, and this may be achieved through applications of different research methods, such as qualitative approaches (Hwang & Kearney, 2013, 2014).

Mindfulness-Based Interventions in IDDs

We reviewed 17 studies that investigated the effects of training people with IDDs in mindfulness-based interventions. The summaries of intervention design and methods and research design and methods are presented in Table 12.1.

Participants

A total of 178 people (95 males and 63 females) with IDDs. participated in mindfulness training. Reflecting the pressing issues (i.e., mental health and overrepresentation in the criminal systems) that IDDs communities have faced, 82 of 178 participants had some sort of mental illness (e.g., psychotic disorder, bipolar disorder, and personality disorder) and 30 participants received forensic mental health care. The majority of participants presented with mild IDDs. Of the 178 individuals, 131 were classified as having mild IDDs (e.g., Singh et al., 2003, 2013a), seven as moderate IDDs (e.g., Singh et al., 2007a), six as mild to moderate IDDs (Chilvers et al., 2011), and one as moderate to severe IDDs (Brown & Hooper, 2009). The severity of IDDs for nine participants was not specified (e.g., Singh et al. 2008b) and the remaining 24 presented with a mean IQ score of 70.7 (e.g., Miodrag et al., 2013). The chronological age (CA) of the participants ranged between 16 and 61 years with a mean CA of 28.62 years. Our review of studies suggested that only four of the 178 participants were teenagers, aged between 16 and 18 years. In other words, mindfulness interventions were predominantly provided to address the difficulties of adults with IDDs rather than children or adolescents with IDDs.

Intervention Objectives

A number of studies (e.g., Howlett et al., 2015; Torr et al., 2008) reported that people with IDDs were at increased risk of behavioral, mental, and physical health problems. Mindfulness intervention studies were conducted to address these issues. The intervention objectives of mindfulness studies for individuals with IDDs were divided into three categories: behavioral, physical, and psychological well-being. Behavioral well-being was the most frequent objective. Of the 17 studies, nine studies aimed to reduce problem behavior of individuals with IDDs, eight addressing aggressive behavior (e.g., Adkins et al., 2010; Singh et al., 2013a) and one deviant sexual behavior (Singh et al. 2011a). Mindfulness training was used to enhance physical well-being in four studies, smoking cessation in three (Singh et al., 2011b, 2013b, 2014), and weight loss in the other (Singh et al., 2008a). The objective of four remaining studies was to enhance psychological well-being by reducing stress (Miodrag et al., 2013), anxiety and obsessive thoughts (Brown & Hooper, 2009), and anxiety and depression (Idusohan-Moizer et al., 2015) and to increase mental health (Sakdalan et al., 2010) in adults with IDDs.

Intervention Content

Intervention content was organized according to the intervention objectives. Reduction in aggressive behavior was the most frequent objective. Meditation on SoF was most frequently used to achieve this intervention objective. Singh et al. (2003) developed ten training steps for the Meditation on SoF (Table 12.2) and applied this mindfulness procedure to reduce the uncontrolled aggressive behavior of a male adult with dual disability, mild IDDs, and psychotic disorder. The application of Meditation on SoF as a self-management skill was successful. Meditation on SoF was used to reduce physical and verbal aggression in five follow-up studies, either as a sole component of the mindfulness intervention (Adkins et al., 2010; Singh et al., 2007a, 2008b, 2011c) or along with breathing meditation (Singh et al., 2013a).

Two studies (Chilvers et al., 2011; Lew et al., 2006) also aimed to enhance the behavioral well-being of individuals with IDDs. Both studies used DBT within which mindfulness was a core skill.

Table 12.1 Mindfulness interventions for individuals with DD addressing their problem behaviors

Study	Participants and settings	Objective	Content	Training strategies and design	Modification and instructor	Research design	Results
1. Singh et al. (2003)	27-year-old male with mild ID and psychotic disorder Psychiatric hospital	Aggressive behavior	Meditation on SoF	Individual training 30-minute role-play and practice twice a day for 5 days 1 week of homework practice assignments	No modification of the content or training strategies No instructor information	Single-subject research Baseline: 5 months Practice: 12 months Follow-up: 12 months Overall reliability (96.5 %) No validity and fidelity measure	Major decreases in 1. Incidents of aggression 3. Use of physical restraints 4. Staff and resident injuries 5. PRN medication Increases in 2. Self-control 6. Physically/socially integrated community activities Drug therapy discontinued Psychotic disorder NOS withdrawn Community placement
2. Singh et al. (2007a)	3 young adults (CA, 27, 43, and 39 years) (gender, 2 males and 1 female) with moderate ID and mental illness (bipolar disorder, schizophrenia, and psychotic disorder, respectively) Group home	Reduce aggressive behavior to maintain community placement	Meditation on SoF	Individual training with guided meditation (1 week) and rehearsing several times per day Imagine past episodes of aggression Audiotape of instructions for self-practice	No modification of the content or training strategies First author	Multiple-baseline design Baseline: 3, 5, and 10 week Practice: 35 week Follow-up: 2 years Interrater reliability (95 %) No validity and fidelity measure	Declined aggressive acts Community placement maintained

3. Singh et al. (2008b)	6 aggressive male adult offenders (CA, 25, 28, 34, 23, 25, and 36 years) with ID and mental illness (e.g., bipolar, impulse control disorder, pedophilia and paraphilia) Forensic mental health facility	Reduce aggressive behavior for transition to community placement	Meditation on SoF	Individual training with guided meditation Intervention: 27 months (practice twice a day)	No modification of the content or training strategies Therapist (no further info)	Multiple-baseline design across participants Baseline: 3, 5, and 7 week Practice: 27 week Interrater reliability (92 %) No validity and fidelity measure	Physical aggressive behaviors decreased to zero across the 27 months of training Lower verbal aggression No requested medication or restraint No staff or peer injuries
4. Adkins et al. (2010)	3 adults (CA, 42, 25, and 22 years) (gender, 2 males and 1 female) with mild ID and mental illness (e.g., obsessive–compulsive disorder and depression) Two in group home and one at home	Reduce verbal and physical aggression	Meditation on SoF	Individual training for 1 hour a day, 5 days a week Twice daily practice and when a trigger was present Prompts	No modification of the content or training strategies Community-based therapist (no further information)	Multiple-baseline design across participants Baseline: 2–4 week Intervention: 2–5 week Self-practice: 12–26 week Follow-up: 4–8 week No validity, reliability, and fidelity measure	Maladaptive behaviors reduced to near-zero levels Improved collateral measures Community placement maintained
5. Chilvers, Thomas, and Stanbury (2011)	15 females (CA 18–47) with mild to moderate ID in a forensic medium secure psychiatric ward 8 with no psychiatric diagnosis, 2 psychosis, 4 mood disorders, and 2 ASDs Ward	Reduce aggressive incidents	Mindfulness activities as part of DBT: Participation (fully engrossed in an activity) Observation (attend to the observation target) Description (providing a factual description) Focus on one thing in the present, nonjudgmental, and doing what works	Group exercise Individual feedback Awareness training to all nursing staff Intervention; 5 months (30-minute group sessions twice weekly)	Brief and simplified explanation Authors received training in conducting mindfulness practice	Pre-post group design No validity, reliability, and fidelity measure	Overall decrease in observed aggression, physical interventions, and seclusions with fluctuations after an initial reduction

(continued)

Table 12.1 (continued)

Study	Participants and settings	Objective	Content	Training strategies and design	Modification and instructor	Research design	Results
6. Lew, Matta, Tripp-Tebo, and Watts (2006)	8 females (CA 25–61) dually diagnosed with mild (7) and moderate (1) ID and psychiatric disorder (e.g., personality disorders) Office, homes, or other convenient locations	Reduce risk behavior	1. Mindfulness activities as part of DBT: Mindfulness (e.g., breathing) Observe and describe common objects 2. Distress tolerance 3. Emotion regulation 4. Interpersonal effectiveness	1 hour individual weekly therapy 2 hour group skills training sessions for 23 week (of these 6 sessions are devoted to mindfulness) Using video characters to explain reasonable mind, emotion mind, and wise mind Intervention: 18 months	Simplified terms and ideas Pictorial representation Individualized care Small group Collaboration with residential caregivers DBT clinicians	Group design without control group Data collection points: Baseline 6 months 12 months 18 months No validity, reliability, and fidelity measure	Gradual reduction with fluctuated results: Increase of risk behavior at 6 months of treatment Decrease of risk behavior at 12 and 18 months
7. Singh et al., (2011c)	3 male adults (CA, 28, 28, and 32 years) with mild ID who were friends of the trainer Workplace	Reduce aggressive behavior and control anger	Meditation on SoF	Intervention initiated on request of participants Discussion with the trainer on antecedents of anger and aggression Step-by-step repeated instruction on SoF Social gatherings with the trainer	No modification of the content or training strategies A 33-year-old man with mild ID and mental illness (the participant of the study conducted by Singh et al., 2003)	Multiple-baseline design across participants Baseline: 8–21 week Intervention: 52–39 week Follow-up: for 2 years Interrater reliability (100 %) No validity and fidelity measure	Declined incidents of anger and aggression during the overall practice period No incidents of anger and aggression during the last 4 week of the practice period Occasional instances of anger but no instances of aggression during the informal follow-up period
8. Singh et al. (2013a)	34 individuals (mean CA 23.4 years for training group and 23.1 years for wait-list group, 27 males and 7 females) with mild ID 27 individuals were on psychotropic medication Settings not stated	Reduce physical and verbal aggression	Introduction to the anger management program Focused attention on arousal states Breathing meditation Meditation on SoF	Verbal instruction and modeling Prompts Audio instructions for self-practice Daily 15–30 minute practice with instructor for five days per week during the intervention period (12 week) Follow-up: 12 week	Individualize the training scripts to meet diverse abilities of participants to understand instruction Parents and support staff	Group experimental: a wait-list control study Baseline: 12 week Intervention: 12 week Follow-up: 12 week Interrater reliability (97 %) Fidelity 89 %–100 % (mean = 96 %) across the parents and support staff individual dyads	A significant reduction in physical and verbal aggression at post-training Further reductions in both physical and verbal aggression at follow-up

9. Singh et al. (2011c)	3 male adults (CA, 34, 23, and 25 years) offenders with ID and mental illness (e.g., pedophilia and sexual abuse of child) Forensic mental health facility	Control deviant sexual arousal	1. Meditation on SoF 2. Mindful Observation of Thoughts	1. Use pictures to induce sexual arousal and switch attention to the SoF 2. Individualized instruction, self-practice homework, and discussion with the therapist	For Mindful Observation of Thoughts, use individualized language, idiom, and explanation of practice to match participants' ability Primary therapist (extensive meditation experience and clinical experience) Secondary therapist (some experience with meditation)	Multiple-baseline design across participants 1. 4 sessions (0.5–1 h) for 4 week 2. 4 individual meetings for the remaining intervention period 3. Intervention (SoF): 13 week 4. Intervention (observation of thoughts): 35–40 week No validity, reliability, and fidelity measure	Sexual arousal levels Baseline: max. 12 levels for all three SoF phase: 7.77, 7.38, and 6.92, respectively Observation of thought phase: 2.95, 3.03, and 1.51, respectively Helped to be more calm
10. Singh et al. (2008a)	A 17-year-old male adolescent with Prader–Willi syndrome and mild ID Home	Lose weight	1. Mindful eating 2. Visualizing and labeling hunger 3. Meditation on SoF	1. Ritualizing eating habits 2. Use of a cartoon character 3. Individual training for a week	No modification of the content or training strategies The participant's mother assisted by the senior author via e-mail	Single-subject research: ABCD design A: baseline (12 months) B: intervention exercise only (12 months) C: intervention exercise and food awareness (12 months) D: intervention exercise, food awareness, and mindfulness (24 months) Follow-up: every 3 months for 3 years No validity, reliability, and fidelity measure	Mean weight A: 256.3 lb B: 249.8 lb C: 242.8 lb D: 200 lb Follow-up 197.8 lb in year 1 192.3 lb in year 2 190.7 lb in year 3
11. Singh et al. (2011b)	A 31-year-old male heavy smoker with mild ID Settings not stated	Cease smoking	1. Intention 2. Mindful Observation of Thoughts 3. Meditation on SoF	1. Discussion with group home staff and self-affirmation regarding intention to quit smoking 2. Observation of arising, lingering, and passing away of a desire to smoke 3. Role-play and self-practice of the SoF Pre-baseline: 10–15 minute breathing meditation twice a day for 3 months	Individualized language, idiom, and explanation of practice Therapist (extensive meditation experience and clinical experience)	Single-subject design: changing criterion design Pre-baseline: 3 months Baseline: 14 days Intervention: 82 days Maintenance: 12 months Follow-up: 3 years Interrater reliability (100 %) SoF training manual was used for fidelity with consideration of individualization	Baseline: 12 cigarettes per day Gradual reduction to zero over 82 intervention days No smoking during 12-month maintenance period and 3-year follow-up period

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Table 12.1 (continued)

Study	Participants and settings	Objective	Content	Training strategies and design	Modification and instructor	Research design	Results
12. Singh et al. (2013b)	3 male adults (CA, 27, 31, and 23 years) with mild ID Trained in group but settings not stated	Cease smoking	1. Concentration meditation 2. Verbal self-affirmation of intention to quit smoking 3. Mindful Observation of Thoughts 4. Meditation on SoF	1. 10–15 minute concentration meditation twice a day for three months (pre-baseline) 2. Use affirmation to control a desire to smoke every morning 3. 20-minute daily meditation on observation of thoughts 4. 30-minute SoF session twice a day for five days with trainer (role-play) and then with practice assignments for 10 days Group training	Individualized language, idiom, and explanation of practice Therapist (extensive meditation experience and clinical experience)	Multiple-baseline design across participants: changing criterion design Pre-baseline: 3 months Baseline: 10 days Intervention: 111, 165, and 77 days Interrater reliability (94–96 %) SoF training manual was used for fidelity with consideration of individualization	Number of smoked cigarettes reduced to 0 within 111, 165, and 77 days Effects maintained for 3 years
13. Singh et al. (2014)	51 adults (41 males and 10 females, mean CA 32.56 years for experimental group and 34.40 years for control group) with mild ID Face-to-face or online settings	Cease smoking	1. Concentration meditation 2. Verbal self-affirmation of intention to quit smoking 3. Mindful Observation of Thoughts 4. Meditation on SoF	1. 20 minute concentration meditation once a day or 10 minute twice a day for one month (pre-baseline) 2. Use affirmation to control a desire to smoke every morning 3. 20-minute daily meditation on observation of thoughts 4. 30-minute SoF session twice a day for five days with trainer (role-play) and then with practice assignments for 10 days Individual, small group, or online training	Individualize the training scripts to meet diverse abilities of participants to understand instruction Trainer (extensive meditation experience and clinical experience)	Randomized controlled group experimental study Pre-baseline: 1 month Baseline: 4 week Intervention: 36 week Follow-up: 1 year Interrater reliability (96 %) Fidelity (100 %)	Statistically significant reduction in number of smoked cigarettes

14. Miodrag et al. (2013)	24 (13 males and 11 females) individuals (mean CA 27.5, range 16–40 years) with Williams syndrome (mean IQ score 70.7, range 43–91) Residential music camp	Examine stress-related physiological symptoms in relation to mindfulness practice	Modified MBSR: Qigong movement (e.g., arm swings, radiant breathing) Deep belly breathing meditation Breath awareness Body scan Sitting meditation Loving kindness Mindfulness in everyday life (e.g., paying attention, focusing on the breath, letting go of thoughts)	Small group Hand-over-hand modeling for Qigong Straightforward language Visual aid Real-life example	Modifications of teaching training strategy: Avoid using abstract language and jargon Use repetition Give enough time to process material Three instructors trained in mindfulness interventions and working experience in the ID field	Pre-post group design Intervention: 5 days for 20 min Fidelity consideration: using scripts and following standard exercises from MBSR	Each day cortisol and self-reported anxiety levels decreased after mindfulness sessions Salivary cortisol and alpha-amylase (sAA) in session 4 and 5 were lower than that of session 1 and 2 Greater self-reported attention problems predicted lower sAA levels
15. Brown and Hooper (2009)	1 female adolescent (CA: 18 years) with moderate/severe ID and neuropsychiatric disorder Settings not stated	Reduce anxiety and obsessive thoughts	Body and thought awareness Acceptance and Commitment Therapy (ACT) Mindfulness exercises on the body Metaphors to understand and defuse thoughts Goal-setting skills	Individual training Prompts	Slow intervention process (e.g., 10 sessions planned but 17 delivered) Activity-based exercise using drawings and real objects Therapist new to ID	A single-case study Intervention: 6 months Follow-up: 4 months No validity, reliability, and fidelity measure	Less avoidant of cognitions, emotions, and motives (AAQ9) Calmer, less affected by thinking, more socially confident, and better empathy (parental reports)
16. Idusohan-Moizer, Sawicka, Dendle, and Albany (2015)	15 (8 female, 7 male) adults (CA 21–44, mean CA 30.75) with ID (4 borderline, 8 mild, 3 moderate) with psychiatric disorders (9 anxiety, 4 anxiety and depression, 2 bipolar) Trained in two groups but settings not stated	Improve mental well-being and reduce depression and anxiety	Combination of MBCT: mindfulness of the breath, basic yoga stretches, the raisin exercise, and diary of pleasant and unpleasant events ACT: metaphors and analogies Modified exercises on self-compassion Meditation on SoF	Powerpoint slides of pictures illustrating the key points Meditation CD Emphasis on repetition and mastery Weekly 1.5 hour intervention session for nine week	Reduce the number of home activities to three repetitive mindfulness exercises (mindfulness of breath, Meditation on SoF, and basic yoga stretches) Facilitators: qualified clinical psychologist with training in mindfulness-based therapies, assistant psychologist, and two trainee clinical psychologists who attended mindfulness workshops	Pre-post group design Intervention: 10 week Follow-up: 6 week No validity, reliability, and fidelity measure	Reduced depression and anxiety and increased self-compassion and compassion for others after the intervention Maintained at 6-week follow-up

(continued)

Table 12.1 (continued)

Study	Participants and settings	Objective	Content	Training strategies and design	Modification and instructor	Research design	Results
17. Sakdalan et al. (2010)	6 forensic clients (5 males and 1 female, mean CA 26.18) with mild to moderate ID (mean IQ 57.17) Settings not stated	Examine the effects of DBT Coping Skills training (combination of adapted DBT training and Coping Skills training) for people with ID	DBT Coping Skills training 1. Orientation and group rules 2. Mindfulness 3. Distress tolerance 4. Emotional regulation 5. Interpersonal effectiveness 6. Closing	Group skill training: Role-playing, formal teaching, experiential exercises Review of individual homework Structuring environment to support treatment	Simple language Concrete examples Visual aids Facilitators without further info	Pre-post group design Intervention: 13 week (sessions for 1.5 h) No validity, reliability, and fidelity measure	A decrease in the level of risks and increase in relative strengths (based on Short-Term Assessment of Risk and Treatability) Increase in global functioning (based on Health of the Nation Outcome Scales for people with learning disabilities)

Table 12.2 Steps of Meditation on SoF training

1. If you are standing, stand in a natural rather than an aggressive posture, with the soles of your feet flat on the floor
2. If you are sitting, sit comfortably with the soles of your feel flat on the floor
3. Breath naturally, and do nothing
4. Cast you mind back to an incident that made your very angry. Stay with the anger
5. You are feeling angry, and angry thoughts are flowing through your mind. Let them flow naturally, without restriction. Stay with the anger. Your body may show signs of anger (e.g., rapid breathing)
6. Now, shift all your attention to the soles of your feet
7. Slowly, move your toes, feel your shoes covering your feet, feel the texture of your socks or hose, the curve of your arch, and the heels of your feet against the back of your shoes. If you do not have shoes on, feel the floor or carpet with the soles of your feet
8. Keep breathing naturally and focus on the soles of your feet until you feel calm
9. Practice this mindfulness exercise until you can use it wherever you are and whenever an incident occurs that may lead to you being verbally or physically aggressive
10. Remember that once you are calm, you can walk away from the incident or situation with a smile on your face because you controlled your anger. Alternatively, if you need to, you can respond to the incident or situation with a calm and clear mind without verbal threats or physical aggression

Chilvers et al. (2011) taught mindfulness through participation exercise, observation exercise, and description exercise based on the principles of focusing on one thing in the present moment, not judging, and doing what works. They delivered these exercises to 15 female forensic patients with IDDs and mental illness in order to reduce their aggressive incidence. Lew et al. (2006) applied mindfulness activities (e.g., mindful breathing) along with other DBT core skills (i.e., distress tolerance, emotion regulation, and interpersonal effectiveness) to reduce the risk behavior (e.g., violence, self-harming, substance use and misuse, sexual risk) of eight females with dual diagnosis, mild/moderate IDDs, and psychiatric disorder.

Controlling deviant sexual behavior is the last objective of mindfulness intervention studies that aimed to enhance the behavioral well-being of individuals with IDDs. Meditation on SoF and Mindful Observation of Thoughts (MOT) procedures were used to achieve this objective. The four components of MOT include: (1) focusing on the breath; (2) observing the beginning, middle, and end of the thoughts; (3) observing the thoughts as clouds passing through the person's awareness; and (4) observing the precursors to the sexual arousal as thought clouds without pushing the thought away, engaging with the thoughts, or becoming emotionally attached to the thoughts (Singh et al., 2013b).

Physical well-being is the second category of intervention objectives. Weight loss and smoking cessation were specifically targeted for individuals with IDDs. Meditation on SoF was again used to achieve these objectives, but along with other mindfulness activities. A male adolescent with Prader–Willi syndrome and mild IDDs practiced Meditation on SoF along with mindful eating and hunger recognition to lose weight (Singh et al., 2008a). Three studies (Singh et al., 2011b, 2013b, 2014) also taught. Meditation on SoF along with concentration meditation, verbal self-affirmation of an intention to quit smoking, and MOT to support heavy smokers with IDDs. Teaching concentration meditation prior to the introduction of mindfulness activities warrants discussion. Although the authors did not discuss it clearly, mindfulness has traditionally been taught alongside concentration and effort (Bodhi, 1994; Pandita, 1993) with the purpose of developing the wisdom to lead a more satisfactory life—in this case, a more healthy life through the cessation of smoking.

Psychological well-being is the last category of intervention objectives. A total of four studies aimed to enhance the .psychological well-being of individuals with IDDs, and they used modified versions of existing MBIs and MIIs. An adapted MBSR program was used to reduce the stress of 24 people with Williams syndrome and IDDs at a residential music camp (Miodrag et al., 2013), and a modified ACT was used to reduce the anxiety and obsessive thoughts of a female adolescent with moderate/severe IDDs (Brown & Hooper, 2009). Another study used an eclectic program combining MBCT, ACT, and Meditation on SoF to reduce the anxiety and depression of 15 adults with dual disability (Idusohan-Moizer et al., 2015). A modified DBT was used to increase the mental health of six adults under forensic care (Sakdalan et al., 2010).

Intervention Strategies

Individuals with IDDs have diverse needs and may require a wide range of supports for learning. Therefore it is important to examine the specific features of an intervention that may affect intervention outcomes (Kaiser & McIntyre, 2010). Intervention teaching strategy, duration, and settings provide contextual information concerning where, how, and for how long an intervention was performed (Horner, Sugai, & Anderson, 2010; West, McCollow, Umbarger, Kidwell, & Cote, 2013). The nature of the modifications to mindfulness programs illustrates ways to meet the diverse learning needs of people with IDDs when training them in mindfulness. Teacher characteristics can play a critical role in the outcomes of mindfulness interventions (Grossman, 2010; Segal et al., 2002).

Of 17 studies, ten used individual one-on-one training often supported by, for example, verbal instruction, guided meditation, role-play, and self-practice using audiotaped instruction. The remaining studies used small group training combined with individual feedback (Chilvers et al., 2011; Lew et al., 2006; Sakdalan et al., 2010), hand-over-hand modeling (Miodrag et al., 2013), or individual practice supported by the use of meditation CDs (Idusohan-Moizer et al., 2015). One study (Singh et al., 2014) used both individual and small group training but did not specify under which conditions they were applied.

The duration of an individual intervention session varied from 20 minutes (Miodrag et al., 2013) to 1.5 hours (Sakdalan et al., 2010), with the majority of studies providing a training session of less than an hour (e.g., Singh et al., 2013b, 2014). The duration of the intervention period also varied. Of 17 studies, ten provided a mindfulness intervention or arranged mindfulness practice for a minimum of 5 months. The shortest was 5 days at a residential music camp where a modified MBSR was delivered (Miodrag et al., 2013). Studies adopting Meditation on SoF tended to have a short-term intervention period, usually for 5 days, but a long-term self-practice period, ranging from 12 weeks to 24 months (e.g., Singh et al., 2003, 2008a). Studies using modified DBT and ACT also provided a relatively long-term intervention, ranging from 13 weeks (Sakdalan et al., 2010) to 18 months (Lew et al., 2006).

Intervention settings also provide contextual information about mindfulness training. Ten studies clearly specified the intervention settings. Of these, nine were residential environments (e.g., home, group home, ward) and one was a workplace (Singh et al. 2011c). This indicates mindfulness was taught and practiced in places the participants were familiar with and spent the majority of their time. This intervention arrangement may have supported participants to incorporate mindfulness as one of their everyday activities.

The intervention modifications concerned the methods used to accommodate the learning needs of individuals with IDDs during the delivery of mindfulness programs. Modifications occurred in four areas: language, material, learning process, and content. Language was the most frequently modified by using individualized idioms and expressions (Singh et al., 2011a) and brief and simplified expressions (Chilvers et al., 2011). Abstract expressions and jargon were also removed (Miodrag et al., 2013). Materials cover another area. Pictures, drawings, and real objects were used to engage participants with IDDs in learning mindfulness practice (e.g., Brown & Hooper, 2009; Sakdalan et al., 2010). The learning process was supported through repetition, provision of time to process information, and activity-based learning (Brown & Hooper, 2009; Idusohan-Moizer et al., 2015; Miodrag et al., 2013). Modifications to content occurred by reducing the number of learning activities (Idusohan-Moizer et al., 2015), and an existing mindfulness program was useful for teaching individuals with IDDs which was initially developed for individuals without IDDs.

Individualization and collaboration with caregivers were the two key aspects of modifications to intervention content and training methods. Researchers in the reviewed studies met the heterogeneity of individuals with IDDs through individualizing language, materials, learning process, and content. Knowledge of caregivers concerning their care recipients was highly valued in the process of individualizing and delivering the program (Lew et al., 2006). For example, caregivers were invited to attend the program along with participants (Miodrag et al., 2013). They were even invited to deliver the intervention (Singh et al., 2008a, 2013a).

Instructor characteristics cannot be overlooked. Of 17 studies, 16 identified an instructor. Of these, three studies (Chilvers et al., 2011; Idusohan-Moizer et al., 2015; Miodrag et al., 2013) employed a team of instructors (e.g., DBT clinicians) and one study employed two instructors, primary and secondary therapists (Singh et al., 2011a). The remaining studies employed a single instructor. Of the 16 studies that identified an instructor/s, nine (e.g., Adkins et al., 2010; Brown & Hooper, 2009; Lew et al., 2006; Singh et al., 2007a, 2008b) did not provide contextual information about their instructor's experience and knowledge of training individuals with IDDs in mindfulness. Some two studies (Chilvers et al., 2011; Idusohan-Moizer et al., 2015) specified that their instructors received training in conducting mindfulness interventions and five studies (Miodrag et al., 2013; Singh et al., 2011a, 2011b, 2013b, 2014) provided the instructor's knowledge and experience of mindfulness as well as those of working with people with IDDs.

Hwang and Kearney (2013) suggested two critical characteristics of mindfulness instructors for individuals with disability, an understanding of mindfulness itself and an understanding of learners with disability. Some studies employed an instructor with more experience and knowledge of mindfulness than of the learners with IDDs (e.g., Brown & Hooper, 2009). Other studies employed an instructor with more experience and knowledge of learners with IDDs than of mindfulness, such as parents and support staff of individuals with IDDs (e.g., Singh et al., 2008a, 2013a). Notably, one study employed as an instructor a 33-year-old man with mild IDDs and mental illness who participated in a previous study conducted by Singh et al. (2003). He taught Meditation on SoF to his three friends with mild IDDs (Singh et al., 2011c). Although his understanding of mindfulness and IDDs was not clearly specified, the self-practice period (i.e., 12 months) he had undergone and his lived experience of IDDs may provide a good example of instructor characteristics.

Intervention Effects

All studies reported positive effects of mindfulness training for individuals with IDDs. Of the 17 studies, nine aimed to enhance behavioral well-being. Of these, eight provided mindfulness interventions to reduce the problem behavior of individuals with IDDs and reported reductions in problem behavior (e.g., Adkins et al., 2010; Chilvers et al., 2011; Lew et al., 2006; Singh et al., 2003, 2007a, 2008b, 2013a). The implications of these results were particularly significant for those with IDDs who were at risk of losing their community living arrangement because of their uncontrolled problem behavior. The participants of two studies (Adkins et al., 2010; Singh et al., 2003) maintained their community living arrangement. The remaining study aimed to enhance the behavioral well-being of individuals with IDDs and suggested that mindfulness practice was successful in controlling deviant sexual behavior (Singh et al., 2011a). Three male adult offenders with IDDs and mental illness reported an initial decrease in sexual arousal levels after practicing Meditation on SoF and further decreases after adding the MOT procedure.

Four studies reported successful applications of mindfulness training in enhancing the physical well-being of individuals with IDDs. Of these, two studies with four male heavy smokers with mild IDDs demonstrated a reduction in the number of cigarettes smoked per day to zero after 82, 111, 165, and 77 mindfulness intervention days (Singh et al., 2011b, 2013b). These participants remained free of smoking for the next 3 years. A recent randomized controlled group study with 51 adults with mild IDDs confirmed the successful use of mindfulness training for smoking cessation (Singh et al., 2014). Obesity is another area threatening physical well-being. A study with an obese adult with IDDs and Prader–Willi syndrome demonstrated weight reduction from 242.8 to 200 lb after 24 months of mindfulness practice (Singh et al., 2008a). A 3-year follow-up showed further reduction in weight to 190.7 lb.

Enhanced psychological well-being was also documented. Miodrag et al. (2013) noted decreased cortisol and self-reported anxiety levels in 24 individuals with Williams Syndrome and IDDs after mindfulness sessions at a residential music camp. Reduction of anxiety and obsessive thoughts was reported for a female adolescent with moderate/severe IDDs and neuropsychiatric disorder who practiced an ACT program combined with exercises in mindfulness of body (Brown & Hooper, 2009). Reduction in anxiety and depression was reported for 15 adults with IDDs and mental illness who participated in an eclectic program consisting of MBCT, ACT, self-compassion, and Meditation on SoF (Idusohan-Moizer et al., 2015). For six adults under forensic care, enhanced mental health was reported after DBT Coping Skills training as evidenced by a decrease in the levels of risks and increase in their relative strengths according to Short-Term Assessment of Risk and Treatability (Sakdalan et al., 2010).

Research Design and Methods

We now look into the research methods resulting in intervention effects in the 17 reviewed studies and how they meet the requirements of evidence-based practice in IDDs. Evidence-based practice is an emerging standard for interventions in social and behavioral disciplines such as medicine, psychology, education, public health, and mental and behavioral health (Kaiser & McIntyre, 2010; Schalock, Verdugo, & Gomez, 2011). Evidence-based practice originated in medicine as “the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients” (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996, p. 71). Evidence-based practice was operationally defined as replicable instructional procedures supported by research that meets prescribed standards (Cook & Cook, 2011). Cook, Tankersley, and Landrum (2009) proposed guidelines for evidence-based practices regarding research design, methodological quality, quantity of supporting research, and magnitude of effect. These guidelines were used to evaluate the 17 mindfulness intervention studies.

Research Design

Evidence standards for research design include experimental, quasi-experimental, and single-subject designs (Cook et al., 2009). Randomized trials and meta-analyses of research findings drawn from randomized trials are emphasized as the gold standard to determine the effectiveness of a treatment (Sackett et al., 1996). Single-subject research designs are, however, predominantly used to investigate the effectiveness of interventions (Kaiser & McIntyre, 2010). This is because heterogeneity of individuals diagnosed with IDDs (e.g., areas and degree of support required, dual diagnosis) poses a significant challenge to the conduct of randomized trials (Odom et al., 2005; West et al., 2013). Sackett et al. (1996) acknowledged that evidence-based practice was not restricted to randomized trials. Although qualitative research is not included in standards for research design of evidence-based practice, it is a valuable tool for identifying individual values, an initial step of evidence-based process (West et al., 2013).

Of the 17 studies, ten used single-subject designs. Of these, seven studies adopted a multiple-baseline design with follow-up phases between 4 weeks and 3 years (e.g., Singh Adkins et al., 2010, Singh et al., 2008a). Some five studies used a pre-post no-control group design (Chilvers et al., 2011; Idusohan-Moizer et al., 2015; Lew et al., 2006; Miodrag et al., 2013; Sakdalan et al., 2010). The two recent studies adopted a randomized controlled group design (Singh et al., 2014) and wait-list controlled group design (Singh et al., 2013b).

Methodological Quality

The methodological quality indicators that are critical for all types of research designs include clear descriptions of participants, settings, interventionists, the nature of instruction, and intervention fidelity (Cook et al., 2009). For group design experimental studies, of particular importance are establishment of comparable characteristics of participants and interventionists across conditions, validity and reliability of outcome measures, and appropriate data analysis (Gersten et al., 2005). For single-subject research, it is critical to clearly describe the nature and measurement of dependent variables (i.e., intervention effects), the nature and implementation methods of independent variables (i.e., intervention), the baseline, and the establishment of internal, external, and social validity (Horner et al., 2005).

The previous sections present descriptions of participants, settings, interventionists, and the nature of instruction of the 17 mindfulness intervention studies. The recent experimental studies using mindfulness training for reduction in aggressive behavior (Singh et al., 2013b) and cessation of smoking (Singh et al., 2014) established comparable characteristics of participants (e.g., age) and instructors (i.e., therapist, participants' family, or professional caregivers) across experimental and control group conditions. Interrater reliability was established ranging between 94 and 97 %. Consideration of intervention fidelity was in place (e.g., 89–100 % across the parents and support staff individual dyads and 100 % fidelity).

Of ten studies using single-subject designs, nine established baseline (Adkins et al., 2010; Singh et al., 2003, 2007a, 2008a, 2008b, 2011a, 2011b, 2011c, 2013b) and five reported the reliability of assessments (range 92–100 %) between two data collectors (Singh et al., 2003, 2007a, 2011b, 2011c, 2013b). Only two studies reported fidelity of mindfulness intervention by adhering to the Meditation on SoF training manuals (Singh et al., 2011b, 2013b). The frequent measures of the mindfulness effects that were socially significant (e.g., reduction in aggression) demonstrated internal and social validity. The replication of the effects established across participants can indicate external validity.

Quantity and Effects

Standards for research quantity are often considered along with magnitude of effect. Gersten et al. (2005) specified evidence standards of a minimum of four acceptable quality group studies or two high-quality studies with weighted effect size significantly greater than zero. Horner et al. (2005) suggested a minimum of five high-quality studies that involve at least 20 total participants, conducted by at least three different researchers across at least three different geographical locations as standards of study quantity. They did not prescribe evidence standards for magnitude of effect but suggested documentation of a causal or functional relationship between use of the intervention and change in socially significant dependent measures (i.e., intervention effects).

Two experimental mindfulness intervention studies reported results with effect size. From a randomized controlled trial, Singh et al. (2014) reported that the difference between the experimental condition and control condition regarding numbers of cigarettes smoked at the conclusion of the treatment phase was statistically significant, with an effect size of 0.74. The results of the wait-list control study (Singh et al., 2013b) established within the experimental condition a significant reduction in the mean number of physical aggression episodes from the baseline phase to the follow-up phase, with an effect size of 4.71.

Although nine studies endeavored to document functional relationships between the use of mindfulness intervention and dependent variables, it was mainly the same research group that conducted these studies. For this reason, the evidence standards for a single-subject design concerning the number of researcher groups (i.e., five different groups) and geographical locations (i.e., three locations) have not been fulfilled. There are also five studies using pre-post no-control group design that were excluded from discussion about evidence-based practice because of the types of research design. However, these studies are not without their value. Intervention studies adopting group designs and single-subject designs together provide reasons to consider mindfulness training as evidence-based practice for enhancing behavioral, physical, and psychological well-being of individuals with IDDs.

Caregiver Training in Mindfulness

We identified five mindfulness intervention studies for caregivers of individuals with IDDs that investigated indirect effects of intervention on their care recipients with IDDs. Of these, two studies (Neece, 2014; Singh et al., 2007b) provided mindfulness training to parent caregivers of young children with IDDs and three (Singh et al., 2004, 2006b, 2009) to professional caregivers of adults with IDDs. The studies are reviewed concerning intervention objectives, intervention design and methods, and intervention results.

Family Caregivers

Singh et al. (2007b) provided 12, 2-h sessions of individual training in mindfulness to four mothers of young children with IDDs (see Table 12.3). The objectives of the training for mothers were to reduce their parenting stress and increase their satisfaction with parenting and parent–child interactions and their use of mindfulness. The effects of the training provided to the family caregivers on the aggressive behavior of the children at home and social interactions at their day care center were recorded.

The first author individually taught mindfulness theory and meditation skills to the mothers (Singh et al., 2007b). The mothers applied their mindfulness skills to the interactions with their child for the 12-week training period and for a 52-week practice period. The 12, 2-hour sessions covered topics on the philosophy of mindfulness and practices conducive to cultivating mindfulness (e.g., being in the present moment, letting go, mindfulness in daily interaction), of which some were reminiscent of the MBSR program (e.g., loving kindness, nonjudgmental acceptance). There were also topics unique to this program, such as problem solving. This teaches how to mindfully address mother–child interaction issues.

Multiple-baseline design across participants was used to assess any change that occurred during baseline, intervention, and practice. Both parents of each child recorded the incidence of their child's aggressive behavior at home (interrater reliability of 96.5 %), and two behavior analysts observed the children's social interactions in their day care center (a mean of 92 % interrater reliability). The results of the parent mindfulness training were consistently positive.

For children with IDDs who had not received the mindfulness training, reduction in the incidence of aggressive behavior was reported from baseline to training by 33 % (first dyad), 26 % (second), 30 % (third), and 36 % (fourth), respectively. It was further reduced by 87 % (first), 94 % (second), 91 % (third), and 88 % (fourth) from the training period to the practice period. The same pattern was reported for social interaction. Small increases ($M=4$ %) of positive social interactions were noted after the training period, and larger increases ($M=18$ %) were recorded after the practice period.

For mothers who learned and practiced meditation skills to enhance mindfulness, a statistically significant decrease in perceived parenting stress was reported along with incrementally increased satisfaction with parenting and parent–child interactions. The perceived use of mindfulness as increased overall, but the trend was intriguing. Mothers rated their use of mindfulness moderately high prior to the mindfulness training. As training progressed, their perceived use of mindfulness decreased and then increased again after the practice period. The mothers noted that they did not fully understand what mindfulness meant when they first started the study, and that is why they rated their level of mindfulness somewhat higher during baseline than they would have otherwise.

Neece (2014) conducted a wait-list control group study with a sample of 46 parents (mean CA, 35.27 years) of children with IDDs (mean CA, 3.84 years) to investigate the efficacy of training parents in mindfulness. The MBSR program was used in the standard format of eight weekly, 2-h training sessions, daily home practice using audio CDs, and a daylong meditation retreat. The core intervention objectives were similar to those of the study by Singh et al. (2007b). Parents learned the concepts of mindfulness along with the psychology and physiology of stress and anxiety, and mindfulness exercises through guided meditation and paired and group

Table 12.3 Mindfulness interventions for care providers addressing problems of care recipients with DD

Study	Participants	Objectives	Content	Strategies	Duration	Outcomes
1. Singh et al. (2007b)	4 mother–child (with DD) dyads (CA, first: 23 years to 4 years 11 months second: 27 years to 5 years third: 26 years to 6 years) fourth: 31 years to 4 years)	Reduce aggression Increase social interactions	Mindfulness parent training program (12 sessions) addressing: Introduction to mindfulness Knowing mind and attention Being in the present moment Beginner's mind Being your child Nonjudgmental acceptance Letting go Loving-kindness Problem solving Using mindfulness in daily interaction	4 sessions of 2 hours individual training (week 3, 6, 9, 12)	Intervention: 12 weeks Practice: 52 weeks	For children: aggression decreased by 33 % (first), 26 % (second), 30 % (third), and 36 % (fourth) from baseline to training and by 87 % (first), 94 % (second), 91 % (third), and 88 % (fourth) from training to practice Small increases of positive social interactions ($M=4$ %) during training and larger increases ($M=18$ %) during practice For mothers: SUPS and SUIS incrementally increased SUUM decreased during training and increased during practice Statistically (*t*-test) significant decrease in PSI between pre and post-intervention
2. Neece (2014)	46 parents (mean CA, 35.27 years) of young children (mean CA, 3.84 years) with DD	For children: decrease behavioral problems For parents: decrease parenting stress	MBSR (8 sessions): Concepts of mindfulness, the psychology and physiology of stress and anxiety Mindfulness exercises Discussion and sharing in pairs and in the larger group	Eight weekly 2-hours sessions: guided meditation, discussion, etc. A daylong (6-h) meditation retreat Daily home practice using audio CDs	Intervention: 8 Weeks	For children: Significant reductions in ADHD symptoms (large ES) Marginally significant reductions in attention (large ES) For parents: Significant reductions in self-reported parenting stress and depression (large ES) Significant increase in satisfaction with life (large ES) (In comparison to the control group)

(continued)

Table 12.3 (continued)

Study	Participants	Objectives	Content	Strategies	Duration	Outcomes
3. Singh et al. (2009)	23 group home staff responsible for 20 individuals with ID in 4 group homes	Reduce staff's use of physical restraints for aggressive and destructive behaviors of individuals with ID	Mindfulness training program (2 hours 12 weekly sessions) Concepts and activities of mindfulness conducing mindful interactions with individuals with ID (e.g., knowing mind, work of attention, being one with the individuals with ID, nonjudgmental acceptance, letting go, loving kindness)	12 weekly themes using various activities to practice mindfulness Mindfulness homework practice	Intervention: 3 months Practice: 6 months practicing mindfulness skills at work	Incremental decreases in 1. Verbal or physical aggressive incidents 3. Verbal redirections of staff to avoid aggression 4. Physical restraints 5. Stat medicine for uncontrolled aggression 6. Staff injuries 7. Peer injuries Increases in 2. Verbal exchanges that could result in physical aggression but not responded to in any way
4. Singh et al. (2006b)	15 group home staff members (CA 22–38) responsible for 18 people with profound ID and aggressive behavior problems	Increase learning and decrease aggression of 18 individuals with profound ID	Concepts of mindfulness in comparison to those of behavioral training Mindfulness meditation conducing a clear understanding of one's own thoughts and problems	Didactic instruction Meditation practice Mindfulness-enhancing exercises	Intervention: 5-day intensive behavior training 30- to 53-week gap Intervention: 5-day intensive mindfulness training	1. Mean # of interventions for aggression decreased from 20.9 (baseline) to 18.4 (B training) and then to 6.2 (M training) 2. Mean # of mastered learning objectives increased from 4.8 (baseline) to 6.2 (B training) and then to 11.6 (M training) 3. Mean # of physical restraints decreased from 12 (baseline) to 7.4 (B training) and then to 0 (M training) 4 and 5. # of social and physical activities increased from 2.1 and 8.0 (baseline) to 2.9 and 9.2 (B training) and then to 7.2 and 18.5 (M training) 6. Mean levels of staff satisfaction increased from 50.3 (baseline) to 56.3 (behavioral training) and then to 87.7 (mindfulness training) 7. Mean levels of satisfaction with caring services increased from 60.7 (baseline) to 65.7 (behavioral training) and then to 94.3 (mindfulness training)

5. Singh et al. (2004)	6 caregivers (CA 28–44) of 3 male adults with profound MD (CA 45, 54, and 55) 3 caregivers learned mindfulness Remaining 3 learned behavioral training	Increase happiness of adults with profound MD	Mindfulness training program (7 sessions) Introduction to the concept of happiness and mindfulness Mindfulness meditation activities including knowing your mind, oneness of everything, being in the present moment, beginner's mind and being the activity	Discussion Meditation exercise on various key concepts conducing mindfulness Journaling	Baseline: 4, 7, and 12 weeks Intervention: 2 months Practice: 4 months	Interacting with mindfulness-trained caregivers: Physical happiness indicators of 3 adults with profound MD increased 146, 322, and 437 %, respectively, from the baseline to the final phase Interacting with behavioral method trained caregivers: no increases

discussion. Parenting Stress Index, Family Impact Questionnaire, Center for Epidemiologic Studies Depression Scale, Satisfaction with Life Scale, and Subjective Units of Distress Scale were used to evaluate the psychological training effects for the parents, and Child Behavior Checklist was used to examine indirect effects for their children with IDDs focusing on problem behavior.

The results of independent-sample *t*-test between the training group and the wait-list control group showed significant reductions in self-reported stress and depression, and significant increases in satisfaction with life. These results were accompanied by statistically significant reductions in ADHD symptoms and marginally significant reductions in attention problems found among children with IDDs of mindfulness-trained parents. The intervention objectives and findings of both studies (Neece, 2014; Singh et al., 2007b) were similar, but the content and duration of the mindfulness training programs differed. Mothers in the study conducted by Singh et al. (2007b) did not learn about stress-related matters. Parents in the study by Neece (2014) were not instructed to apply mindfulness skills to interactions with their child. Yet stress reductions in mothers (Singh et al., 2007b) and reductions in child problem behavior (Neece, 2014) were found, indicating a strong potential of mindfulness training for supporting children with IDDs though supporting their parents. Both studies called for future studies investigating the mechanisms of the indirect mindfulness training effects (i.e., reductions in child problem behavior). The indirect training effects were only reported for young children so far, and future studies also need to investigate whether older children too will benefit from mindfulness parent training.

Paid Caregivers

Positive effects were also reported for adults with IDDs from training their professional caregivers in mindfulness. Table 12.3 summarizes three intervention studies that trained professional caregivers of adults with IDDs in mindfulness and examined the effects on their care recipients. In the study conducted by Singh et al. (2009), 23 group home staff of 20 adults with IDDs participated in the mindfulness staff training, composed of 12 weekly 2-h sessions. The same weekly topics as those of the mindfulness parent training program were taught with slight modifications (e.g., being one with the individual with IDDs instead of being one with the child) to meet the specific learning requirements of the professional caregivers. They learned meditation methods and exercises in the group training sessions and were encouraged to keep a practice journal while continuing their practice at home and work. They were then instructed to independently practice for 40 weeks.

Using a multiple-baseline design, the effects of the training on the adults with IDDs were monitored through the number of incidents of aggressive behavior, verbal aggression that did not escalate into physical aggression, verbal redirections of staff to avoid aggression, physical restraints, Stat medicines for uncontrolled aggression, and staff and peer injuries. The results were consistent with those of mindfulness intervention studies for family caregivers of children with IDDs. The reductions were observed in every indicator of physical aggression, along with the increases in verbal exchange that did not escalate into physical aggression.

Singh et al. (2006b) demonstrated similar results of training professional caregivers of adults with IDDs in mindfulness but using different research and intervention approaches. In this study they compared the effects of mindfulness training for professional caregivers to those of behavior management training with changing staff ratios. They first provided 5-day intensive behavior management training to 15 caregivers (age range = 22–38 years) from three different group homes responsible for 18 individuals with profound IDDs and aggressive behavior (age range = 25–47 years). The 5-day intensive mindfulness training was introduced 30–53 weeks after the behavior management training. The effects of this training for their care recipients were measured through the number of staff interventions for aggression, mastered learning objectives, physically and socially integrated activities, and the use of physical restraints.

The results indicated that the behavior management training appeared somewhat beneficial for care recipients, but the mindfulness training was more so, regardless of differences in staff ratios. For example at the conclusion of the behavioral training, the mean number of staff interventions for aggression and physical restraints used for uncontrolled aggression decreased from 20.9 and 12 to 18.4 and 7.4, respectively. At the conclusion of the mindfulness training they reduced significantly to 6.2 and 0, respectively. The same improvement patterns were found in the mean number of mastered living skills objectives, which increased from 4.8 to 6.2 upon the completion of behavioral management training and then further increased to 11.6 upon the completion of mindfulness training.

Unlike other studies that trained professional caregivers, this study also examined the direct effects of mindfulness training on professional caregivers who underwent mindfulness training. The mean level of staff satisfaction with work increased slightly to 56.3 after the behavioral training. This further increased to 87.7 after the mindfulness training. This change was socially validated. Families and friends of care recipients with IDDs reported their satisfaction with the quality of caring service performed by the professional caregivers with a slight increase from 60.7 to 65.7 after behavior training and a remarkable increase to 94.3 after mindfulness training.

Enhancement of happiness for adults with profound IDDs was another effect of mindful caring. Singh et al. (2004) trained six caregivers (age range = 28–44 years) of three male adults (ages = 45, 54, and 55 years) with profound multiple disabilities, three of them with mindfulness training and three with behavioral training. At the end of a 2-month training period, consisting of seven training sessions, and a 4-month practice period, the quality of the interactions between care recipients and caregivers was examined. Observational data from daily leisure activity sessions were collected and analyzed (93.4 % interobserver reliability). The results suggested that the physical happiness indicators (e.g., grinning, widely opened eyes in excitement, clapping) of three care recipients were remarkably increased when they interacted with the three caregivers trained in mindfulness (146, 322, and 437 %, respectively, from the baseline to the final phase), while they remained unchanged when they interacted with those trained in behavioral training.

The five studies have dissimilar participants, intervention content, interventionists, and intervention design. More studies are required to provide evidence that fulfills the standards for research design and quantity. The results of these studies, however, collectively suggest that training family or professional caregivers in mindfulness may enhance the quality of life of the individuals with IDDs in their care.

Perspectives of Individuals with IDDs

There are at least three different perspectives on evidence-based practices, empirical–analytical, phenomenological–existential, and poststructural (Schalock et al., 2011). It is important to take multiple perspectives on evidence-based practice in the field of IDDs (Schalock et al., 2011). Empirical–analytical perspectives emphasize experimental or scientific evidence as the basis for evidence-based practices. The previous discussion on evidence standards for research practices reflects this perspective. The phenomenological–existential perspective takes into consideration the reported experiences of well-being in individuals with IDDs for determining intervention decisions and success (Schalock et al., 2011). The aims of mindfulness intervention studies were to enhance the behavioral, physical, and psychological well-being of individuals with IDDs. Reported experiences of individuals with IDDs will be useful for determining whether and to what degree these aims were met. From the poststructural perspective, public policy principles such as inclusion, participation, self-determination, and empowerment are critical for making decisions on intervention selection and success (Schalock et al., 2011). Mindfulness interventions are clearly in line with this last perspective.

Mindfulness intervention encourages the participation of individuals with IDDs and promotes inclusion. A systematic review suggested that long-term practice and long-lasting effects characterize mindfulness interventions for individuals with IDDs (Hwang & Kearney, 2013). Long-term active commitment to mindfulness practice is essential for whatever effects (e.g., self-management) that arise to last over the long term. Inclusion, along with independence, was the ultimate aim of the first mindfulness intervention study in the field of IDDs (Singh et al., 2003), training a male adult in mindfulness to self-manage his uncontrolled aggression so that he could maintain his community living arrangement. The same intention of promoting inclusion of individuals with IDDs was found in the follow-up study (Adkins et al., 2010). Training family and professional caregivers in mindfulness with an intention to support their care recipients with IDDs also reflects the concept of inclusion. The focus is not on uncovering the deficits of individuals with IDDs but on understanding the ecological environments within which behavioral and psychological problems occur. The attitudes and well-being of family and professional caregivers influence interactions with their care recipients and constitute ecological environments.

Self-determination is another central principle that was observed in mindfulness interventions. For example, the most recent study provided mindfulness training to individuals with IDDs for smoking cessation (Singh et al., 2014). A changing criterion design was used for self-determining how many cigarettes the participants could smoke per criterion, which enabled them to pace their own smoking levels. Gradual increase of independence in individuals with IDDs was also noted as the intervention began, based on explicit/external instruction and a movement toward independent practice (Singh et al., 2013b). Self-determination and independence is a way of respecting and empowering individuals with IDDs. The use of mindfulness training as a self-management skill highlights the internal regulation of individuals with IDDs rather than the imposition of external intervention. The emphasis is on the ability rather than the disability of individuals with IDDs, and this view leads to a sense of empowerment. However, although the current practice of mindfulness intervention supports the key principles of evidence-based practice for individuals with IDDs from the poststructural perspective (e.g., participation, inclusion, self-determination, and empowerment), mindfulness interventions are not without issues and challenges.

Issues and Challenges of Training Individuals with IDDs in Mindfulness

Implementation of evidence-based practice is a challenging process and it involves multiple stakeholders (Cook & Cook, 2011). The same challenge applies to mindfulness interventions. Training individuals with IDDs often requires not only the involvement of individuals with IDDs but also that of family and professional caregivers. The caregivers' knowledge of individuals with IDDs is crucial for accommodating the individual learning requirements of individuals with IDDs. Engaging these individuals in long-term practice necessitates a great deal of encouragement and prompting, which can only be provided by caregivers who spend the most time with the individuals with IDDs. Reflecting this challenge, some studies were arranged for individuals with IDDs to practice mindfulness exercises with their family or professional caregivers (e.g., Singh et al., 2014) and some even invited caregivers to become mindfulness instructors (e.g., Singh et al., 2008a). Commitment to mindfulness training for individuals with IDDs may also require that their caregivers make the same commitment.

Engagement is another issue. A mindfulness intervention can only promote participation, inclusion, self-determination and empowerment when individuals living with IDDs actively engage in mindfulness practice. Practicing mindfulness can be encouraged, but it cannot be forced. Long-term active engagement is the key to success. In their study with 15 adults with IDDs and mental illness, Idusohan-Moizer et al. (2015) noted that two participants with mild IDDs dropped out after the first session because they did not like the meditation practice. Brown and Hooper (2009) mentioned the difficulty of engaging a female adolescent in their program. However, the problem of finding ways to engage individuals with IDDs in mindfulness training, ways that differ from the training that the mindfulness instructors themselves have learned, has received little attention in comparison to the effects of mindfulness training.

As noted previously, in training individuals with IDDs in mindfulness, the intervention content and learning process were modified to meet the wide diversity of their learning requirements (e.g., Brown & Hooper, 2009; Miodrag et al., 2013). This is an important issue, especially when mindfulness programs that were initially developed for individuals without IDDs are used. Language, materials, learning process and content are four areas we identified where modifications can occur. However, the review of existing mindfulness intervention studies suggests that more information about modifications is required. This process of modification cannot be prescribed. However, contextual information, explaining when, how, and for whom modifications occur, will assist practitioners in the field of IDDs to translate mindfulness research into practice. The reported experience of individuals with IDDs in response to modified language, materials, learning process and content will be of great importance for both researchers and clinical practitioners in the fields of mindfulness and IDDs.

Although accommodation of the variety of needs of individuals with IDDs is highly recommended, or even inevitable, this can threaten intervention fidelity. The diversity of the learning requirements of individuals with IDDs indicates the need for individual variations in response to treatment (Kaiser & McIntyre, 2010) and suggests that intervention engagement and the specific features of the intervention may affect outcomes (Kaiser & McIntyre, 2010). The provision of mindfulness interventions that accommodate individual learning requirements but do not compromise intervention fidelity necessitates a high level of knowledge and skill among the instructors.

The quality of the teacher cannot be overemphasized in mindfulness intervention, for training individuals with IDDs in mindfulness requires not only an understanding of IDDs but also that of mindfulness. Mindfulness can be learned through intellectual knowledge and practical experience, but a mere intellectual understanding of it, as a technique to be administered, can enrich neither the instructor nor the instructed (Grossman, 2010). Substantial and prolonged practice of mindfulness is a prerequisite for helping others to develop mindfulness (Kabat-Zinn, 2003; Segal et al., 2002). As a result, the statement "trained in conducting mindfulness training" may not provide sufficient information regarding the qualities and qualifications of the instructor in a mindfulness intervention study.

Recommendations for Research and Practice

There are four areas that future research and practice may consider. Precise descriptions of the nature and methods of engagement of individuals with IDDs will assist the process of translating research into practice. Existing research used collaboration with family or professional caregivers as a way to enhance engagement of individuals with IDDs in training. This approach is worth pursuing and expanding to other professionals (e.g., teachers) who are playing critical roles in service delivery. Contextual information about the nature and methods of collaboration would be useful for enabling multidisciplinary support to individuals living with IDDs.

The second area concerns modifications to intervention content and process in relation to intervention fidelity. Although modifying the intervention and intervention fidelity (delivering the intervention according to its design and plan) appear to be in contradiction to each other, this may not be the case if the instructor(s) fully understand mindfulness and how to communicate it. For example, a practitioner with IDDs may learn mindfulness and express her understanding through a verbal mode (e.g., verbal instruction, audio material), while another practitioner may learn and express through a visual mode (e.g., drawings, pictures). The communication media are different, but the core ideas and content of instruction might not be different. What matters is communicating the key ideas in such a way that individuals with IDDs can comprehend them, not using the same communication pathways for everyone. What is important for the intervention is that the nature and level of modifications, conducted in consultation with individuals with IDDs, are described with precision. The quality of the mindfulness instructor once again becomes critical. Mindfulness instructors need both an intellectual understanding and an experiential depth of practice in mindfulness, as well as an intellectual and experiential understanding of individuals with IDDs, if they are to conduct mindfulness interventions in a flexible yet faithful manner.

So far the recipients of mindfulness interventions have been mostly adults. Our review of mindfulness intervention studies suggested the youngest practitioner with IDDs was 16 years old. Future research may diversify the age of the intervention participants to explore the feasibility of training children in mindfulness. If mindfulness training is a feasible option for children with IDDs, individuals with IDDs may be able to avoid living through unnecessary difficulties that threaten their behavioral, physical, and psychological well-being. The same recommendation applies to individuals with profound IDDs. All studies except one (Brown & Hooper, 2009) provided mindfulness intervention to individuals with mild or moderate IDDs. It would be useful to explore whether individuals with profound IDDs can learn and practice mindfulness to the degree that they can help themselves behaviorally or psychologically. If it is not a feasible option, and this needs to be explored, training their caregiver in mindfulness can be an option to use mindfulness intervention as a way to support them.

We introduced five studies that demonstrated the feasibility of supporting individuals with IDDs through training their caregivers in mindfulness. Although the results of these studies are promising, the mechanisms of the indirect effects of mindfulness training are still unknown. Unconditional acceptance, loosening automaticity, and quality interactions between caregivers and care recipients were suggested to explain the nature of the indirect effects of mindfulness training. Future studies may explore and clarify this issue.

In sum, this is a rapidly emerging area of research and practice in the field of IDDs. The current research offers a promise yet to be realized in making the lives of children, adolescents, and adults better. It also offers a way forward to reducing stress and enhancing the psychological well-being of their caregivers—parents, paid carers, and teachers.

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Psychopharmacology

13

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Introduction

A high proportion of individuals with intellectual disabilities (ID) receive medication for either physical or mental health conditions (Deb & Fraser, 1994). The reported rate of use of medication including specific use of antipsychotic medications among individuals with ID who live in community settings varies between 32 and 85 % (Aman, Sarpharc, & Burrow, 1995; Branford, 1996a; Burd et al., 1997; de Kuijper et al., 2010; Doan, Lennox, Taylor-Gomez, & Ware, 2013; Holden & Gitlesen, 2004; Lunsky, Emery, & Benson, 2002; Singh, Ellis, & Wechsler, 1997; Stolker, Koedoot, Heerdink, Leufkens, & Nolen, 2002). Nøttestad and Linaker (2003) found that the proportion of adults with ID who received psychotropic medication remained similar before and after resettlement into the community from long stay institutions. Spreat, Conroy, and Fullerton (2004) compared use of psychotropic medication in Oklahoma ID system in the USA in 1994 and 2000. They found that approximately 35 % of people with ID in 2000 received at least one psychotropic medication. Antipsychotics were prescribed for 20 %, antidepressants for 15.8 %, antianxiety medication for 11.1 %, antiepileptics for 6.9 % for management of mental disorder, and 2 % other mediation. The rate of use of antidepressant medications increased from 1994 to 2000, possibly because of increased use of newer antidepressants but the use of antipsychotics has remained the same although the newer antipsychotics have replaced the older ones in many cases. Interestingly an increased trend of psychotropic medication use was noted when people moved from institutions to community settings. A similar trend in increase in psychotropic medication use after de-institutionalization, particularly involving antidepressant medications, was reported by Radouco-Thomas et al. (2004) in Canada. Medication is a commonly used strategy in ID to manage problem behavior (PB) when no diagnosis of a psychiatric disorder can be confirmed, notwithstanding the fact that the accurate diagnosis of psychiatric disorders can be particularly difficult in individuals with ID (see Deb, Matthews, Holt, & Bouras, 2001).

Clarke, Kelley, Thinn, and Corbett (1990) found that 36 % of individuals with ID who received psychotropic medications did not have a psychiatric diagnosis. Deb and Fraser (1994) reported that individuals with ID often receive multiple medications and often at a high dose. In order to provide some idea about the extent of use of different psychotropic medications for individuals with ID, data from a recent study by Deb, Unwin, and Deb (2015) have been presented here.

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Similar findings have been reported in other prevalence studies (de Kuijper et al., 2010; Kierman, Reeves, & Alborz, 1995; McGillivray & McCabe, 2004; Spreat, Conroy, & Jones, 1997).

In a recent prospective 12 months follow-up study of 100 adults who have been seen by psychiatrists in the UK in their outpatient clinics for the management of aggressive behavior, Deb et al. (2015) found that 90 % received psychotropic medication. The new generation of antipsychotics was prescribed most frequently with 48 participants being prescribed one or more new generation of antipsychotics. The next most commonly prescribed medication class was mood stabilizers/antiepileptic medications ($n=41$), followed by new generation of antidepressants ($n=29$), typical antipsychotics ($n=27$), antianxiety medications ($n=9$), beta-blockers ($n=8$), older generation antidepressants ($n=5$), and psychostimulants ($n=4$). As 31 of the individuals who received antiepileptic medication also had a diagnosis of epilepsy, it could be argued that antiepileptic medications were used specifically for the management of aggressive behavior only in a relatively small proportion of cases. For example, 12 of the 21 participants for whom carbamazepine was prescribed had epilepsy. Similarly, 13 of the 17 participants for whom sodium valproate was prescribed had epilepsy. The rest of the antiepileptic medications such as lamotrigine, levetiracetam, gabapentin, zonisamide, and topiramate were all used specifically for the treatment of epilepsy. The rate of antiepileptic medication use reported in this study is not unexpected as epilepsy is known to affect 25 % or more adults with ID (Berney & Deb, 2012).

Deb et al. (2015) found that among the antidepressants, mostly the new generation of antidepressants such as citalopram ($n=10$), paroxetine ($n=7$), fluoxetine ($n=6$), sertraline ($n=3$), and escitalopram/mirtazapine ($n=2$ each) were prescribed. Only a few received old generation of antidepressant medications such as amitriptyline ($n=2$), clomipramine ($n=2$), and dosulepin ($n=1$). This is in line with the current clinical practice of antidepressant use among non-ID populations for the treatment of depression (see guideline by the National Institute of Health and Clinical Excellence, UK, NICE; www.nice.org.uk) and also in line with the suggestions proposed in expert consensus studies in ID (Aman et al., 2000; Bhaumik, Branford, Barrett, & Gangadhara, 2015; Unwin & Deb, 2008a). Among PRN (as required) medications, lorazepam ($n=12$), risperidone ($n=10$), and diazepam ($n=8$) were prescribed most frequently.

The profile of psychotropic medication prescription found in Deb et al.'s (2015) study is similar to what was reported in a UK psychiatrists' consensus survey by Unwin and Deb (2008a). Unwin and Deb (2008a) found that most psychiatrists preferred to use a non-medication based approach first. However if they had to use a psychotropic medication, the order of preference was generally an antipsychotic followed by an antidepressant followed by a mood stabilizer. Among the antipsychotics, the newer antipsychotics were preferred in the order of risperidone followed by olanzapine, quetiapine, amisulpride, aripiprazole, and clozapine. In Deb et al.'s (2015) study among the antipsychotics the most commonly used medication was risperidone ($n=39$), followed by chlorpromazine (13), haloperidol (9), olanzapine/zuclopenthixol (6 each), quetiapine (3), flupenthixol (2), and amisulpride (1). For the sake of convenience we have included flupenthixol under antipsychotics instead of antidepressants. It seems that the use of old generation (typical) antipsychotics such as chlorpromazine and haloperidol is still prevalent in the UK, although among the new generation (atypical) antipsychotics, risperidone seems to be gaining popularity and surpassed the use of old generation antipsychotics. The use of thioridazine was banned in the UK a few years ago; until that time, thioridazine was widely used in the UK to treat aggressive behavior among adults with ID. Aman et al.'s (2000) international consensus study found a similar trend that preferred valproic acid and carbamazepine among the mood stabilizers/antiepileptics. In the UK it seems that the use of lithium among people with ID as a mood stabilizer medication as well as for the management of problem behavior is falling out of favor.

In an old study (Branford, 1996a), lithium was prescribed for 29 (17 %) of individuals with ID in Leicestershire in the UK. However, Deb et al. (2015) found that lithium was prescribed for only 3 % of patients. It is possible that these patients were initially prescribed lithium many years ago, but it has now become difficult to withdraw it. The reasons for the decline of lithium use for individuals with ID are: (a) there is a narrow window between lithium's serum therapeutic and toxic level; (b) in many individuals with ID it is not possible to carry out blood tests to measure serum lithium level; (c) in many individuals with ID it is not possible to carry out the mandatory blood tests that are required to assess adverse effects, and (d) in many individuals with ID it is difficult to assess adverse effects of lithium. Lithium may cause long-term adverse effects such as thyroid dysfunction and renal impairment for which regular blood tests are mandatory. Also, it is difficult to withdraw lithium once prescribed, which creates an ethical dilemma for prescribing this for an individual who cannot give informed consent, which may be the case in a number of adults with ID.

In Branford's (1996a) population based prevalence study of psychotropic medication use among adults with ID in Leicestershire in the UK, anticholinergic medication was prescribed for 23 % of patients. This is similar to what Deb et al. (2015) have found in their study, which was 24 %. Concurrent prescribing of regular (as opposed to PRN) anticholinergic medications with antipsychotic drugs is not uncommon, but this increases the long-term risk of tardive dyskinesia particularly among people who have an underlying brain damage such as individuals with ID.

McGillivray and McCabe (2004) reported that among 873 individuals with ID who lived in Australia 82.9 % received antipsychotic medications, 17.9 % antidepressant medications, 22 % antianxiety/sedative medications, 12.2 % antiepileptic/mood stabilizers, and 2.4 % other types of psychotropic medication. None received psychostimulants. Similarly de Kuijper et al. (2010) reported that among 2373 individuals with ID in the Netherlands 32.2 % (95 % Confidence Interval 30.1–33.9) received antipsychotic medications, 17 % received antidepressants and 20 % received benzodiazepine. Among the antipsychotics 65 % were old generation of antipsychotics, 23 % were new generation antipsychotics and 12 % were a combination of these. In 58 % of cases the reason for use of antipsychotic medications was problem behaviors and in 22.5 % of cases psychotic disorders or psychotic symptoms. In 11.7 % cases the diagnosis of psychotic disorder was specified according to DSM-IV criteria. In 18.5 % of cases no reason for prescribing psychotropic medications had been recorded. Similar findings have been reported from the USA (Tsiouris, Kim, Brown, Pettinger, & Cohen, 2013). Reilly, Senior, and Murtalgh (2015) reported among individuals with ID in the UK and in Ireland that, of four neurogenetic syndromes, psychostimulants were used among 21 % of individuals with Fragile X syndrome (FXS), 3 % with Prader–Willi syndrome (PWS), 4 % with Williams syndrome (WS), and none with Velo-cardio-facial syndrome (VCFS). Risperidone was used among 7 % of FRX, 6 % of PWS and none of WS or VCFS individuals. SSRIs were used for 1 % of FRX, 4 % of PWS, and none of WS or VCFS individuals. On the other hand melatonin was used among 9 % of FRX, 3 % of PWs, 15 % of WS, and 8 % of VCFS individuals.

Psychiatrists usually consider psychotropic medications for the management of problem behavior in individuals with ID under following circumstances (see Unwin & Deb, 2010): (a) failure of non-medication based interventions; (b) risk/evidence of harm to others, property and self; (c) high frequency and severity of problem behaviors; (d) to treat an underlying psychiatric disorder or anxiety; (e) to help with the implementation of non-medication based interventions such as positive behavioral support (with concurrent use of medication); (f) risk of breakdown of the individual's community placement; (g) lack of adequate or available non-medication based interventions (although this should not be used as a rationale for using medication); (h) good response to medication in the past; and (i) patient/caregiver choice.

There is public concern regarding the use of psychotropic medication in individuals with ID for the management of problem behavior in the absence of a diagnosed psychiatric disorder. Some of the reasons for this concern are: (a) perceived excessive use of medication (sometimes multiple medications are used, particularly antipsychotics at doses exceeding the national guideline such as the British National Formulary (BNF) (www.bnf.org) in the UK recommended maximum dose); (b) medications are used without review for a long period; (c) problems with adverse events such as somnolence, weight gain and other metabolic adverse effects caused by the new generation of antipsychotic medications and extrapyramidal symptoms and tardive dyskinesia particularly associated with old generation antipsychotics; (d) overall lack of evidence to support the effectiveness of psychotropic medications to manage problem behavior—especially aggressive behavior; (e) out of license use of psychotropic medications as these medications are generally licensed for treatment of psychiatric disorders but not problem behavior; (f) use of medication without explicit patient consent which often occurs in ID; (g) difficulty in assessing adverse effects in many individuals with ID; and (h) difficulty in obtaining necessary investigations such as serum lithium level or blood tests for other adverse effects (Deb, 2013).

Therefore, systematic reviews were carried out on the effectiveness of different types of psychotropic medications that are summarized in this chapter. These systematic reviews were carried out in order to develop a national and an international guide for the management of problem behavior in people with ID (Deb et al., 2009; Unwin & Deb, 2010). As advised by the Guideline Development Group (GDG) any study that included less than ten participants were excluded from the systematic reviews. Also the studies on individuals with ASD for which no separate data were available for individuals with ID specifically were excluded. In this chapter findings from the randomized controlled trials (RCTs) of antipsychotics are presented in some detail.

The general principles for using psychotropic medications for different psychiatric disorders among individuals with ID are similar to those used for the general population who do not have ID. No specific evidence base exists to recommend specific medications for psychiatric disorders among adults with ID, and therefore, in this chapter the main principles for pharmacological management of common psychiatric disorders such as schizophrenia, depressive disorders as suggested in the NICE guidelines (www.nice.org.uk) and the Maudsley Prescribing Guidelines Guide (Taylor, Paton, & Kapur, 2012) in the UK (see also the Frith Prescribing Guidelines; Bhaumik, Branford, Barrett, & Gangadhara, 2015 for specific application to individuals with ID; Deb, 2009; de Leon, Greenlee, Barber, Sabaawi, & Singh, 2009) are summarized first. However, the primary aim of this chapter is to advise on the use of psychotropic medications for the management of problem behaviors among adults with ID because psychotropic medications are used outside their licensed indications for these problems, therefore, good clinical practice is essential in this context.

Pharmacological Interventions for Mental Disorders

Schizophrenia

Treatment with medication comprises only a part of a comprehensive package of care. The NICE (www.nice.org.uk) advises that newer antipsychotic medications should be the first choice. Newer antipsychotic medications (e.g., risperidone, olanzapine) should be considered for patients showing or reporting unacceptable adverse effects caused by older antipsychotic medications (e.g., haloperidol, chlorpromazine). Patients unresponsive to two different antipsychotic medications (one being a new generation) should be given clozapine. Depot antipsychotic medications should be used where there is ground to suspect that a patient may not adhere to prescribed oral therapy. New and old generation antipsychotic medications should not be prescribed together except during changeover of medication.

Bipolar Affective Disorders

Acute Mania or Hypomania

Patients with no prior diagnosis of bipolar affective disorder should be started on antipsychotic medications (e.g., olanzapine, risperidone, quetiapine, or conventional antipsychotic medications such as haloperidol). A patient with hypomania not receiving mood stabilizers should be started on sodium valproate (e.g., epilim chrono 500 mg/day or depakote 250 mg three times/day) or lithium (400 mg MR/day) or carbamazepine (200 mg MR twice/day). In patients with mania or mixed episodes a mood stabilizer should be added or the dose optimized and commenced on antipsychotic medications. For all patients antidepressants should be withdrawn. As a second step benzodiazepine such as lorazepam up to 4 mg/day or clonazepam up to 2 mg/day may be added.

Maintenance Treatment

For bipolar affective disorder mood stabilizers such as lithium or carbamazepine or sodium valproate or lamotrigine or topiramate could be used. For bipolar depression lithium alone or in combination with antidepressant medications or lamotrigine or a combination of olanzapine and fluoxetine can be used. For rapid cycling bipolar affective disorder, antidepressant medications should be withdrawn and possible precipitants such as alcohol, thyroid dysfunction, external stressors should be evaluated. Optimization of the treatment with mood stabilizers should include combination of medications though lithium may be less effective in this context. As a further step other medication options may be considered such as clozapine (usual dose), lamotrigine (up to 225 mg/day), levetiracetam (up to 200 mg/day), nimodipine (180 mg/day), olanzapine (usual dose), quetiapine (300–600 mg/day), risperidone (up to 6 mg/day), and thyroxine (150–400 μg/day) (in alphabetical order). However, caution should be used when prescribing lithium in individuals with ID as discussed earlier in this chapter.

Depression

Antidepressants may be started and titrated to recommended therapeutic dose and their efficacy should be assessed over 4–6 weeks. If poorly tolerated, antidepressants from a different class can be prescribed. If ineffective, the dose should be increased and assessed over 2 weeks. If still ineffective, the diagnosis should be reconsidered and antidepressants from a different class may be prescribed. If still not effective, consider treatment for refractory depression including electroconvulsive therapy (ECT). If the patient responds to antidepressant medication, the treatment should be continued for 6 months to 1 year in case of first episode and longer in case of patients who had more than one episodes of depression. Psychological and behavioral therapies such as cognitive behavior therapy (CBT), and also newer treatments such as trans-cranial magnetic stimulation (TMS) have also been shown to be effective.

Generalized Anxiety Disorder (GAD)

Non-pharmacological interventions such as reassurance, anxiety management including relaxation training and CBT should be tried first. For emergency management a short course of benzodiazepine for 2–4 weeks could be tried. For long-term psychotropic medications, selective serotonin reuptake inhibitors (SSRIs) (although may initially exacerbate symptoms, therefore, a lower starting dose is often required or use in combination with a small dose of benzodiazepine initially) or venlafaxine (NICE recommends specialist referral) or a tricyclic antidepressant medication such as imipramine/clomipramine or pregabalin may be used. Other treatments include buspirone (has a delayed onset of action and low efficacy), hydroxizine, beta-blockers (useful for somatic symptoms, particularly tachycardia; the evidence base for beta-blockers' efficacy on anxiety symptom is poor), and tiagabine.

Obsessive Compulsive Disorder (OCD)

Making a diagnosis of OCD may be very difficult in adults with limited verbal skills and in those with autism as obsessions and compulsions may be confused with rituals that are a significant feature of autism spectrum disorder (ASD) (see Deb et al., 2001). However, in cases where OCD is ascertained, the primary interventions include psychological treatments such as exposure therapy, response prevention and other behavior therapies such as CBT but a combined medication and psychological therapy may be most effective. Pharmacological options include SSRIs and clomipramine. Other medications to consider are antipsychotics such as risperidone or quetiapine but not haloperidol; venlafaxine, buspirone, clomipramine, clonazepam (in general used to reduce associated anxiety), and mirtazepine augmentation of SSRIs.

Panic Disorder

The primary treatment options are non-pharmacological such as CBT, anxiety management including relaxation training though a combined medication and psychological therapy may be most effective. In an emergency, a short-term use of benzodiazepine can be recommended. In the long term the options for psychotropic medications are SSRIs (therapeutic effect can be delayed and patients can experience an initial exacerbation of panic symptoms), some tricyclic antidepressants such as imipramine or clomipramine, and reboxitine. Other pharmacological options include monoamino-oxidase inhibitors (MAOIs), mirtazepine, sodium valproate, and inositol.

Use of Psychotropic Medications for the Management of Problem Behavior in Individuals with ID

Systematic reviews have found that the highest number of randomized controlled trials (RCTs) are on new generation antipsychotics, particularly risperidone (Deb, Sohanpal, Soni, Unwin, & Lenôtre, 2007; Unwin & Deb, 2011a) and aripiprazole (Deb et al., 2014). There are also primarily crossover RCTs on the opioid antagonist naltrexone involving children (Roy, Roy, Deb, Unwin, & Roy, 2015a) and adults (Roy, Roy, Deb, Unwin, & Roy, 2015b) with ASD and/or ID. There are also a few poor quality dated RCTs on the mood stabilizer lithium and one on carbamazepine that included only 10 participants (see review by Deb et al., 2008). There is a small crossover RCT of an antidepressant clomipramine that recruited only 10 patients in the study (see review by Sohanpal et al., 2007).

Antipsychotic Medications

There are a number of old controlled trials involving old generation antipsychotics (see review by King, 2002; Matson & Neal, 2009). Some of them have been summarized here. La Malfa, Lassi, Bertelli, and Castellani (2006) reviewed the literature on the use of antipsychotic medications in people with ID. The authors identified 195 studies of which 127 were of type V, 44 of type IV, 9 of type III, 21 of type II, and 4 of type I evidence. One hundred and seventeen studies included use of old generation antipsychotics and 78 new generation. Wardell, Rubin, and Ross (1958) randomized 26 adults with ID to chlorpromazine treatment (100–200 mg three times/day; average daily dose 400–600 mg) and 15 adults with ID to placebo in a double blind RCT for 3 months. There was no significant difference in the outcome in problem behavior between two groups and in fact the chlorpromazine group was marginally worse. Weir, Kernohan, and MacKay (1968) randomized 45 in-patients with ID into pericyazine vs. chlorpromazine vs. placebo (doses are unknown), each condition lasting for 12 weeks. There was no significant difference in the outcome of problem behavior either between two treatment groups or between placebo and each of the treatment group.

Vaisanen, Kainulainen, Paavilainen, and Viukari (1975) used sulpiride (50–100 mg three times/day) vs. chlorpromazine (25–50 mg/day) vs. placebo in 60 in-patients with ID in a crossover trial for 4 weeks. Behavior changed towards a more positive direction when sulpiride replaced placebo as indicated on the global assessment scale only ($p<0.05$). Sulpiride was found to be as effective as or possibly superior to chlorpromazine ($p<0.1$). Elie, Langlois, Cooper, Gravel, and Albert (1980) randomized 51 adults with ID to receive either thioridazine 50 mg/day or placebo, which showed placebo was superior to thioridazine in improving problem behavior. Vaisanen, Viukari, Rimon, and Raisanen (1981) prescribed either haloperidol (10–60 mg/day) or thioridazine (100–600 mg/day) in a randomized fashion after a period of placebo washout for 30 adults with ID. There were eight responders to haloperidol and six to thioridazine. There were few differences in adverse events between the two treatments. Aman, Teehan, White, Turbott, and Vaithianathan (1989) randomized 20 children and adults in institutions in a crossover trial to receive either haloperidol high dose (average daily dose of 0.05 mg/kg body weight) or low dose (average daily dose 0.025 mg/kg body weight) or placebo for 3 weeks. Haloperidol was found to be marginally better than placebo in high dose. Malt et al. (1995) compared efficacy of zuclopenthixol (5.5 mg/day average dose; range 2–20 mg) with that of haloperidol (1.5 mg/day average dose; range 0.5–5 mg) using a crossover design among 35 adults with ID, which showed better efficacy for zuclopenthixol. Singh and Owino (1992) also highlighted the efficacy of oral zuclopenthixol among adult in-patients with ID in a double-blind study.

However, recent RCTs involved newer generation of antipsychotics (primarily risperidone but two recent studies on aripiprazole as well) and used better designs, which are described next in this chapter.

Risperidone

There are three RCTs of risperidone among adults with ID (Gagiano, Read, Thorpe, Eerdekens, & Van Hove, 2005; Tyrer et al., 2008; van Den Borre et al., 1993). Two of these studies showed that risperidone was significantly better than placebo in improving problem behavior, but Tyrer et al.'s (2008) study did not find a significant difference in outcome among groups treated with risperidone, haloperidol, and placebo. There are six RCTs among children with ID and with or without ASD (Aman, De Smedt, Derivan, Lyons, & Findling, 2002; Buitelaar, van der Gaag, Cohen-Kettenis, & Melman, 2001; Research Units on Pediatric Psychopharmacology (RUPP) Autism Network, 2002; Shea et al., 2004; Snyder et al., 2002; Van Bellinghen & De Troch, 2001). RUPP (2002) and Shea et al. (2004) primarily included children with ASD, some of whom also had ID whereas Aman et al. (2002) and Snyder et al. (2002) primarily included children with ID, but excluded those who had ASD. Of these four studies, only the RUPP study (2002) was not sponsored by a pharmaceutical company.

McDougle et al. (1998) in an RCT showed that some core symptoms of ASD improved significantly in the risperidone group compared with the placebo group. Many of these children also had ID and some showed problem behavior such as aggression as well. All these studies showed a significant improvement in problem behavior in the risperidone group compared with the placebo group. Three of the RCTs involving children were continued for many weeks using open label designs (Findling, Aman, Eerdekens, Derivan, & Lyons, 2004; RUPP continuation study, 2005; Turgay, Binder, Snyder, & Fisman, 2002). Another open label prospective study also described long-term effects of risperidone on children with ID (Croonenberghs et al., 2005). These studies showed that the efficacy of risperidone had been maintained over 48–52 weeks and medication adverse effects were by and large tolerable.

Adult Studies

The first published RCT on risperidone involving adults with ID was carried out in the Netherlands. van Den Borre et al. (1993) included 37 adults (15–58 years) with ID in their study who showed aggression, SIB, agitation, hyperactivity, and irritability. It is not clear whether or not the authors excluded participants who had a diagnosis of psychiatric disorder. Risperidone ($n=30$ after seven dropouts) 4–12 mg/day was used as add-on to the existing medications. A crossover RCT design was used, which included 1 week washout followed by 3 weeks RCT followed by 1 week washout followed by 3 weeks crossover RCT. Primary outcome measure was Aberrant Behavior Checklist (ABC) (Aman, Singh, Stewart, & Field, 1985) total score. Secondary outcome measures included Clinical Global Impression (CGI) (Guy, 1976a), Visual Analogue Scale (VAS) (target behaviors); extrapyramidal symptoms (Extrapyramidal Symptoms Rating Scale; ESRS) (Chouinard, Ross-Chouinard, Annable, & Jones, 1980), blood tests, electrocardiograph (ECG), and the participants' weight.

In the first phase there was 16 % drop in the total ABC score in the risperidone group and 15 % in the placebo group. In the second phase there was 27 % drop in the total ABC score in the risperidone group and 0 % in the placebo group. The difference in phase one was not statistically significant but the difference in phase two was. There was statistically significant improvement in the risperidone group according to CGI ($p<0.01$) (both phases). However, there was no statistically significant change according to VAS. There was also no change between the two groups in the ECG or the ESRS score. However, the participants in the risperidone group showed sedation ten times more commonly than the placebo group. Blood tests did not detect any statistically significant change in the two groups.

Risperidone was found to be more efficacious in this study. However, conflicting results were found in two phases of the study in that two groups did equally well in phase one and the risperidone group did better only in phase two. It is therefore possible that the same group of participants continued to show improvement irrespective of the intervention used. There was also conflicting results found according to different outcome measures. For example, the risperidone group did better according to the total ABC score and CGI but not according to VAS.

The other problems with the study include a very short washout period, which also increased the chance of contamination from potentially withdrawal symptoms as being rated as problem behavior, and short follow-up period. Authors did not clarify how many participants were included in each group. The method of randomization and blinding were not described, and the IQ level or gender ratio was not specified in the paper. The total score of ABC is not valid, hence most studies now use the Irritability (ABC-I) sub scale. As authors did not exclude underlying psychiatric disorders, it is possible that in some cases risperidone may have improved behavior by treating the underlying psychiatric disorder. The dose of risperidone is higher than what is usually used for problem behavior now.

The second published study on risperidone involving adults with ID was a multicenter trial, which was led by clinicians from South Africa. Gagiano et al.'s (2005) study included 77 adults (18–57 years) with ID who did not have a diagnosis of a psychiatric disorder. The first phase of the study was a parallel design RCT in which 39 participants were randomly allocated to the risperidone group and 38 into the placebo group. The RCT lasted for 4 weeks after which 58 participants continued to receive risperidone in an open label design for another 48 weeks. Participants received risperidone as an add-on to other medications at a dose of 1–4 mg/day (mean dose: 1.8 mg/day) both in the RCT as well as in the open label study.

The primary outcome measure was the ABC total score, and secondary outcome measures included Behavior Problems Inventory (BPI) (Rojahn, Matson, Lot, Esbensen, & Smalls, 2001) score, CGI-S, and VAS (target behaviors). According to the authors 52 % in the risperidone group improved as opposed to 31 % in the placebo group (Number Needed to Treat; NNT = 5). There was a statistically significant improvement in the ABC total score in the risperidone group compared with the placebo group ($p = 0.036$) and also according to CGI ($p < 0.05$). In the risperidone group 23–41 % complained of somnolence and mean weight gain was 3.8 ± 0.6 kg. There was no difference between the groups in the QTc interval according to ECG and extrapyramidal symptoms according to the ESRS.

Overall this is a good quality study and supports the use of risperidone among adults with ID, included a reasonable number of participants (although the study could still be underpowered!) and the overall design was good. However the ABC total score lacks validity and ABC-I score instead should have been used as the primary outcome measure. The follow-up period in the RCT of 4 weeks is short. The study was sponsored by a pharmaceutical company.

The most recently published RCT on risperidone involving adults with ID was by Tyrer et al. (2008) who in a multicenter parallel design RCT randomly allocated 86 adults with ID and aggressive challenging behaviors into three groups, namely, risperidone (mean dose of 1.07–1.78 mg/day), haloperidol (mean dose of 2.5–2.94 mg/day), and placebo. Clinical assessments of aggression, aberrant behavior, quality of life, adverse drug effects, and carer burden, together with measurement of total costs, were recorded at 4, 12, and 26 weeks. The primary outcome was change in aggression after 4 weeks treatment according to the Modified Overt Aggression Scale (MOAS) (Ratey & Gutheil, 1991).

The rate of aggression declined dramatically with all three treatments by 4 weeks, with placebo showing the greatest reduction according to MOAS median score (79 % as opposed to 57 % for combined medication groups) ($p = 0.06$). Placebo treatment was also cheaper than the other two treatments over a 6-month period in terms of total costs (Tyrer et al., 2009). However, the risperidone group showed a higher level of aggression at the baseline compared with the placebo group and had the highest level of improvement according to the ABC-I subscale. The period of follow-up of 4 weeks when the data were analyzed was short and the participant number is small, which may not have provided adequate power to the study.

In one study (Amore, Bertelli, Villani, Tamborini, & Rossi, 2011), older antipsychotic medications were changed to risperidone and olanzapine among 62 adults with ID for the management of aggressive behavior. According to Overt Aggression Scale (OAS) (Yudofsky, Silver, Jackson, Endicott, & Williams, 1986) the new generation antipsychotics showed significantly better efficacy than the older generation. Apart from verbal aggression for which olanzapine was significantly better, no significant difference was reported in efficacy between the two new generation antipsychotics.

Children Studies

Aman et al.'s (2002) study included 115 children (87 included) (age 5–12 years) with ID. The authors have excluded children with ASD. A multicenter parallel design RCT was used in which 43 children were randomly allocated to risperidone group in order to receive 1.2 mg/day mean dose and 44 allocated to the placebo group. Children were followed up for 6 weeks at the end of which Nisonger Child Behavior Rating form (conduct problem subscale) (NCBR-F) (Aman, Tassé, Rojahn, & Hammer, 1996) was used as the primary outcome measure along with ABC-I, BPI, VAS, and CGI as secondary outcome measures. According to the authors, 15.2 % of children in the risperidone group as opposed to 6.2 % in the placebo group showed significant improvement. Analysis was conducted on an intention-to-treat basis. Forty three (78 %) and 44 (70 %) completed the study from the risperidone and placebo groups respectively. The reasons for those withdrawn were variable including insufficient response to medication and noncompliance. The risperidone group showed a significant decrease in NCBR-F conduct subscale scores (change in score at endpoint −15.2) than did the placebo (−6.2). In the risperidone group, problem behavior ratings significantly decreased and pro-social behaviors increased according to the social competence subscale. There was significant improvement in the ABC-irritability, hyperactivity, lethargy subscales, BPI-aggressive, destructive behavior subscales, CGI ($p < 0.001$), and VAS (at week 6: $p < 0.05$). Forty (76.9 %) and 21 (33.4 %) individuals were rated as improved on the CGI in the risperidone and placebo groups respectively. Fifty four (98 %) and 44 (70 %) individuals reported adverse events in the risperidone and placebo groups respectively. Adverse events in the risperidone group included headache and somnolence but not extrapyramidal symptoms. Mean weight gain in the risperidone group was 2.2 kg as opposed to 0.9 kg in the placebo group. Overall this seems to be a good quality study and supports the use of risperidone among children. However, the study could still be underpowered and the follow-up period was short although improvement was apparent within the first week or two of treatment. The improvement was not defined, and methods of randomization and allocation concealment were not well described.

Findling et al. (2004) followed up 107 children from Aman et al. (2002) study in an open label design for 48 weeks extension. The same outcome measures as in Aman et al.'s (2002) study were included such as NCBR-F, ABC-I, CGI-I, BPI, and VAS. Fifty (47 %) children completed the trial. Improvement with risperidone at 1.51 mg/day mean dose was maintained for 48 weeks. Although the dropout rate was high, they are not always necessarily due to the adverse effects of risperidone.

RUPP (2002) study included 101 children (5–17 years) with ASD, 74 of whom had ID and 12 borderline intelligence. The authors used multicenter parallel design RCT for 8 weeks in which 49 children were randomized to receive 0.5–3.5 mg/day mean dose of risperidone and 52 to receive placebo. The primary outcome measure was ABC-I and the secondary measure was CGI-I.

Data were analyzed using an intent-to-treat principle. There were four withdrawals (three in the risperidone group and one in the placebo group). An additional 17 individuals in the placebo group failed to complete the study due to various reasons including the lack of efficacy and consent withdrawal. In the risperidone group there was 57 % mean reduction in the ABC-I score at follow-up as opposed to 14 % in the placebo group ($p < 0.001$). Similarly 69 % in the risperidone group and 12 % in the placebo group respectively showed much or very much improvement according to CGI ($p < 0.001$). Average weight gain for the risperidone group was 2.7 ± 2.9 kg as opposed to 0.8 ± 2.2 kg in the placebo group ($p < 0.001$). A higher proportion of children in the risperidone group reported increased appetite, fatigue, drowsiness, dizziness, drooling ($p < 0.05$). In the subsequent open label study two thirds of subjects with a positive response to risperidone at 8 weeks maintained the improvement at 6 months. Overall this is a good quality study and supports the use of risperidone among children. Cohort size is still relatively small and the follow-up period is relatively short. The method of randomization and concealment were not described well either.

RUPP (2005) continuation study was conducted in two phases. In phase one, 63 children (5–17 years) with ASD (53 with ID and seven with borderline intelligence) continued to receive risperidone at a mean dose of 1.96 mg/day in an open label trial for 4 months. In phase two, 38 children with ASD (31 with ID and five with borderline intelligence) were allocated randomly in a double blind study either to continue to receive risperidone or being replaced by placebo for 8 weeks. The ABC-I subscale was used as the main outcome measure.

At the end of phase one, the change in ABC-I score was small and nonsignificant and the average weight gain was 5.1 kg ($p < 0.001$). In phase two, 63 % children showed relapse in problem behavior in the gradual placebo substitution group as opposed to 13 % that continued to receive risperidone.

Risperidone showed persistent efficacy and good tolerability for intermediate length of treatment for children with ASD and ID. It seems that the adverse events such as somnolence disappeared after a few weeks but the problem with weight gain persisted. It is not clear whether or not the authors took into account the behavioral adverse effect of withdrawal, which may disappear after a few weeks.

Shea et al.'s (2004) study included 79 children (5–12 years) with ASD of whom 42 had ID and ten had borderline intelligence. The authors used a multicenter parallel design RCT in which 40 children were randomly allocated to receive 1.17 mg/day mean dose of risperidone and 39 to receive placebo for 8 weeks. ABC, NCBR-F, VAS, CGI-C, and safety data were used as outcome measures. Data were analyzed using the intention-to-treat principle. Of the 79 participants, 72 completed the study; two of the withdrawals were from the risperidone group and five from the placebo group. ABC-irritability subscale scores at endpoint revealed that there was a 64 % improvement in the risperidone group vs. 31 % in placebo ($p < 0.001$). Significant improvement was also apparent according to other subscales of the ABC ($p < 0.05$), NCBR-F subscales (conduct problem subscale: $p < 0.01$), and VAS ($p < 0.05$) on which the most frequently reported symptom was aggression (23.4 %). CGI global improvement at endpoint was 87 % in the risperidone group vs. 40 % in placebo ($p < 0.001$). Adverse effects revealed that extrapyramidal symptoms were comparable between the two groups, weight gain with risperidone was 2.7 kg as opposed to 1 kg in the placebo group ($p < 0.001$), and somnolence with risperidone was present in 73 % as opposed to 8 % in the placebo group.

Overall this is a good quality study and supports the use of risperidone among children. However, the study sample was relatively small and the follow-up period relatively short. One major criticism of the study is that the children were excluded if they did not respond to risperidone previously. This is likely to produce a major bias in the study. Also there was no correction for multiple testing (Type I error).

Snyder et al. (2002) included in their study 110 children (5–12 years) with ID (52 %) and borderline intelligence (48 %). In a 6-week parallel design RCT the authors randomized 53 children to receive risperidone at a mean daily dose of 0.98 mg (range 0.4–3.8 mg/day) and 57 children to receive placebo.

NCBR-F-conduct behavior subscale, ABC, BPI, VAS, and CGI were used as outcome measures. Cognition was also assessed using the Continuous Performance Task (CPT) and verbal learning by means of the California Verbal Learning Test for children (CVLT) (Delis, Kramer, Kaplan, & Ober, 1998). Extrapyramidal symptoms were assessed with the ESRS. Analysis was conducted on an intention-to-treat basis. Twenty five (23 %) participants withdrew from the study, 19 (33 %) from the placebo group and six (11 %) from the risperidone group. There were highly significant changes on the Conduct Problem subscale of the NCBR-Form ($p < 0.001$); reduction in symptom rating for the placebo group was 6.8 (20.9 %) compared with 15.8 (47.3 %) for the risperidone group at endpoint. There were significant improvements on all subscales of the ABC. The BPI only demonstrated significant differences for the aggressive behavior subscale ($p < 0.01$)—21.5 % reduction in the scores in the placebo group and 45.9 % in the risperidone group. The VAS/symptom scale showed a greater reduction in the scores for risperidone (37.4 %) than placebo (15.8 %) ($p < 0.001$). At endpoint, 14 (25 %) on placebo and 42 (77 %) on risperidone were rated as improved to some degree on CGI ($p = 0.001$). Forty two (73.7 %) individuals in the placebo group and 46 (86.8 %) in the risperidone group experienced at least one adverse event. Commonly reported adverse events included somnolence, headache, appetite increase, and dyspepsia. Extrapyramidal adverse effects were noted in seven (13.2 %) and three (5.3 %) individuals in the risperidone and placebo groups respectively ($p = 0.245$). Average weight gain in the risperidone group was 2 kg as opposed to 0.2 kg in the placebo group ($p < 0.001$). Overall this is a good quality study and supports the use of risperidone among children. However, the cohort size was relatively small and the follow-up period was short.

Turgay et al.'s (2002) study is the continuation of Snyder et al.'s study (2002). The authors continued to prescribe risperidone on an average dose of 1.38 mg/day to 77 children (5–12 years) with ID and borderline intelligence for 48 weeks in an open label design. The authors were particularly interested to assess the long-term adverse effects of risperidone among children with ID.

Over the study period, 52 % complained of somnolence, 38 % headache, 36 % weight gain (mean gain was 7.1 kg), and 27 % increased appetite. Prolactin level peaked at 4 weeks and then came down to normal. Extrapyramidal symptoms affected 26 % children (mild/moderate). No change was observed in cognitive measures, hematology, vital signs, and ECG. Improvement in behavior was maintained over the 48 weeks of the study. According to this study, risperidone showed persistent efficacy and good tolerability for intermediate length of treatment for children with ID. Somnolence and weight gain were the common adverse effects. Authors did not check for lipid profile and glucose intolerance.

Croonenberghs et al. (2005) (cited in Farmer & Aman, 2013) have also followed up 504 children with ID for 1 year who were treated with mean dose of 1.6 mg/day risperidone. Seventy-three percent of 504 children enrolled completed the study. The mean ESRS score decreased with risperidone treatment over time. No clinically significant change in the laboratory values were noted apart from a transient rise in the prolactin level. The initial improvement in the NCBR-F which was noted within the first week of treatment with risperidone was maintained throughout the study period along with improvement in positive social behavior, ABC score, CGI and cognitive performance ($p < 0.001$). Two smaller RCTs that included 38 children and adolescents (Buitelaar et al., 2001) and 13 children with ID and ASD (Van Bellinghen & De Troch, 2001) also showed significant improvement in problem behavior in the risperidone group when compared with the placebo group.

McDougle et al. (1998) in a placebo-controlled RCT included 31 children with ASD, many of whom also had ID. Risperidone (1–6 mg/day) was compared with placebo for the management of repetitive behavior, SIB, aggression, and ASD symptoms. Nine out of the 11 participants with ID in the risperidone group improved compared with two out of 13 in the placebo group. Overall, risperidone was found to be superior to placebo on all measures. Mild sedation was reported with risperidone.

Zarcone et al. (2001) gave for 4 weeks risperidone high dose (average doses for children and adolescents was 1.8 mg/day, and for adults was 4.52 mg/day) vs. low dose (average doses for children and adolescents was 1 mg/day, and for adults was 2 mg/day) to 20 children and adults with ID. Although classified as a prospective RCT with a double blind, placebo-controlled, crossover design, this study does not qualify as a proper crossover trial. Instead of medication being given parallel to placebo, as one would anticipate in a crossover trial, this study has high vs. low dosages of medication, with two separate placebo periods. Mainly the medication effects were evaluated using ABC-C scores in each placebo phase versus the total score of high vs. low dose phases. Mean ABC-C ratings showed lower scores occurred in the second phase of the medication sequence regardless of whether the sequence was low dose to high or vice versa (no significant dose effect at 0.05 level for the medication sequence was apparent). The NCBR-Form ratings on the conduct scale for children demonstrated better effects on high doses of risperidone. For the NCBR-SIB subscale, there were greater reductions in aberrant behavior whilst on the low dose. CGI scores showed similar results across medication phases. The study design is complicated and, therefore, the results are confusing to interpret. However, overall it seems that risperidone was more effective than placebo but there was not much difference between two different dose regimes. It is unclear why high and low doses of risperidone were administered if the overall purpose of the study was to compare risperidone with placebo. It does appear that the study is indeed comparing low with high doses of medication rather than with placebo. The study does mention that caregivers were not blinded to the conditions of the study and this could have influenced their ratings.

Aripiprazole

Deb et al. (2014) recently published a systematic review on the efficacy of aripiprazole in the management of problem behavior among individuals with ID and with or without ASD. The authors reported two RCTs (Marcus et al., 2009; Owen et al., 2009) that included 218 and 75 children (age 6–17 years) with ASD and with and without ID respectively in a parallel design RCT over 8 weeks period. Both of these studies were carried out by the pharmaceutical company that produces aripiprazole and it is not clear whether there is any overlap among the participants in these two studies. In both studies the diagnosis of ASD was confirmed by an Autism Diagnostic Interview-Revised (ADI-R) (Lord, Rutter, & Le Couteur, 1994) assessment and both studies included children with ABC-I score of ≥18 and CGI-S ≥ 4. Both studies excluded children with a diagnosis of Fragile X syndrome and any other major psychiatric disorder such as schizophrenia, depression and bipolar disorder. Both studies have reported significant improvement in behavior in the aripiprazole group compared with the placebo group.

The first RCT (Owen et al., 2009) gave flexible doses of aripiprazole with the average daily dose being 10 mg. There was a significant improvement in the ABC-I score (−12.9) in the risperidone group compared with a score change of −5 in the placebo group, and a significant mean improvement of 2.2 (much improved) in the CGI-I score in the risperidone group compared with 3.6 (no change) for the placebo group. The second study (Marcus et al., 2009) used fixed doses of aripiprazole. According to the ABC-I score the aripiprazole groups showed significant improvement compared with the placebo group (−12.4 for 5 mg, −13.2 for 10 mg, −14.4 for 15 mg aripiprazole respectively compared with −8.4 for the placebo group). CGI-I showed statistically significant improvement for all the aripiprazole groups compared with the placebo group (2.6 for 5 mg and 2.5 for 10 and 15 mg aripiprazole respectively compared with 3.3 for the placebo group).

Most studies reported adverse effects from aripiprazole in the form of weight gain, increased appetite, sedation, tiredness, drooling, and tremor. However, aripiprazole improved serum prolactin level in some participants and overall did not show any adverse effect on QTc interval. There was an open label extension of one study (Marcus et al., 2011a) following the RCT that included 330 children, which showed that the improvement shown in the aripiprazole group during the RCT lasted for 52 weeks and the adverse events were tolerable (Marcus et al., 2011b). Deb et al. (2014) have also found another 12 studies of either prospective or retrospective case reports that reported improvement in most people with ID treated with aripiprazole.

Other Newer Antipsychotic Medications

Singh, Matson, Hill, and Pella (2010) reviewed studies on clozapine for the management of problem behavior in individuals with ID. They included 13 small studies, of which only three seem to be controlled studies with very small number of participants of one, two and three respectively. However, Boachie and McGinnity's (1997) study was not included in this review, who examined case notes and medication charts of 17 individuals with ID who received clozapine 200–900 mg/day (average dose 640 mg/day in females and 357.1 mg/day in males) with an average range of treatment for 32.1 months (range 9–47 months). According to Singh et al.'s (2010), review the dose range of clozapine in different studies varied from 10 to 900 mg/day, average being 300–400 mg. Most studies are retrospective case notes review that included small number of participants. All studies reported improvement according to subjective measure such as CGI and about one third of those who used rating scales, have shown improvement according to a rating scale although most studies did not use any rating scale. Adverse events reported included extrapyramidal side effects, vomiting, drowsiness, weight gain, hypersalivation, tachycardia, hypotension as well as hypertension, urinary incontinence, leukopenia (reported in one study), and seizures (reported in one study that used 10 mg to 300 mg daily dose).

Janowsky, Barnhill, and Davis (2003a) reported a retrospective study on 20 individuals with ID whose age ranged from 18 to 55 years, and of whom 45 % were male. The majority had severe to profound ID. Olanzapine 2.5–22.5 mg/day (mean dose 9.1 mg/day) was used as an add-on for up to 6 months. Aggression displayed in 14 participants decreased in 93 % ($p < 0.01$) and SIB displayed in seven participants decreased in 86 % ($p < 0.044$). Disruptive and other behaviors displayed in 11 participants decreased in 73 % ($p < 0.021$). Eighty percent showed a decrease in the global ratings, 15 % showed an increase and 5 % showed no change. Adverse effects were reported as follows: sedation in 4 (20 %), constipation in 2 (10 %), gait problem in 1 (5 %), and pre-olanzapine weight was 68.2 kg and post-olanzapine 72.0 kg ($p < 0.006$). No increase in serum glucose levels was seen.

McDonough, Hillery, and Kennedy (2000) reported that olanzapine reduced the stereotyped form of chronic SIB in four of seven individuals with ID. Williams, Clarke, Bouras, Martin, and Holt (2000) treated 12 adults with mild to moderate ID who had variety of reasons for giving olanzapine, including psychosis, problem behaviors, adverse effects of other medications, and inadequate treatment responses. Williams et al. (2000) found that 58.3 % of the participants "greatly improved," a proportion essentially same as for those who improved on risperidone treatment. Among children with ID, one controlled study by Hollander et al. (2006) including 11 participants, and two uncontrolled case reports by Kemner, Willemsen-Swinkels, de Jonge, Tuynman-Qua, and Engeland (2002) and Harden and Hardan (2006) who included 25 and 16 participants respectively showed efficacy of olanzapine (cited in Häβler & Reis, 2010).

La Malfa, Bertelli, and Lassi (2003) reported a prospective case series on use of quetiapine 300–1200 mg/day for 6 months on 15 individuals with ID, whose age ranged from 25 to 47 years, and of whom 66.7 % were male. La Malfa et al. (2003) reported significant improvement from the use of quetiapine, particularly among those who had mild to moderate ID. Findling et al. (2006) in an uncontrolled case report showed efficacy of quetiapine among 17 children with ID.

Cohen, Fitzgerald, Okos, Khan, and Khan (2003) reported adverse effects from ziprasidone (average dose 145 mg) among 40 individuals with ID who received other antipsychotic treatment before but developed adverse effects in the form of weight gain or did not respond to the treatment. Previous treatments included risperidone among 28 (70 %), quetiapine in five (12.5 %), olanzapine in 2 (5 %), haloperidol/clozapine among one (2.5 %), and no treatment for four (10 %) individuals. Among 19 individuals who showed mild to moderate frequency of problem behavior there was reduction in behavior frequency after ziprasidone treatment whereas six individuals who showed high frequency of problem behavior did not show much change after ziprasidone treatment. As for adverse events, ziprasidone treatment was associated with a significant weight loss of 3.6 kg as well as significant reduction in total cholesterol and triglycerides ($p <= 0.5$). This drug is withdrawn from the UK market for its serious cardiac adverse effects. Bertelli (2013) recently presented retrospective case notes based data on the efficacy of asenapine for the management of problem behaviors in psychiatric disorders in people with ID.

Scheifes, Stolker, Egberts, Nijman, and Heerdink (2011) found that of 100 RCTs of antipsychotic medications for the management of problem behavior detected through a systematic review, only 27 % involved people with ID, 11 % were on patients with schizophrenia and 62 % involved patients with dementia. However, compared with other studies the sample sizes of studies involving people with ID are relatively small (only 11 % of the total patient population recruited in 100 RCTs had ID). However, this review does not include RCTs of antipsychotic medications for patients with personality disorders and impulse control disorders (see review by Bellino, Bozzatello, Brignolo, & Bogetto, 2013).

Polypharmacy

Despite the widespread condemnation of and lack of evidence for the efficacy of polypharmacy (simultaneous use of more than one) of antipsychotic medications, this practice remains widespread (Taylor, 2010). On the other hand, the merits and demerits of combining an antipsychotic with another group of psychotropic medication specifically for the management of aggressive behavior in adults with ID are currently unknown (Olson, Ingram, & Mann, 2002). In Deb et al.'s (2015) study, however, the rate of polypharmacy of antipsychotics alone was relatively low (10 % at baseline and 9 % at 6 months follow-up), although the use of polypharmacy of all types of psychotropics was relatively high (45 % at baseline and 41 % at 6 months follow-up).

Branford (1996b) showed that with an active program, polypharmacy of antipsychotics per se could be reduced and in some cases antipsychotics could be withdrawn altogether or their dose reduced without any adverse consequences. However, most places lack such active program for antipsychotic withdrawal. However, it is worth keeping in mind that in a number of individuals where two antipsychotics were prescribed simultaneously, the clinicians may be in the process of switching over from one to another.

High Dose Antipsychotics

Deb et al.'s (2015) study also highlighted a trend towards use of high dose antipsychotic medications in a number of patients. According to the BNF, the usual maintenance dose of chlorpromazine for the treatment of psychoses is up to 300 mg a day, although a maximum dose of 1000 mg has been recommended for exceptional cases. In Deb et al.'s (2015) study 23 % of patients at baseline and 20 % at 6 months follow-up received daily chlorpromazine equivalent dose of more than 300 mg. There was a slight reduction at follow-up in the proportion of patients who received chlorpromazine equivalent dose of antipsychotic medications less than 100 mg a day (37 % at baseline vs. 32 % at 6 months follow-up), however, there was an increase in the proportion that received chlorpromazine equivalent daily dose between 100 and 299 mg (40 % at baseline vs. 48 % at 6 months follow-up).

Interestingly, these proportions are very similar to what was described in Branford's (1996a) study 19 years ago, which reported the rate of antipsychotic medication use in a population-based sample of adults with ID in the Leicestershire district of the UK. In Branford's (1996a) study of the 198 patients who received antipsychotic medication, 50 (25 %) received this at a daily chlorpromazine equivalent dose of less than 100 mg, 92 (46 %) received at a daily dose between 100 and 299 mg, 36 (18 %) received at a daily dose between 300 and 499 mg, and 20 (10 %) received at a daily dose of higher than 500 mg. The proportion of patients in Branford's (1996a) study who received chlorpromazine equivalent dose of over 300 mg a day was slightly higher (28 %) than what was found in Deb et al.'s (2015) study.

In Deb et al.'s (2015) study the dose used for both risperidone and olanzapine was very low. However, the recommended daily dose suggested in the BNF is for the licensed indication for individuals with psychosis. Therefore, it is anticipated that dosages will perhaps be lower when used for the management of aggressive behavior. It is possible that in the case of antipsychotics, clinicians feel that a lower dose acts as an anti-anxiety/anti-arousal medication rather than an antipsychotic, with the primary intention of the behavioral management being to decrease the underlying anxiety/arousal.

Withdrawal Studies

As for antipsychotics specifically, a number of studies have shown that it is possible to either reduce the dose of antipsychotic medications or successfully withdraw them altogether after many years of use (Ahmed et al., 2000; Branford, 1996b; de Kuijper, Evenhuis, Minderaa, & Hoekstra, 2014; Luchins, Dojka, & Hanrahan, 1993). However, it is only possible if an active program of antipsychotic withdrawal is implemented (Branford, 1996b). Branford (1996b) has shown that certain factors influence the success of antipsychotic withdrawal regimes. These factors include lower initial dose (<100 mg chlorpromazine equivalent daily dose), monopharmacy, presence of minimal psychopathology, lack of hyperactivity, aggression, stereotyped behavior, resident in community staffed residential facilities, and presence of epilepsy.

Withdrawal studies specifically of antipsychotic medications have shown that in 25–50 % of cases antipsychotic medications could be withdrawn successfully after long-term use and in a proportion of cases the dosage could be reduced without any adverse consequences (Ahmed et al., 2000; Branford, 1996b; de Kuijper et al., 2014; May et al., 1995; Wressell, Tyrer, & Berney, 1990). Encouragingly, Janowsky, Barnhill, Khalid, and Davis (2006) found 66.3 % (55/83) of individuals remained antipsychotic free almost 10 years after withdrawal. However, in a subsequent study Janowsky, Barnhill, Khalid, and Davis (2008) demonstrated that unfortunately it becomes extremely difficult to withdraw antipsychotic medications altogether in a very high proportion of those who showed a relapse of problem behavior after one or two attempts of drug withdrawal. A number of authors (Aman, Singh, & Fitzpatrick, 1987; Christian, Snycerski, Singh, & Poling, 1999; de Kuijper et al., 2014; Singh et al., 1996) have highlighted the influence of staff attitude on withdrawal studies that used open label design which shows an urgent need to conduct placebo controlled withdrawal studies.

Adverse Events

Mahan et al. (2010) showed that among 80 individuals with ID in the USA, polypharmacy of psychotropic medication from different classes increased the likelihood of developing adverse events. A number of measures have been used either in their original form or in adapted versions in order to assess adverse effects of psychotropic medications in individuals with ID. Some of these are: Udvalg for Kliniske Undersøgelser (UKU) scale (Lingjaerde, Ahlfos, Bech, Dencker, & Elgen, 1987), Abnormal Involuntary Movement Scale (AIMS) (Guy, 1976b), Simpson Angus Scale for extrapyramidal side effects (Sampson & Angus, 1970), the Dyskinesia Identification System Condensed User Scale (DISCUS) (Kalachnik & Sprague, 1993), Barnes Akathisia Rating Scale-Revised (Barnes, 2003). Some scales were specifically designed for use among individuals with ID such as the Matson Evaluation of the Drug Side Effects (MEDS) (Matson et al., 1998), CLAMPS Abnormal Movement Scale (Ellis et al., 1996), and Monitoring of Side Effects Scale (MOSES) (Kalachnik, 1999).

Matson and Mahan (2010) reviewed the studies on adverse events due to psychotropic medication use among individuals with ID, and Matson and Hess (2011) did the same for individuals with ASD. As expected, most studies are on adverse effects of antipsychotic medications as they are the most widely used psychotropic medication for individuals with ID. Most studies reported adverse events associated with old generation antipsychotic medications such as haloperidol and chlorpromazine. For the old generation antipsychotic medications, extrapyramidal adverse effects such as parkinsonism, akathisia, and tardive dyskinesia are reported in most studies. There is an argument whether some of these abnormal movements are due to use of medication or the underlying brain damage as studies show that individuals with ID are more prone to develop these symptoms (Nowell & Sprague, 1996). However, within the ID population the rate of these symptoms are higher among those who are treated with antipsychotic medications than those who are not.

Ganesh, Rao, and Cowie (1989) reported among 66 institutionalized adults with ID in the UK who were treated with antipsychotic medication, 5 (7.6 %) developed akathisia and 18 (27 %) individuals developed tardive dyskinesia. However, it was also reported that severity of ID is a risk factor for tardive dyskinesia (Nowell & Sprague, 1996), perhaps indirectly implicating the role of underlying brain damage in the causation of these symptoms. Similar argument exists as to whether schizophrenia itself is a risk factor for some of these adverse events, particularly glucose intolerance, than the antipsychotic medications per se. Another argument is whether or not the new generation of antipsychotic medications is less prone to develop adverse events in general but extrapyramidal adverse effects in particular when compared with the old generation antipsychotic medications.

In general it has been shown that the new generation antipsychotic medications produce less adverse events particularly extrapyramidal adverse events than the old generation medications, although these adverse events have also been reported among individuals with ID who have been treated with risperidone and also olanzapine. There are also anecdotal reports that risperidone can cause serious adverse events such as neuroleptic malignant syndrome (NMS) in individuals with ID. However, for the new generation antipsychotic medications the metabolic syndrome including weight gain, diabetes mellitus, change in lipid profile and hyperprolactinemia are more commonly described adverse events. Only a handful of studies have assessed these symptoms in individuals with ID (see next section). However, interestingly a number of studies have reported dyskinesia and other extrapyramidal symptoms upon withdrawal of antipsychotic medication in a high proportion of individuals with ID (Newell, Bodfish, Mahoney, & Sprague, 2000; Newell, Ko, Sprague, Mahoney, & Bodfish, 2002) (60 % in Wigal et al.'s, 1993 study, cited in Matson & Mahan, 2010). This phenomenon suggests that these symptoms may sometimes have been suppressed by the use of antipsychotic medications.

There is also concern whether antipsychotic medications have effect on cognition particularly among children. Aman et al. (2009) have reviewed this subject and Aman et al. (2008) have reviewed the cognitive effect of risperidone on children with autism and irritable behavior. At least one RCT (Snyder et al., 2002) did not find any effect of risperidone on cognition of children with ID when compared with the effect of placebo. On the other hand, Stratta, Riccardi, and Rossi's (2013) review has shown that in the non-ID general population administering antipsychotic medication in an individually optimized manner seems to have the potential for improving cognitive aspect of schizophrenia, regardless of the kind of antipsychotic medication. Similar findings were reported for children with ID who were treated with risperidone for problem behavior (Aman et al., 2009).

The main concern of using the new generation of antipsychotic medications is the adverse effect of metabolic syndrome. Zuddas, Zanni, and Usala (2011) reviewed the adverse effects of newer antipsychotic medication including metabolic indices among children and adolescents including those with ASD, but not necessarily with ID. Based on the review of RCTs, the authors showed that adverse event of weight gain is worst with treatment with olanzapine and best with aripiprazole with intermediate effect from risperidone and quetiapine. Indeed, Deb et al.'s (2014) systematic review on aripiprazole has shown that adverse events such as weight gain and hyperprolactinemia have improved in a number of individuals with ID when switched from other antipsychotics such as risperidone.

A number of studies assessed the effects of newer antipsychotic medications in causing metabolic syndrome/disorders in individuals with ID (Findling et al., 2004; Frighi et al., 2011; Hellings, Zarcone, Crandall, Wallace, & Schroeder, 2001; Hellings et al., 2005; Khan, 1997; McKee, Bodfish, Mahorney, Heeth, & Ball, 2005; Turgay et al., 2002). Frighi et al. (2011) observed the rate of metabolic syndrome among 138 antipsychotic treated and 64 antipsychotic naïve individuals with ID and compared that with a non-ID general population that was treated with antipsychotic medication. Among individuals with ID, 48 % received risperidone, 18 % olanzapine, 10 % thioxanthenes, and 24 % other antipsychotic medication. Ninety five percent of individuals with ID received monotherapy of average duration of 8 years and of average chlorpromazine equivalent daily dose of 108 mg (range 16–667). Metabolic indices were the same or more favorable in individuals with ID compared with the non-ID general population. However, overweight/obesity and type 2 diabetes were more prevalent among women with ID than the non-ID control group. There were no statistical or clinical differences in the metabolic indices between the antipsychotic treated versus antipsychotic naïve individuals with ID. However, there was a nonsignificant trend towards a higher rate of type 2 diabetes in the group that received antipsychotic medication. The authors reported that a total of 100 and 70 % treated with amisulpride/sulpiride and risperidone respectively showed hyperprolactinemia, with secondary hypogonadism in 77 and 4 % of affected women and men respectively. It is not clear whether or not individuals with ID are more prone to develop metabolic syndrome compared with the non-ID general population.

Among Taiwanese population, Chang et al. (2012) reported that metabolic syndrome and obesity are common in adults with ID. The authors also found that heart rate variability (a marker of autonomic functioning) is significantly lower in individuals with ID compared with that in the non-ID general population. de Winter, Magilsen, van Alfen, Willemsen, and Evenhuis (2011) reported that among 412 elderly Dutch population with ID over age 50 years a weighted prevalence of metabolic syndrome was 25.1 % (95 % confidence interval: 21–29.3 %) with a significantly higher risk for individuals with mild ID. The prevalence of metabolic syndrome among individuals with ID was significantly higher compared with the non-ID Dutch population over age 50 years (15.7 %; 95 % confidence interval: 13.5–17.9 %). On the contrary, Hsu et al. (2012) reported a lower rate of metabolic syndrome among 164 institutionalized (overall rate of 11.6, with 8 % in males and 17.2 % in females) individuals with ID compared with the non-ID general Taiwanese population. The authors defined metabolic syndrome on the basis of presence of three or more of the following; (a) central obesity, (b) elevated blood pressure, (c) elevated fasting glucose level, (d) elevated triglycerides, and (e) reduced high density lipoprotein (National Institute of Health, 2002).

Rossi, Bertelli, and Piva Merli (2014) reported from a retrospective 36 months study of metabolic effects of new generation antipsychotics (clozapine, olanzapine, risperidone, quetiapine, aripiprazole, and to a lesser extent asenapine) on 60 adults with ID. They did not find any significant difference from baseline to the endpoint in weight, BMI, fasting blood glucose level, total cholesterol, HDL or triglyceride. Four (7 %) people reported increased BMI, two (3 %) developed type 2 diabetes mellitus, six (10 %) had hypercholesterolemia, five (8 %) had hypertriglyceridemia, and three (5 %) had low HDL.

Conclusion

As antipsychotic medications are the most widely used drugs for the management of problem behavior in individuals with ID, it is not surprising that most of the evidence is based on their efficacy. Most evidence for the new antipsychotic medications was based on RCTs on risperidone (which is the most widely used antipsychotic medication for this purpose) apart from two RCTs on aripiprazole. There are also some RCTs conducted on the older antipsychotics such as chlorpromazine and haloperidol. It appears from the RCTs available so far that there is at present equivocal evidence for the efficacy of risperidone among adults with ID with problem behaviors, two studies showing positive and one showing negative finding.

There is, however, now sufficient good quality RCT based evidence available to support risperidone's efficacy among children with ID (with or without ASD) in the management of problem behaviors. These studies found a significant reduction in scores for the risperidone group compared with the placebo group on the Clinical Global Impression-Improvement (CGI-I), Aberrant Behavior Checklist, and Visual Analogue Scale as an outcome measure to rate the most troublesome target behavior ($p<0.05$). A total of 109 (54.5 %) participants were rated as "much improved" or "very much improved" at endpoint on the CGI-I in the risperidone treated groups ($n=200$) and 24 (11 %) in the groups that received placebo ($n=218$). Our meta-analysis (Unwin & Deb, 2011a) showed that the overall Number Needed to Treat (NNT) to achieve a rating of "much" or "very much improved" on the CGI over a period of 4–8 weeks of treatment with risperidone versus placebo is 3 with a range between 2 and 5. However, main concern about using risperidone is its adverse effects such as somnolence and weight gain (not much evidence is available from the RCTs on other adverse events such as metabolic and cardiac). Long-term follow-up studies among children are reassuring showing that initial improvement continues over many weeks and overall, the adverse events are tolerable. There is also concern about use of high dose antipsychotic medication and polypharmacy.

Two RCTs conducted by the pharmaceutical companies showed efficacy of aripiprazole in children with ASD. However, there is a need for more carefully designed RCTs into the use of aripiprazole in the management of problem behavior including aggression in individuals with ID and/or ASD independent of pharmaceutical companies. It seems that it is possible to successfully withdraw antipsychotic medications after long-term use in a high proportion of individuals with ID.

Antidepressants

On the whole, ten studies were retrieved using the systematic review. Further information on the antidepressants is provided in the systematic review by Sohanpal et al. (2007). Of these studies, there was one RCT (Lewis, Bodfish, Powell, & Golden, 1995), which investigated the effectiveness of the tricyclic antidepressant clomipramine. The remaining studies explored the effectiveness of selective serotonin reuptake inhibitors (SSRIs). One cohort study (Troisi, Vicario, Nuccetelli, Ciani, & Pasini, 1995) ($n=19$; median follow-up for 36 weeks) and two open trials (Cook, Rowlett, Jaselskis, & Leventhal, 1992; Markowitz, 1992) ($n=10$ and 20, respectively, with variable follow-up for 7–467 days and 3 months respectively) looked at the efficacy of fluoxetine. Of the prospective case series studies, there was one on fluoxetine (Bodfish & Madison, 1993) ($n=16$; follow-up for 4 months), two on fluvoxamine (La Malfa, Bertelli, & Conte, 2001; La Malfa, Bertelli, Ricca, Mannucci, & Cabras, 1997) ($n=60$ and 14 respectively; 6 weeks follow-up each) and one on paroxetine (Davanzo, Belin, Widawski, & King, 1998) ($n=15$ and add-on in 8; follow-up for 4 months). In addition, there was one retrospective, uncontrolled study on paroxetine (Janowsky, Shetty, Barnhill, Elamir, & Davis, 2005) ($n=38$; follow-up for 6 months) and one on both paroxetine and fluoxetine (Branford, Bhaumik, & Naik, 1998) ($n=33$). In addition, Garber, McGonigle, Slomka, and Monteverde (1992) reported improvement in stereotype and SIB in 10 (91 %) of 11 individuals with ID who were treated with clomipramine. Singh (1993) highlighted the interaction between fluoxetine and carbamazepine in the treatment of SIB in individuals with ID.

The only RCT on antidepressant was by Lewis et al. (1995), which included only ten patients. This study included ten adults whose age ranged between 18 and 42 years of whom 80 % were male. This was a double blind, placebo controlled crossover study. Different phases of the study included a single-blind placebo phase in weeks 1 and 2. In weeks 3–9 clomipramine was compared with placebo in a double blind design (titration stage—weeks 3–5; maintenance phase—weeks 6–9) followed by a titration down phase in week 10. Crossover second titration phase were in weeks 10–12, and second maintenance phase were between weeks 13 and 16 followed by a second titration down phase in week 17. Finally in weeks 18 and 19 a single-blind placebo design was used.

Of the ten participants, four had severe ID and six profound ID, four had ASD symptoms, two had seizure disorder and two were taking concurrent antipsychotic medications for aggression. Participants presented with either stereotyped (body rocking and object such as toy shaking, $n=6$) or repetitive self-injurious (i.e., head hitting, $n=5$) or repetitive compulsive (checking, hording, arranging, touching, ordering, etc., $n=3$) behaviors or a combination of these. Intervention included clomipramine, the dose of which was titrated up to 225 mg/day, which was prescribed as add-on to antipsychotic medications in four participants and placebo. Participants were observed on 3 or 4 days every week during the study period of 19 weeks.

Outcome measures included teachers' ratings on the ABC scale as well as the staff ratings on a 5-point Likert scale for the intensity of repetitive behavior. Nurses recorded adverse effects using the Treatment Emergent Side Effects Scale as a secondary measure. Improvement was observed in body stereotyped ($p < 0.01$) and object stereotyped ($p < 0.05$) behaviors. Three (30 %) participants developed adverse events. Six (60 %) of the seven who tolerated the medication exhibited a clinically significant improvement in one or more repetitive behaviors.

The main problem with this study is the small cohort size, which does not provide enough power to the study. Crossover is not a good design because opposite results can be found across the two phases, namely, pre- and post-crossover phases. Also emergence of behavior due to withdrawal dyskinesia etc. is difficult to control for because the overall duration of the study is short. The outcome measure (staff rated Likert scale) is not validated. Although detailed results are given in the text of the study, the graphs alone are difficult to understand and interpret. Furthermore, the target behaviors were part of obsessive-compulsive spectrum disorder for which clomipramine is indicated in any case.

King et al. (2009) conducted a controlled trial of citalopram on 149 children and adolescents with ASD of whom 40 % had ID that did not show efficacy as assessed by CGI-I subscale of "much or very much improved" of the SSRI but no specific data were presented for ID population separately.

Conclusion

The existing evidence on the use of antidepressants for the management of problem behavior in adults with ID is scant. The study on clomipramine showed beneficial effects (Lewis et al., 1995) but the cohort size was very small ($n = 10$). However, responses to the SSRIs were varied whereby some studies reported clear favorable results (Janowsky et al., 2005; La Malfa et al., 1997, 2001; Markowitz, 1992), some showed negative effects (Bodfish & Madison, 1993; Branford et al., 1998; Troisi et al., 1995) and other studies demonstrated both positive and negative outcomes (Cook et al., 1992; Davanzo et al., 1998). This discrepancy in findings, therefore, makes it difficult to come to a definite conclusion regarding the effectiveness of antidepressants in this context.

Improvements were largely reported in SIB and perseverative/compulsive behaviors. It may, therefore, be the case that medications were in effect treating underlying behaviors that are part of the OCD spectrum for which SSRIs are indicated anyway. Not surprisingly the antidepressants were most effective in the management of problem behavior when depression or anxiety was present in the background. In a number of cases deterioration in behavior is reported which may have been caused by the adverse effects of some of the antidepressants. In general, the majority of the evidence based on open trials and case series studies was fraught with methodological concerns. The small sample sizes meant that the studies were statistically underpowered and often control groups were not included. There was a dearth of validated outcome measures utilized and where more than one assessor conducted the outcome measurements, inter-rater reliability was not contemplated.

The efficacy of antidepressants certainly deserves more attention in research, as there is evidence to suggest (Deb et al., 2015) that these medications are used commonly in the management of problem behaviors in individuals with ID. This review does not suggest that they are ineffective but that there is not enough good quality evidence for their usefulness at present.

Mood Stabilizers (Lithium and Antiepileptic Medication)

Deb et al.'s (2008) systematic review revealed eight studies of which three were small scale primarily crossover RCTs on lithium of which only two have been published in peer reviewed journals (Craft et al., 1987, Tyrer, Walsh, Edwards, Berney, & Stephens, 1984) and the other one was published as a book chapter (Tyrer, Aronson, &

Lauder, 1993). There are other concerns regarding the use of lithium that are mentioned earlier in this chapter. Among other mood stabilizers such as antiepileptics, only a small RCT involving ten individuals is available on the use of carbamazepine (Reid, Naylor, & Kay, 1981) and the rest of the studies are case series. The other four studies included one retrospective case notes study on lithium (Langee, 1990) ($n = 66$; follow-up over 10 years); one prospective (Verhoeven & Tuinier, 2001) ($n = 28$; follow-up 6–12 months) (sodium valproate add-on average 1345 mg/day) and another retrospective (Ruedrich, Swales, Fossaceca, Toliver, & Rutkowski, 1999) ($n = 28$; 2–73 months) (sodium valproate add-on average 920 mg/day) case series on sodium valproate; and one retrospective case notes study on topiramate in the management of problem behaviors in adults with ID (Janowsky, Kraus, Barnhill, Elamir, & Davis, 2003b) ($n = 22$; follow-up 12 months) (topiramate add-on average daily dose of 202 mg). Additionally Spreat, Behar, Reneski, and Miazzo (1989) gathered data retrospectively from case notes of 38 individuals with ID who were treated with lithium. The authors reported that in 63 % of cases there was 30 % or more reduction in aggressiveness. Better improvements were observed among those who had a higher serum lithium level and who showed more aggression prior to treatment.

The Tyrer et al. (1984) study included 26 participants whose age ranged from 14 to 50 years and 65 % of whom were male. All were inpatients in a psychiatric hospital. Of the 26 participants, eight (31 %) had epilepsy. Inclusion criterion was four episodes of aggressive behavior per month for the last 6 months. The target behavior was aggression. Participants with an affective disorder were excluded. This was a double blind, placebo-controlled, crossover design. Dummy lithium blood level results were given to keep blindness. Intervention initially involved placebo, which was given to both groups for 1 month. Then there was a 2-month period of lithium carbonate given at 500 mg/day adjusted to achieve a blood level of 0.5–0.8 mmol/l or placebo, followed by a crossover phase. Lithium was given as add-on medication and the doses of antiepileptics were kept constant throughout the study. Although follow-up intervals were not given, it is assumed that participants were assessed at the end of each of the 2-month study periods and the overall duration of follow-up was for 5 months.

Outcome measures used included psychiatrist's ratings of 13 behavioral items on a visual analogue scale (VAS). Nurses also made 20 behavioral ratings relating to aggression, hyperactivity, antisocial behavior and destructiveness. Episodes of seclusion and accident reports were noted. Results were available for 25 of the 26 patients as one withdrew from the study. Seventeen (68 %) of the 25 patients showed overall improvements on lithium. Rhythmic movement and stereotypy ($p < 0.05$) was the only symptom in which significant improvement was made, although there were improvements of a nonsignificant nature relating to the other areas of behavior that were considered in the ratings. There was no evidence of safety problems except a small increase in fit frequency was noted in one patient. This study does not provide convincing evidence for the use of lithium to reduce aggression in individuals with ID. The degree of disability of the participants is unknown. This was a small, controlled, crossover trial that used nonvalidated outcome measures. There was a short period of follow-up and it is unknown whether there was a washout period during the crossover phase.

In another study, Tyrer et al. (1993) included 52 in-patients whose age ranged from 24 to 51 years (gender ratio unknown). All participants were described as "mentally handicapped." Participants presenting with four episodes of aggression per month for 3 months or self-harm sufficient to cause physical damage or damage to property were included. Those with a comorbid psychiatric diagnosis other than unipolar or bipolar disorder were included. The study used a prospective, double blind, placebo-controlled, crossover trial. All participants received placebo for 1 month at the start of the trial. After that either lithium carbonate as add-on, initially 500 mg/day adjusted to achieve plasma level of 0.5–0.8 mmol/l or placebo was used followed by a crossover phase. Participants were assessed every 2 weeks. The overall length of follow-up was 5 months (1 month placebo, 2 months on lithium, and 2 further months on placebo).

The outcome measure included nursing assessments using visual analogue scale (VAS) rating on 11 behavioral domains including physical aggression and self-injury. Blood tests were carried out every 2 weeks during the trial for full blood count, urea and electrolyte, creatinine, and thyroxine to monitor effects of lithium toxicity.

Of the 52 patients, two dropped out before completion due to deterioration in behavior. Fifteen of the 50 (30 %) participants who completed the trial showed a marked improvement and could be managed in a different setting. Thirteen (26 %) improved but not enough to affect their residence or occupation. Twenty two (44 %) did not improve and five (10 %) patients became more aggressive on lithium compared with placebo. Lithium significantly reduced scores of physical aggression ($p<0.01$), posturing ($p<0.05$) and rebellious behavior ($p<0.05$). Lithium did not affect nonphysical aggression, SIB, destructiveness, temper tantrums, or hyperactivity. There were no episodes of lithium toxicity.

In this study lithium has been shown to be of benefit in some areas of behavior but not all. The study population was well defined and the sample represents a very high percentage of those eligible. Blinding techniques have been adequately described. The paper was confusing when reporting overall behavior changes and improvement in relation to the whole sample and did not differentiate whether this was a result of the lithium or placebo treatments. Participants were receiving concomitant medications and this could have confounded the results. The study period was short and a crossover design makes the effects of lithium withdrawal another potential confounder. Inter-rater reliability was not considered appropriate, as numerous nurses were involved in recording the outcome measures.

Craft et al. (1987) included 42 hospitalized patients in their study whose age ranged from 19 to 65 and 69 % of them were male. Ninety percent had severe ID and 10 % had mild ID. Participants presented with aggression ($n=22$; 52.4 %), SIB ($n=1$; 2.4 %) and both behaviors ($n=19$; 45.2 %). Aggression, however, was the only target behavior investigated. Those already receiving lithium were excluded from the study. The authors used a randomized, double blind, placebo-controlled, multicenter, parallel design. Lithium was administered to 22 (52 %) patients and placebo to 20 (48 %) patients. Lithium carbonate was used initially at 800 mg/day dose, titrated to achieve plasma levels of 0.7–1.0 mmol/l. Any previous medications were continued throughout the trial. Assessments took place daily by nursing staff for 12 weeks. The overall follow-up period was 4 months. The level of aggression was recorded by means of a 5-point scale (1 = well behaved to 5 = seclusion required). A mean weekly aggression score and the number of days with and without aggressive behavior were recorded, as were any adverse events.

Craft et al. (1987) reported a reduction in aggressiveness in 16 (73 %) participants, an increase in 2 (9 %) participants, and no change in 4 (18 %) participants treated with lithium. Six (30 %) participants in the control group had a reduction in aggression. Adverse events such as tremor, drowsiness, thirst, polyuria, incoordination, and vomiting were reported in eight (36 %) participants on lithium, one needing temporary discontinuation of lithium. No reports of lithium toxicity were noted. Adverse events were reported by four (20 %) participants in the control group. The authors calculated the number needed to treat (NNT) as 3 with a 95 % confidence interval of 1.6–10.

This study supports the use of lithium. Blinding and randomization procedures have been adequately described and target behaviors were well defined, although there were no findings relating to SIB that was present in many of the participants. The sample size was small and the follow-up period was short. Participants took concomitant medications, the details of which were not provided and nor were there any data on any comorbid illness in the participants. The main flaw of the study is that the outcomes were measured very crudely without the use of any validated assessment tools.

Reid et al. (1981) included 10 adults whose age ranged from 19 to 50 years of whom 20 % were male. Forty percent had severe and 60 % profound ID. Five (50 %) participants had epilepsy. The target behavior chosen by the authors for intervention was overactivity. This was a double blind, placebo controlled, crossover trial whereby the treatment period for each patient was compared with his or her control period. There were two 3-month periods of treatment with either placebo followed by carbamazepine or vice versa. There was a 3-week washout period separating the two phases. Carbamazepine was started initially at 200 mg twice daily dose as add-on (adjusted to achieve a blood carbamazepine level of 25–42 µg/l; average level was 25–26 µg/l).

Nursing staff assessed participants twice a day throughout the study. The overall follow-up period lasted for a maximum of 7 months. Participants were divided into two groups; Group A ($n=5$): overactivity since childhood, distractible, some mood elevation; and Group B ($n=5$): overactivity as part of a broader spectrum of problem behaviors (e.g., self-injury, stereotypy). A single non-validated weekly mean behavior score was computed. Nurses rated each patient on a scale of −3 to +3 (a score of −3 indicated behavior as "worst I have known," 0 as behavior as usual, and +3 as behavior "best I have known").

In group A (pure overactivity), three (60 %) of the participants were significantly better on carbamazepine than placebo and one was withdrawn from the study due to reasons unrelated to the medication. In group B (overactivity in a spectrum of behaviors), two (40 %) participants were significantly better on placebo than carbamazepine and one was significantly better on carbamazepine than placebo. Participants in group A tended to show improvements whereas those in B deteriorated and these differences were statistically significant ($p<0.029$). Therefore, those with pure overactivity tended to respond to carbamazepine rather than those who exhibited it within a spectrum of problem behavior. There was no difference in response between those with and without epilepsy.

The trial is not of sufficient quality to recommend the use of carbamazepine as it is too small and furthermore, uses a single, non-validated outcome measure. Concomitant medications were used and this could have confounded the results. Adverse effects were not systematically assessed.

Conclusion

There are only a small number of RCTs on mood stabilizers primarily on lithium. Although all these studies showed that a proportion of patients treated with lithium improved it was not clear whether this improvement was significant compared with the placebo group and also the outcome measures used were not validated and standardized. Also the participants were all in-patients, which makes it difficult to generalize these findings for individuals with ID who are living in community settings. Therefore, it is difficult to draw any definitive conclusion on the efficacy of lithium for the treatment of aggression in people with ID. Some studies showed effectiveness of lithium on particular problem behaviors but not on others. There is also the ethical issue of using lithium on individuals with particularly severe ID who cannot give informed consent to which is effectively a lifelong treatment as it is difficult to withdraw lithium once started. Therefore, it may not be ethical to prescribe lithium to someone who cannot give informed consent to a treatment which has potential long-term major adverse effects and narrow window between therapeutic serum level and toxic level. In some individuals with severe and profound ID it may not be possible to carry out blood tests that are mandatory.

There are also potentially less toxic alternatives to lithium available, which may not require regular blood tests. Within this context it is difficult to recommend lithium for use in people with severe and profound ID unless absolutely necessary. In the Deb et al. (2015) prospective 12 months follow-up study, there is little evidence of use of lithium by the UK psychiatrists. Unfortunately currently there is not much evidence for the effectiveness of other mood stabilizers such as sodium valproate, carbamazepine and lamotrigine, which may provide a better alternative to lithium. However, lack of evidence does not mean that there is evidence that these antiepileptic mood stabilizers are not effective in the management of problem behavior in individuals with ID. As mood stabilizers such as carbamazepine and sodium valproate are used regularly to treat aggression in individuals with ID (Unwin & Deb, 2008a, b), there is an urgent need to carry out properly designed RCTs involving these drugs notwithstanding the practical difficulties of carrying out RCTs in this population (Oliver-Africano et al., 2010).

Antianxiety Medications/Beta-Blockers

Antianxiety Medication

King and Davanzo (1996) reported in a prospective uncontrolled study of 26 adults with ID (age range 25–63 years) (46 % male) on the effect of buspirone 25–60 mg/day (average 52 mg/day) on aggression and/or SIB in people with ID. This study did not show any improvement from buspirone.

Beta-Blockers

Ward, Tharian, Roy, Deb, and Unwin (2013) have recently published a systematic review on the use of beta-blocker medications such as propranolol, nadolol, acebutalol, metoprolol, and oxprenolol in the treatment of problem behavior in individuals with ID. They found 14 studies primarily on propranolol, dose ranging up to 340 mg a day, which included between one and 19 participants. However, as none of these studies are RCTs it is difficult to draw any definitive conclusion on the efficacy of beta-blocker medications in the treatment of problem behavior including aggression among individuals with ID.

There were nine prospective studies: Ratey et al. (1986) ($n=19$; average follow-up for 6 months) (propranolol average daily dose for women 132 mg, men 130 mg; one patient was on nadolol); Connor, Ozbayrak, Benjamin, Yusheng, and Fletcher (1997) ($n=12$; follow-up for 5 months) (nadolol 130 mg/day with a range from 40 to 200 mg); De Leersnyder et al. (2001) ($n=9$; follow-up for 6 months) (acebutalol 10 mg/kg after 2 weeks washout); Kuperman and Stewart (1987) ($n=8$; follow-up for minimum 3 months) (propranolol 164 mg/day); Ratey et al. (1987) ($n=5$; follow-up for 4–19 months) (propranolol 144 mg/day with a range from 100 to 180 mg); Lang and Remington (1994) ($n=1$; follow-up was for 12 months) (propranolol started at 20 mg three times a day and increased to 100 mg three times a day); Calamari, McNally, Benson, and Babington (1990) ($n=1$; follow-up was for 17 months) (propranolol started at 30 mg/day, increased to 340 mg/day); Connor (1994) ($n=1$; follow-up was for 3 months for propranolol and 5 months for nadolol) (propranolol dose was titrated up to 80 mg/day for 4 weeks, then nadolol 80 mg/day was used for 5 weeks); Cohen, Tsiouris, and Pfadt (1991) ($n=1$; follow-up period was not specified) (2 weeks placebo, then 11 weeks propranolol LA 80 mg/day titrating up to 320 mg /day, then 11 weeks placebo).

There were five retrospective case notes review; Hiremath, Gangavati, Bhaumik, Kiani, and Devapriam (2010) ($n=84$; follow-up period was not stated) (propranolol dosage was not stated); Luchins and Dojka (1989) ($n=6$; follow-up was for 3 months) (propranolol 286.7 mg/day average dose with a maximum dose of 360 mg/day); Knabe and Bovier (1992) ($n=2$; follow-up was for 2 years) (one patient received oxprenolol 80 mg/day and the other patient received propranolol 320 mg/day); Ruedrich (1990) ($n=1$; follow-up was for 25 months) (propranolol started at 20 mg three times a day, increased to 120 mg/day); Kastner, Burlingham, and Friedman (1990) ($n=2$; one patient was followed up for 12 months and the other patient was followed up for 24 months) (one patient received metoprolol 100 mg/day titrating up to 250 mg/day and the other received this initially at 40 mg/day titrating up to 200 mg/day).

The target symptoms included aggression, SIB, irritability, hyperactivity, impulsive behavior, etc. and in one case anxiety, and in another case somnolence. Target behavior improved in a number of cases, in some cases the improvement was moderate and in some cases there was no improvement, and in a minority of cases behavior deteriorated. Not all studies mentioned the proportion of patients reporting adverse events. Common adverse events included bradycardia, hypotension, vomiting, sedation as well as insomnia. No study reported any severe adverse effects.

Conclusion

There is little evidence currently to recommend any antianxiety medication for the long-term management of problem behaviors including aggression in people with ID. The benzodiazepine group of medications carries the risk of tolerance and may lead to dependence in the long run. The evidence for the effectiveness of buspirone is currently poor, and therefore, it cannot be recommended. However, for the general population some Selective Serotonin Reuptake Inhibitors (SSRIs); Selective Norepinephrine Reuptake Inhibitors (SNRIs); an antiepileptic medication, pregabalin; and an antipsychotic, quetiapine are now recommended treatment for anxiety related disorders (Bandelow et al., 2008; NICE guide on the management of anxiety disorders; www.nice.org.uk). In the field of ID, some antipsychotics are prescribed at a lower dose to manage problem behaviors with the assumption that at a lower dose antipsychotics may work as antianxiety/anti-arousal medications.

Opioid Antagonists

Opioid antagonist drug naltrexone has been used to treat problem behaviors in children with ASD and with or without ID. A recent systematic review by Roy et al. (2015a) has found 10 studies that used an RCT design. Two studies used a parallel design (*n* = 59) and the rest of the studies used a crossover design. The number of children included in these studies ranged from 4 to 41. Target behaviors included symptoms of ASD but also SIB, hyperactivity and irritability in some cases. Less than half of the studies showed a statistically significant improvement in irritability and hyperactivity in the naltrexone group compared with the placebo group but none has shown any significant effect on the core symptoms of ASD. Most studies either did not observe any adverse events or report any. Adverse events included sedation, loss of appetite, vomiting, and stereotyped behavior, and in some cases paradoxical increase in aggression.

Roy et al. (2015b) in their recent systematic review have included 10 crossover trials of naltrexone for the treatment of primarily SIB in adults with ASD and with or without ID. The number of participants included is small ranging from four to nine but one study included 24 and another 33 individuals. The study period ranged from 4 to 17 weeks. Target behaviors primarily included SIB. The dose of naltrexone varied from 50 to 150 mg/day or 0.5–2 mg/kg body weight. Only two studies found a significant improvement in the naltrexone group compared with the placebo. Eleven (9 %) out of overall 124 participants included in these ten studies reported minor adverse events. Adverse events included weight loss, loss of appetite, mild liver function abnormalities, sleep problems, etc. Because of the small number of participants included, a relatively short period of follow-up and lack of significant results, it is difficult to draw any definitive conclusion about the efficacy of naltrexone in the treatment of SIB and aggression among adults with ASD and/or ID.

Conclusion

There are only a handful of RCTs on naltrexone that included a small number of participants, different doses and crossover design, which has its drawbacks. The findings are equivocal in that some showed beneficial effect from naltrexone and the others did not. One study showed differential effect depending on the dose, particularly the higher dose being effective and lower doses being noneffective.

Psychostimulants

Most studies of psychostimulants have been used on individuals with a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD). Therefore, almost all the studies used ADHD symptoms as outcome measures than problem behavior or aggression per se, although problem behaviors are often included in the outcome measures as part of the ADHD symptoms. Therefore, it is difficult to find any evidence to prove effectiveness of psychostimulants specifically for the management of problem behavior or aggression per se in individuals with ID without a diagnosis of ADHD. One study by Aman and Singh (1982) used an RCT design to compare methylphenidate with placebo for the management of different problem behaviors among 28 participants (age 13.6–26.4 years) with ID. Overall no significant effect was found from the medication.

Discussion

The evidence presented in this chapter on the effectiveness of psychotropic medications has to be interpreted with caution. Most studies in this field are case reports on a small number of participants. It is known that studies with positive findings are more likely to be published than studies with negative findings. This is likely to create a reporting bias for the published case reports. There are only a few RCTs, but they often used a small cohort size, resulting in insufficient statistical power to draw firm conclusions. The outcome measures used are often not appropriate or validated. The method of selection of the control group and the experimental group is not always clear or appropriate, and outcome data are often not presented in an appropriate manner. For example, most studies neither quote the “number needed to treat” (NNT) nor use analysis based on the “intention to treat” (ITT). Most studies do not distinguish symptoms of psychiatric illness from those of problem behaviors, and often researchers do not take into account the existence of ASD and ADHD symptoms in the context of problem behavior. Also in many studies participants with comorbid psychiatric disorders were not excluded. It, therefore, remains unclear whether the psychotropic medications used in these studies treated the underlying psychiatric condition or the problem behavior per se. It is important, however, to recognize the difficulty in diagnosing psychiatric disorders in people with ID, particularly among those who have severe ID (see Hemmings, Deb, Chaplin, Hardy, & Mukherjee, 2013). However, conducting RCTs involving individuals with ID (Oliver-Africano et al., 2010) is not easy, particularly because of difficulties in securing consent in adults who lack capacity. The consequence of which is that these people are deprived of the opportunity to have treatments that are based on strong evidence.

Problem behaviors are usually long standing; therefore, short follow-up periods used in most studies meant that it is not possible to know whether patients would derive any benefit in the long term. Only long-term follow-up will determine the effect of many confounding factors, such as environmental changes, that are concomitant with the use of psychotropic medications. Most studies do not take into account the confounding effect of concomitant non-medication based management of behavior, which may have a profound effect on the behavior. Similarly in most studies the antipsychotics were used as add-on therapy, which made it difficult to tease apart the confounding effect of the other medications that have been used simultaneously. For example, the use of antiepileptic medications is common among adults with ID (Deb, 2007) and these medications may have an effect on the behavior. However, an RCT design should take care of some of these confounding factors.

Another problem of interpreting the case report based data is that many patients who showed improvement on a particular medication may have had an unsuccessful trial of other medications that have been shown to be effective in other case studies. Therefore, the individualized response to specific medication is always going to be difficult to determine. There may be many causes of problem behaviors among individuals with ID and many factors including medical, psychological, and social may influence behavior (see Deb, Bethia, Havercamp, Rifkin, & Underwood, 2016). It is, therefore, imperative to carry out a detailed assessment of the causes and consequences of problem behaviors before an intervention is implemented (See Chap. 27, Didden et al., 2016). However, none of the studies provide any detail of behavior analysis. This sort of issue could be addressed by including an overall quality of life (QoL) measure. However, up until Unwin and Deb's (2014) publication no health related QoL (HRQoL) existed for individuals with ID who manifest aggressive behavior. Future studies should also assess the effect of interventions on family caregivers' burden (Unwin & Deb, 2011b) and cost effectiveness (see Unwin & Deb, & Deb, 2016).

On the basis of the evidence available it is difficult either to recommend or to refute the use of psychotropic medications for the management of problem behaviors in people with ID. Furthermore, there is no evidence to show effectiveness of particular psychotropic medication for particular problem behaviors. However, there is now sufficient good quality evidence available on the efficacy of risperidone and some initial evidence for the efficacy of aripiprazole particularly for children with ASD, but also with ID. In the absence of this evidence, guidelines have been developed in order to provide advice to clinicians when using psychotropic medications for the management of problem behaviors in individuals with ID (Banks et al., 2007; Deb et al., 2009; Deb, Clarke, & Unwin, 2006; Einfeld, 2004; Reiss & Aman, 1998; Unwin & Deb, 2010).

These guides advise that a thorough assessment of the causes and effects of the problem behaviors including organic, psychiatric, psychological, and social factors should be carried out before a medication is prescribed. Before initiating medication, a formulation should be documented including the assessment and a rationale for the use of medication. Non-medication based management of problem behaviors should always be considered and be used either instead of or along with medication when appropriate. Individuals with ID and their caregivers as well as the multidisciplinary team should be fully involved in the decision making process from the outset (Hall & Deb, 2008).

There are accessible versions of information leaflets (with audio versions) on psychotropic medications (Unwin & Deb, 2007) freely available for downloading from the Web (http://www.ld-medication.bham.ac.uk). These should be handed over to patients and their caregivers where appropriate. The time, methods, and personnel to conduct the follow-up assessment should be recorded at the outset. Both the impact of the intervention on the behavior as well as the adverse events should be assessed as objectively as possible, if necessary using validated instruments. At each follow-up, the original formulation should be reassessed, non-medication based interventions should be considered along with the possibility of withdrawing medication. The psychotropic medication, if needed, should be used with as small a dose as possible for as short a period of time as necessary. If medication is withdrawn, a relapse plan should be in place and the possibility of withdrawal symptoms in the form of problem behaviors should be considered before taking a decision to reinstate any psychotropic medication. The ultimate aim of the management should be symptom reduction as well as to improve the quality of life of the individual with ID and their caregivers.

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Assistive Technology

14

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Introduction

The expression "assistive technology" is normally used to indicate any technical device that can be employed to help persons with different disabilities to improve their general performance and thus reduce the negative impact of their disability conditions (Bauer, Elsaesser, & Arthanat, 2011; Belva & Matson, 2013; Brown, Schalock, & Brown, 2009; Lancioni, O'Reilly, Singh, Oliva, & Groeneweg, 2003; Lancioni, Singh, O'Reilly, Sigafoos, & Oliva, 2014b; Reichle, 2011; Shih, 2011). The forms of device used as assistive technology can vary widely depending on the objectives planned for the persons being served and the help they need to master those objectives. A point to underline here is that different technology solutions may be required for different persons even if they are to achieve the same objective. In fact, a basic requirement for a successful use of any form of assistive technology is that it matches the needs of the persons that are scheduled to use it, that is, it fits their characteristics (i.e., response repertoires and abilities) (Bauer et al., 2011; Borg, Larson, & Östegren, 2011; Burne, Knafelc, Melonis, & Heyn, 2011; Lancioni, Sigafoos, O'Reilly, & Singh, 2013b). A second important point to underline is that the technology cannot be considered a solution to the person's problems by itself. Rather, its effectiveness depends largely on the intervention program designed to ensure that the person learns how to use it effectively (Banda, Dogoe, & Matuszny, 2011; Lancioni et al., 2011d, 2013b; Mechling & Gustafson, 2009).

In view of the latter point made above, it is clear that the development of technological resources needs to be paralleled with the development of intervention programs aimed at introducing such resources and making them work in the most efficient way possible. For the near future, one might predict (a) an increasing use of technology in the work for persons with intellectual and

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multiple disabilities and thus (b) an increasing cooperation between technical (engineering) experts and rehabilitation personnel (Borg et al., 2011; Burne et al., 2011; Lancioni et al. 2013b, 2014b; Rispoli, Franco, van der Meer, Lang, & Camargo, 2010). This type of cooperation would be expected to further the knowledge so far available and enhance the rehabilitation perspectives for persons with extensive disabilities that (a) are prevented from physical interaction with their context, any (functional) communication, basic forms of movement (e.g., assisted ambulation), and meaningful occupational engagement, (b) are affected by some of the aforementioned restrictions combined with problem postures or behavior (e.g., hand mouthing), and (c) are likely to be marginalized/isolated with extremely negative consequences for their practical and social role as well as for their stimulation input and their overall quality of life (Brown et al., 2009; Holburn, Nguyen, & Vietze, 2004; Lui, Falk, & Chau, 2012; Moisey, 2007; Moisey & van de Keere, 2007; Ripat & Woodgate, 2011; Scherer, Craddock, & Mackeogh, 2011; Tam, Phillips, & Mudford, 2011).

This chapter is aimed at providing a picture of the technological resources and intervention programs actually available to help persons with intellectual and multiple disabilities: (a) develop a basic control of environmental stimulation, (b) improve their assisted ambulation, (c) exercise stimulus choice opportunities, (d) manage environmental stimulation and call for caregiver's attention, (e) manage environmental stimulation and curb inappropriate behavior or posture, (f) exercise request opportunities, and (g) manage occupational engagement and vocationally relevant activities. For each of the aforementioned areas, the technology and intervention programs available are illustrated through detailed summaries of a few relevant studies published in scientific journals (see also Lancioni et al., 2013b). The final part of the chapter (a) provides general considerations about the evidence (technological resources and intervention strategies) available within the areas covered and its relevance for daily programs and (b) also suggests several issues for new research in those different areas (cf. Furniss et al., 2001; Lancioni et al., 2007a, 2008a; Rispoli et al., 2010; Sigafoos et al., 2009; Sigafoos, O'Reilly, Lancioni, & Sutherland, 2014a; Thunberg, Ahlsén, & Sandberg, 2007). Table 14.1 presents a brief map of the chapter by listing (a) the research areas covered in the chapter and (b) the studies summarized in the text for illustrating the technology and intervention conditions available within those areas.

Microswitch-Aided Programs to Allow Stimulation Control via Minimal Responses

Persons with pervasive disabilities have no contact with the outside world and no opportunity to control any element of that world (Holburn et al., 2004; Lancioni, Singh, O'Reilly, Sigafoos, & Oliva, 2014c). This condition causes them to be totally dependent on others and risk inadequate stimulation inputs. For example, they might be provided with excessive or insufficient levels of stimulation; they might also receive not highly preferred types of stimulation. The only way to modify this situation is to enable these persons to develop some control of their surrounding with the minimal response repertoire that they have. The only way to achieve such a goal might be represented by the use of microswitch technology (Gutowski, 1996; Mechling, 2006; Saunders, Smagner, & Saunders, 2003). This technology allows one to monitor minimal responses of the person (e.g., eyelid, chin, and lip movements). Linking such technology to sources of environmental stimulation would then enable the minimal responses to activate those sources and, consequently, allow the person to achieve control of his or her stimulation input (Holburn et al., 2004; Lancioni et al., 2007a, 2007b, 2010a, 2011a, 2013b; Mechling, 2006). For example, an optic microswitch (e.g., a photocell) placed under the person's chin and linked to a series of chimes may allow the person to activate the chimes' stimulation with a simple downward movement of his or her chin. A pressure microswitch fixed to the armrest of a child's wheelchair and linked to a video (i.e., a preferred cartoon) may allow the child to activate the video for a brief period of time with a light finger-push response. In essence,

Table 14.1 Chapter summary map

Areas	Studies	Participants	Age (years)	Technology to detect responses or provide instructions
Microswitch-aided programs to allow stimulation control via minimal responses	Lancioni et al. (2005a)	1	9	Optic microswitch to detect eyelid responses
	Mechling (2006)	3	6–19	Pressure microswitches to detect hand/arm responses
	Lancioni et al. (2011a)	3	5–12	Camera-based microswitch to detect mouth, eyebrow, and eyelid responses
	Lancioni et al. (2013d)	2	21, 26	Optic microswitch to detect eyebrow responses
Microswitch-aided programs to foster assisted ambulation	Lancioni et al. (2005c)	1	13	Optic microswitches to detect step responses
	Lancioni et al. (2007d)	4	7–41	Optic microswitches to detect step responses
	Lancioni et al. (2010b)	5	5.5–11	Optic microswitches to detect step responses
Microswitch-aided programs to promote choice	Sullivan, Laverick, and Lewis (1995)	1	3.5	Two pressure microswitches for two responses
	Lancioni et al. (2003)	1	16.5	Optic and tilt microswitches for two responses
	Lancioni et al. (2006c)	2	32, 19	Vocal discrimination microswitches and stimulus presentation system
	Lancioni et al. (2011b)	2	20, 14	Camera-based microswitch for smile responses and stimulus presentation system
	Lancioni et al. (2011c)	2	34, 31	Pressure microswitch for hand-closure and stimulus presentation system
Microswitch-aided programs for promoting positive responding and reducing problem behavior or posture	Lancioni et al. (2007e)	2	8, 12	Wobble or vibration microswitch for adaptive response and optic microswitch for hand/object mouthing
	Lancioni et al. (2008c)	3	8–17	Touch, tilt or pressure microswitch for adaptive response, and tilt microswitch for head forward bending
	Lancioni et al. (2013a)	2	19, 20	Screen or pressure microswitch for adaptive response and optic microswitch for hand mouthing
	Lancioni et al. (2013e)	2	10, 27	Optic microswitches for adaptive response and problem behavior
Programs with a microswitch and a speech-generating device (SGD) to allow stimulation control and requests of caregiver attention	Lancioni et al. (2009a)	11	5–18	Microswitch and SGD-related sensor for two different responses
	Lancioni et al. (2009b)	8	5–18	Microswitch and SGD-related sensor for two different responses

(continued)

Table 14.1 (continued)

Areas	Studies	Participants	Age (years)	Technology to detect responses or provide instructions
SGDs for active communication (making requests)	Lancioni et al. (2011e)	1	33	SGD with five requests activated with touch response
	Van der Meer et al. (2012a)	4	5–10	SGD with three symbols and one target request activated with a touch response
	Van der Meer, Sutherland, O'Reilly, Lancioni, and Sigafoos (2012b)	4	5–11	SGD with four requests activated with touch response
	Sigafoos et al. (2013)	2	4, 5	SGD with one request activated with touch response
Technology-aided programs for promoting functional activities	Lancioni et al. (2000)	6	23–47	Computer-aided system providing step-related pictorial instructions
	Lancioni et al. (2011d)	3	33–38	Computer-aided system providing step-related verbal instructions
	Cannella-Malone et al. (2011)	7	11–13	Computer-aided system providing step-related video prompts
	Lancioni et al. (2013c)	2	31, 33	Computer-aided system providing verbal cues to guide object assembling
	Lancioni et al. (2014a)	3	36–44	Computer-aided system providing visual cues to guide object assembling

microswitch-aided programs may be viewed as intervention strategies, which are often developed and used for helping persons gain control over environmental stimuli, in spite of the fact that they do not possess the response repertoire necessary to manipulate the sources of such stimuli (Holburn et al., 2004; Lancioni et al. 2007a, 2007b, 2013b; Mechling, 2006).

The ten figures that follow provide illustrative examples of microswitches developed for monitoring small/minimal responses. In particular, the figures show schematic representations of microswitch devices for monitoring (a) sound-emission (vocalization) responses (Figs. 14.1 and 14.2), (b) chin- and lip-/mouth-movement responses (Figs. 14.3, 14.4, and 14.5), (c) eyelid responses (Fig. 14.6), (d) forehead skin movements or eyebrow movements (Figs. 14.7 and 14.8), and (e) hand-closure responses (Fig. 14.9) (Lancioni et al., 2013b). Figure 14.10 shows a face with small dots on the side of the nose and under the lower lip. These dots are used to enable a camera-based microswitch to monitor any mouth-opening or mouth-closing movement (Lancioni et al. 2011a, 2013b).

Four studies are summarized here to illustrate microswitch-aided programs for allowing stimulation control via minimal responses (Lancioni et al. 2005a, 2011a, 2013d; Mechling, 2006). Lancioni et al. (2005a) carried out their work with a boy of 9 years of age with congenital encephalopathy, profound multiple disabilities, and minimal motor behavior. The response considered feasible for the boy and targeted within the study was a repeated blink (i.e., two blinks within a 2-s interval). Such response was already present in the child's repertoire but at a relatively low frequency. The microswitch selected for detecting the response included an optic sensor mounted on an eyeglasses frame (similar to that shown in Fig. 14.6) that the boy wore during the sessions. Activation of the microswitch via repeated blinking triggered a regulation unit and a control system that operated sources of stimulation such as video recordings and moving lights. In practice, every response occurrence allowed the child to access a brief period of preferred visual stimulation during the intervention phases of the study. Data showed that the child's response frequency during those phases was higher than that observed in the baseline phases, suggesting that he was eager to increase his stimulation input.

Mechling (2006) taught three participants to use hand/arm movements and head-turning responses in combination with pressure microswitches to access various environmental stimuli. The participants were between 6 and 19 years of age and presented with profound intellectual disabilities and serious motor impairment. The study included nine sessions of 9 min. Every session contained three intervention segments of 3 min. Each segment involved a specific stimulus condition, that is, a specific type of consequence occurring contingent on the responses for 10 s at each response. The stimulus conditions involved adapted toys and devices, commercial cause-and-effect software, and instructor-created video programs. Subsequent to this period, which was aimed at verifying possible differences in

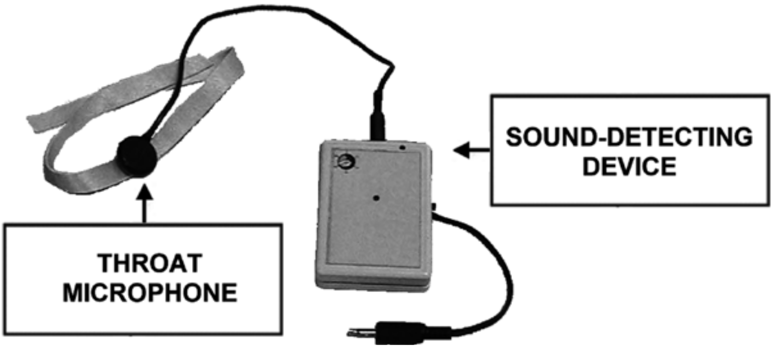


Fig. 14.1 Pictorial representation of a sound-detecting device connected to a throat microphone to monitor sound-emission responses (Lancioni et al., 2013b)

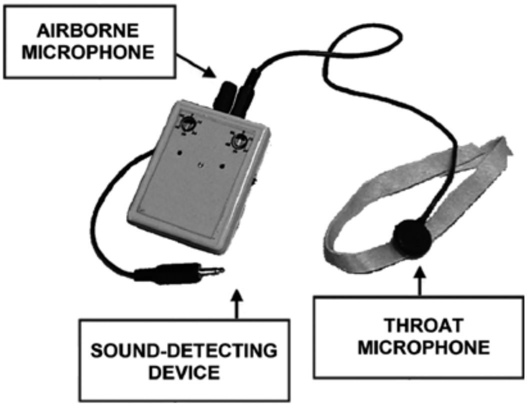


Fig. 14.2 Pictorial representation of a sound-detecting device connected to a throat microphone and an airborne microphone to monitor sound-emission responses (see Lancioni et al., 2013b)

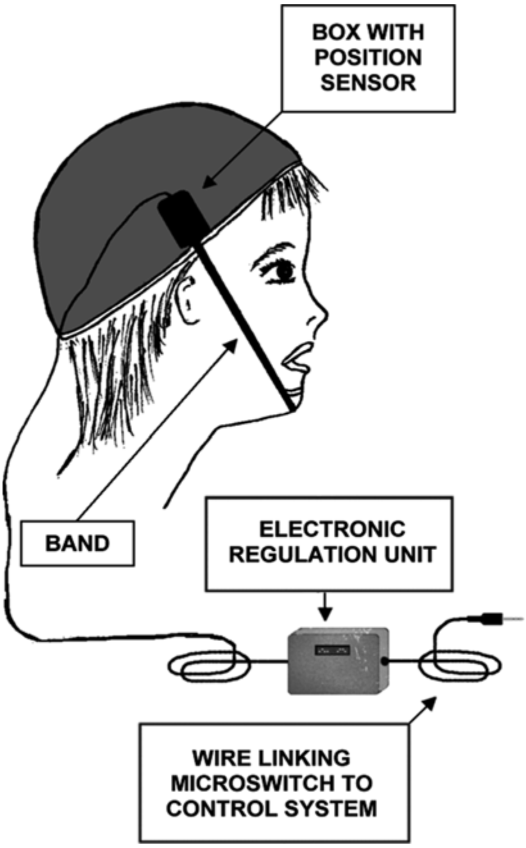


Fig. 14.3 Schematic representation of **(a)** a *box* with position sensor, **(b)** a band tied to the position sensor and to the other side of a hat the child wears, and **(c)** an electronic regulation unit to monitor chin-movement (mouth opening/closing) responses (see Lancioni et al., 2013b)

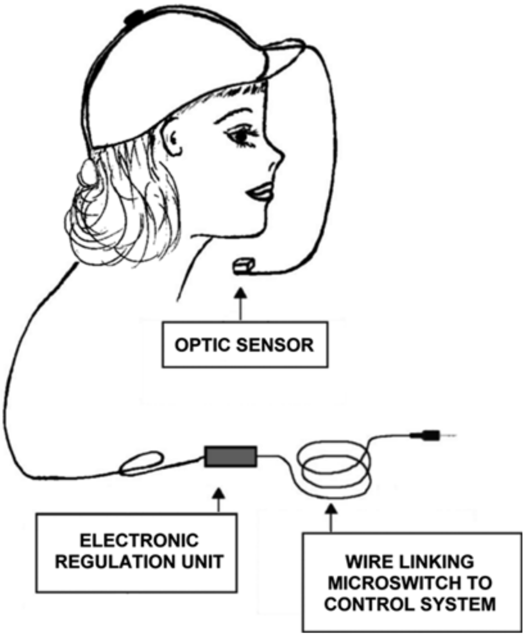


Fig. 14.4 Schematic representation of an optic sensor held under the child's chin and of an electronic regulation unit to monitor chin-movement (mouth opening/closing) responses (see Lancioni et al., 2013b)

responding under the different stimulus conditions, a program extension was implemented. Such an extension consisted of three sessions, in which only the stimulus condition that had promoted the highest level of responding was used. The results of the first assessment period showed that the level of responding was highest (i.e., between five and nine responses per 3-min segment) with the instructor-created video condition. During the program extension, the response level remained satisfactory for all three participants.

Lancioni et al. (2011a) worked with three children who were between about 5 and 12 years of age and presented with profound intellectual disabilities, severe visual impairment or blindness, spastic tetraparesis, lack of any engagement with objects, and absence of communication skills. The responses selected for them consisted of mouth closing (i.e., a reduction of the distance between the upper and lower lips), eyebrow lifting (i.e., an upward movement of the right eyebrow of about 4 mm), and repeated eyelid

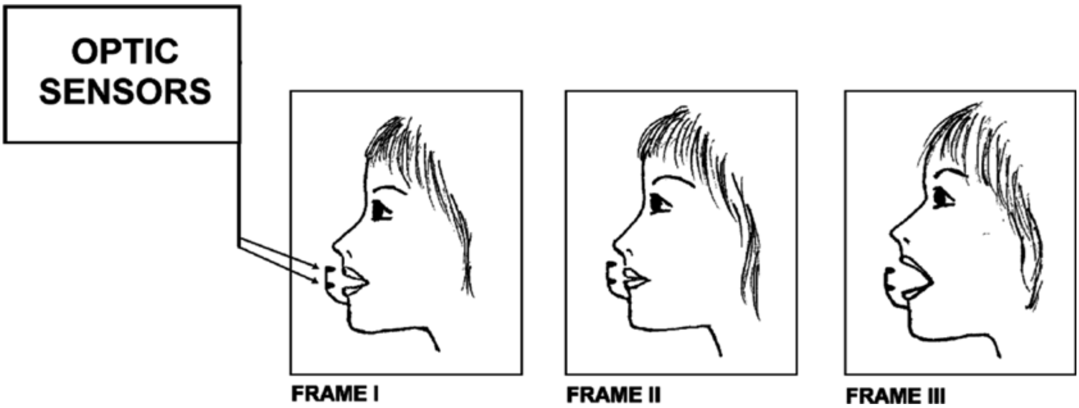


Fig. 14.5 Schematic representation of optic sensors held in front of a person's mouth to monitor lip/mouth positions and possible changes in those positions (*frames I–III*) (see Lancioni et al., 2013b)

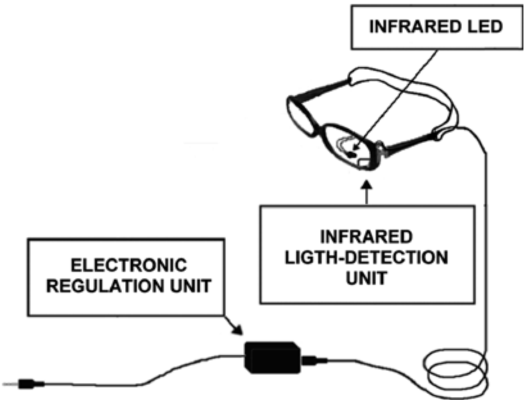


Fig. 14.6 Schematic representation of an optic sensor (infrared LED and infrared light-detection unit) mounted on an eyeglasses frame and connected to an electronic regulation unit to monitor eyelid responses (see Lancioni et al., 2013b)

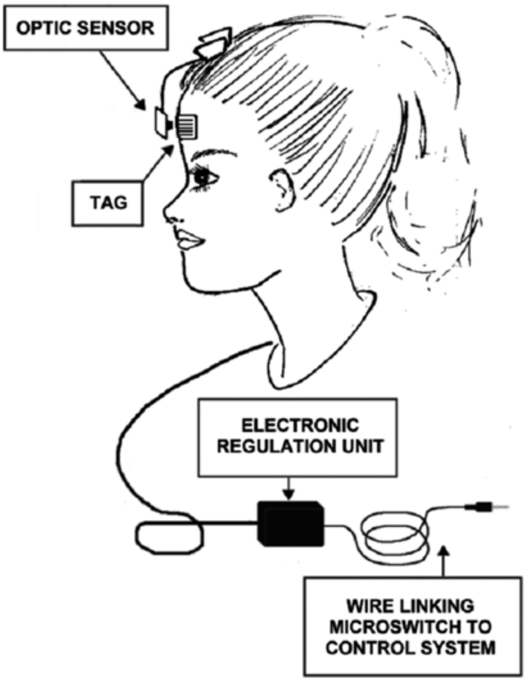


Fig. 14.7 Schematic representation of **(a)** an optic sensor (barcode reader), **(b)** a small tag with horizontal bars, and **(c)** an electronic regulation unit used to monitor forehead skin movements (see Lancioni et al., 2013b)

closures (i.e., two closures of the eyelid within a 2.1 s interval), respectively. The responses were present in the children's repertoire, but at low frequencies. The microswitch consisted of a computer-linked camera device placed at a distance of about 1 m from the children's face. The computer analyzed the children's face pictograms every 200–300 ms and recognized the responses selected on the basis of the distance or dimension of color spots that the children had at the base of the nose and lower lip (for mouth closing) (see Fig. 14.10), on the forehead (for eyebrow lifting), and on the eyelid (for eyelid closures). Response detection led the computer to activate stimulation sources selected for the children (e.g., music, audio recordings of parents and staff's voices, and vibratory inputs). All three children increased their response frequencies during the intervention phases of the study (i.e., when the stimulation was available), indicating

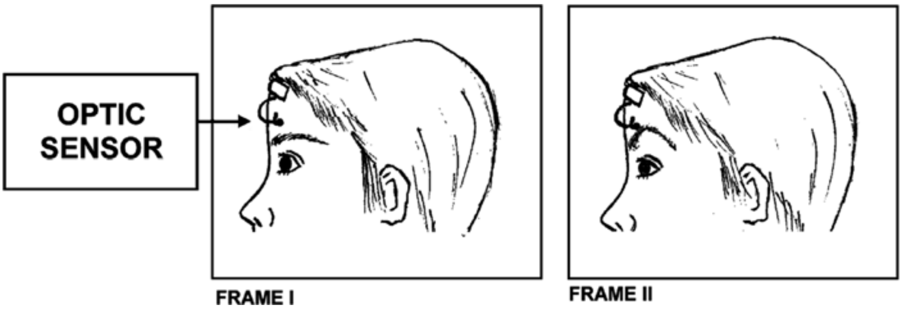
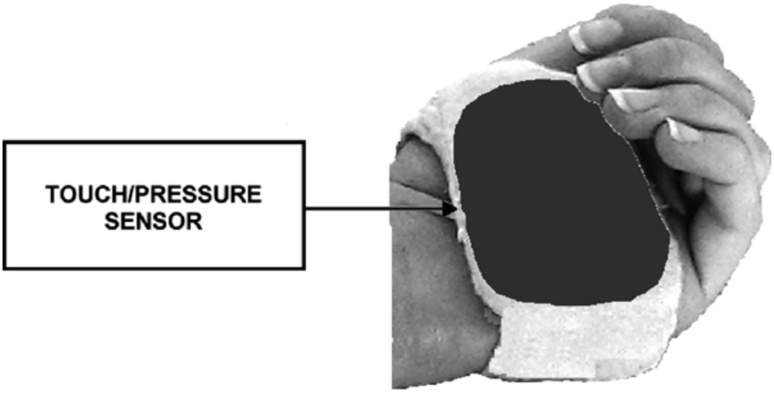


Fig. 14.8 Schematic representation of an optic sensor fixed on the person's forehead to monitor forehead skin movements or eyebrow movements (see Lancioni et al., 2013b)

Fig. 14.9 Schematic representation of a touch/pressure sensor fixed to the person's hand to monitor hand-closure responses (see Lancioni et al., 2013b)



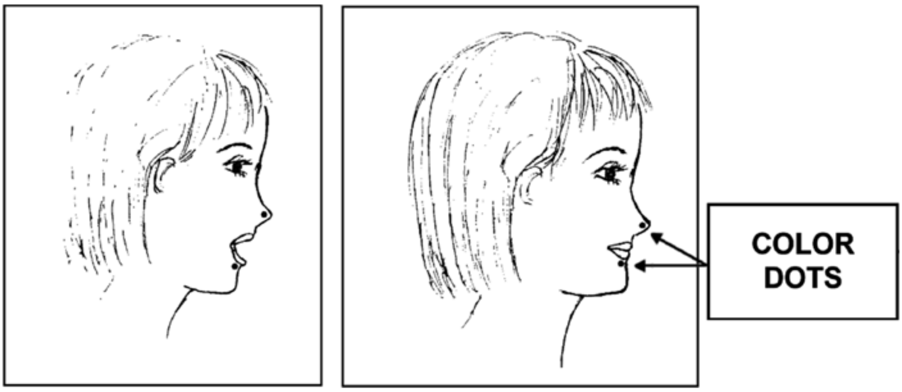


Fig. 14.10 Schematic representation of color dots on the side of the nose and under the lower lip used to enable a camera-based microswitch to monitor mouth-opening or mouth-closing movements (see Lancioni et al., 2013b)

that they enjoyed such stimulation and were eager to increase its presence thus extending/enriching their sensory inputs.

Lancioni et al. (2013d) conducted a study with two men of 21 and 26 years of age, who had congenital encephalopathy with spastic tetraparesis, lacked interaction with objects and recognizable communication, and were provided with gastrostomy tubes for enteral nutrition. They spent their time in bed or in a wheelchair in a condition of passivity and without any chance to influence their context or control sources of stimulation. Their intellectual disability was estimated to be in the profound range. The response selected as feasible for them was a slight upward movement of their forehead skin. The microswitch consisted of an optic sensor that involved an infrared light-emitting diode and a mini-infrared light-detection unit and was used in connection with a mini-sticker (i.e., a variation of that shown in Fig. 14.8). The sensor was positioned above the participant's eyebrow, and the black mini-sticker (15-mm wide and 5-mm high) was immediately below it. The sensor was activated when it overlapped with the sticker due to upward movement of the forehead skin. Microswitch/sensor activation triggered a computer system that ensured the presentation of preferred stimuli for 8–10 s except during the baseline phases of the study (see below). Both participants increased their response frequencies during the intervention phases of the study (i.e., when such responses allowed them to access preferred stimulation and thus enrich their sensory input).

Microswitch-Aided Programs to Foster Assisted Ambulation

Ambulation (walking) is a critical skill with a multitude of practical and social implications. In fact, ambulation can be instrumental to allow a person to reach different places in order to get involved in different activities and/or meet different people (Hayakawa & Kobayashi, 2011; Lancioni et al., 2009d). Ambulation can also be used as a strategy by which a person promotes his or her overall fitness and health condition (Cirignano, Du, & Morgan, 2010; Lee, Watson, Mulvaney, Tsai, & Lo, 2010; Lotan, Isakov, Kessel, & Merrick, 2004). While walking and the fulfillment of all its functions appear very natural in typically developing persons, a different picture may characterize persons with developmental disabilities (Cernak, Stevens, Price, & Shumway-Cook, 2008; Cherng, Liu, Lau, & Hong, 2007; Chia, Guelfi, & Licari, 2010; Katz-Leurer, Rotem, Keren, & Meyer, 2010). Many of these persons may present with neuromotor impairment and fail to acquire independent and fluent ambulation (Maher, Evans, Sprod, & Bostok, 2011; Whittingham, Fahey, Rawicki, & Boyd, 2010). For a number of them, ambulation may eventually be feasible only through some level of support, such as the use of walker devices or crutches and orthoses (Lancioni et al. 2009d, 2013f; Nolan, Savalia, Yarossi, & Elovic, 2010; Van Gestel, Molenaers, Huenaerts, Seyler, & Desloovere, 2008).

The use of support devices such as those just mentioned, albeit technically functional, may often be insufficient to establish satisfactory ambulation. Indeed, the person may have no places that he or she wants (i.e., is motivated) to reach, no activities that he or she wants to carry out, or no curiosity that he or she wants to satisfy. With persons who are in a similar condition, the question is how to motivate them to make the effort to walk (Lancioni et al., 2009d). A technology-based approach employed for these persons combines the use of walker devices with microswitches. The walker devices can be equipped with supporting features to promote postural control and partial weight lifting (i.e., ensure the basic physical requirements for the step responses involved in ambulation). The microswitches can be connected to the participant's feet so as to allow the monitoring of his or her step responses and the automatic delivery of brief periods of preferred environmental stimulation contingent on those responses (Lancioni et al. 2005c, 2007d). This stimulation could provide the motivation for the participant's commitment to make an effort to ambulate (Catania, 2012; Kazdin, 2001; Lancioni et al., 2007c, 2013b).

For example, Lancioni et al. (2005c) conducted a study with an adolescent of 13 years of age who was considered to function in the profound intellectual disability range and was affected by blindness, spastic tetraparesis, and scoliosis. He could walk only if he was physically supported by a person or used a four-wheel support walker device ensuring postural control. His ambulation performance with the walker, however, was relatively modest (i.e., he walked only few steps), and this was attributed to a motivation problem, that is, to his lack of interest in engaging in a behavior that was quite costly and did not produce any positive/reinforcing consequences. To increase his motivation and thus promote ambulation, a microswitch-aided program was used. In practice, optic microswitches monitored his step responses and ensured the occurrence of stimulation contingent on their performance, through the control system to which they were linked. The stimulation consisted of audio recordings of brief music segments and praise statements. The study involved an ABAB sequence in which A represented baseline phases and B intervention phases (Barlow et al. 2009). During the first intervention phase, his mean frequency of steps per session more than doubled the baseline values. Those values declined during the second baseline to increase again during the second intervention phase. During the intervention phases, the participant also showed an increase in indices of happiness (i.e., smiles or excited vocalizations).

Lancioni et al. (2007d) conducted a study aimed at promoting ambulation with two children (of about 7 and 9 years of age) and two adults (of about 19 and 41 years of age). Three of the participants presented with spastic tetraparesis, while the other participant was diagnosed with low muscle tone. All participants (a) were able to stand and make some steps with support, (b) were considered to function in the profound intellectual disability range, and (c) had been involved in the use of four-wheel support walkers. For three of them, the walkers also included a harness holding them and lifting part of their weight. To follow the step responses with positive stimulation, microswitch solutions and a control system were used for each participant. For two of the participants, microswitches were used to detect each (left- and right-foot) step. For the other two participants, microswitches would detect only their right-foot steps. The stimulation available for the single steps of the former participants was shorter than the stimulation available for the right-foot steps of the latter participants (i.e., 2.5 s versus 5 or 6 s). The study included an ABAB sequence in which A and B represented baseline and intervention phases, respectively. Data showed that all participants had large increases in their frequencies of steps during the intervention phases of the study. They also showed increases in indices of happiness during the same phases of the study.

Lancioni et al. (2010b) extended the use of microswitch-aided programs to promote ambulation to five new children between about 5.5 and 11 years of age. The children had a level of functioning, which was reported to be in the severe or profound intellectual disability range and were affected by spastic tetraparesis. Four of them also had visual impairment. The children were known to manage some ambulation steps if provided (a) with extensive physical support from a caregiver or (b) with a four-wheel walker containing a frame to support them around their chest and under their arms and a harness or saddle so as to secure their postural control and lift part of their body weight. Although the walker could be considered sufficiently secure/supportive for the children, their tendency to ambulate when using it was low. They performed only a few steps, and the suggestion was that their motivation to walk was modest and needed improvement. Given this evidence and the question about their motivation, the use of microswitches and contingent stimulation (i.e., preferred stimulation following the performance of steps) was considered to be a possibly decisive intervention package. The microswitches used and their position changed across participants in line with their practical condition and context. For example, some children had the microswitches linked to their shoes, and others had the microswitches attached to their walker's panels. Four of them went through the study according to an ABAB design, while the fifth had only an AB sequence. Sessions lasted 5 min for all participants and were generally implemented several times a day. During the intervention (B) phases, steps were followed by brief periods of preferred stimulation. These periods were (a) 3–5 s for the children who received stimulation at each (right- and left-foot) step and (b) 8 s for the child who received stimulation only in relation to his right-foot steps. Initial baseline data showed that the participants' mean frequencies of steps were 7–26 per session. Data of the first intervention phase showed that the mean frequencies of steps increased to between 23 and 110 per session. The frequencies increased further for each of the four children who had a second intervention phase.

Microswitch-Aided Programs to Promote Choice

The computer-aided programs previously examined were successful in helping participants to get active (i.e., via the performance of a minimal response or of ambulation steps) and thus obtain positive environmental stimulation (Lancioni et al., 2014b, 2014c). The positive (appealing/motivating) characteristic of the stimulation, which was ensured through the use of a selection procedure based on repeated observations and stimulus preference screening, was to guarantee the participants' eagerness to receive such stimulation and thus their general motivation to respond with consistency over time. Microswitch-aided programs are also available in which the participants are provided with an active role so that they can choose the stimulation they want to have by themselves (Lancioni et al., 2006b, 2013b; Sullivan et al., 1995). The choice opportunity can be exercised in two main ways. One of these ways involves the performance of different responses connected to different microswitches, each of which provides access to a specific form of stimulation. The second way involves the (a) performance of an affirmative/selection response in relation to the presentation of samples (previews) of stimuli that the participant wants to obtain and (b) abstention from the affirmative/selection response in relation to the presentation of samples of stimuli that the participant does not want to have at that particular time or at all.

First Way to Choice

Among the studies conducted in this area, two early efforts by Sullivan et al. (1995) and Lancioni et al. (2003) may be easily summarized to clarify the approach. Sullivan et al. assessed the possibility of teaching a girl of 3.5 years of age, who had a diagnosis of Rett syndrome, to use two responses with two separate microswitches. The two responses selected for the girl involved head backward movements and hand pushing/stroking movements. The microswitch devices employed to detect those responses were simple pressure instruments that are commercially available. The microswitches were displayed simultaneously during the sessions, and the girl could activate either one of them. During the intervention sessions, a microswitch activation allowed her to access the set of preferred stimuli linked to that specific microswitch. The preferred stimuli included events such as musical toys and tapes. Data showed that the girl's performance during the intervention conditions exhibited an increase of both responses. No conclusive statement could be made as to whether the girl had specific preferences for either response or set of stimuli used contingent on the responses.

Lancioni et al. (2003) assessed the possibility of teaching an adolescent with multiple (intellectual, motor, and visual) disabilities two responses connected to two microswitches leading to different types of stimulation. Psychological reports described the participant as functioning in the profound intellectual disability range (but no specific/formal testing was carried out given her condition). She did not possess speech or other forms of communication and had a feeding tube for enteral nutrition. Bringing the hand to the forehead and moving the knee laterally were the two responses selected for use during the study. The first response was monitored through a microswitch, which involved a combination of optic sensors attached to a headband that the participant wore. The second response was monitored through a microswitch, which consisted of a tilt-like device. The study was carried out according to a multiple probe across response design (Barlow et al. 2009). In practice, baseline sessions were initially carried out on both responses. Then intervention focused on the first response, and, when this had increased, it extended to the second response. This extension enabled the participant to obtain specific stimulation with each of the two responses and thus allowed her to have a larger increase of the response/stimulation she preferred. The results showed that the participant increased the frequency of each response during the intervention conditions, without clarifying whether she had specific/strong preferences for one or the other.

Second Way to Choice

Three studies may be summarized here to illustrate this second type of approach (Lancioni et al. 2006c, 2011b, 2011c). Lancioni et al. (2006c) worked with two participants of 32 and 19 years of age who were reported to be functioning in the profound intellectual disability range (but caution is required about this, as it resulted from estimates rather than test scores). They also presented with total blindness or minimal residual vision, spastic tetraparesis, lack of speech or other standard communication skills, and absence of self-help skills and toilet control. The responses selected for them were specific sound emissions that were recorded and discriminated by specific software available in the computer system that served as their microswitch. At each session, the computer system presented 3-s samples of 18 stimuli (12 were considered pleasant for the participants and six negative). The presentation of a sample was accompanied by a recorded verbal expression, such as "and this?" If the participants had a response (verbal emission recognized via the system) within 5 s from the end of the sample, the computer system turned on the corresponding stimulus for 15–30 s. Similarly, if the participants had a response within 5 s from the end of the stimulus event, this was repeated. If the participants refrained from responding to a stimulus sample or after the end of a stimulus event, the computer implemented a small pause and then presented the next sample of the set available within the session. The conditions mentioned above applied until all samples had been presented. The negative samples served to verify the participants' choice behavior. It was, in fact, thought that one could speak of purposeful choice behavior if the participants displayed high responding levels in relation to the samples/stimuli considered to be positive (preferred) and low responding levels in relation to the stimuli considered to be negative (non-preferred). During the 129 and 109 intervention sessions available, the participants responded to (i.e., chose) 55 and 75 %, respectively, of the stimuli considered preferred and to less than 20 % of the stimuli considered negative. For the stimuli considered positive, the participants tended to require several repetitions. In fact, the mean frequencies of activation for the positive stimuli were over six and about four for the two participants, respectively. Their mean frequencies of activation for the negative stimuli were slightly above one.

Lancioni et al. (2011b) worked with two participants of 20 and 14 years of age, whose level of intellectual functioning was estimated to fall within the profound range (caution is required on this point, as suggested above). They had spastic tetraparesis and were unable to interact with objects and carry out activities, lacked any recognized form of communication, did not possess sphincteric control, and had minimal residual vision or light perception. Both participants seemed to enjoy music, familiar voices, and a variety of other environmental stimuli. This stimulus preference was largely inferred from the fact that they showed forms of smiles in relation to such stimuli. The same response was also used as the affirmative/selection response during the study and was monitored via a camera-based microswitch. At each session, the computer system presented 23 stimulus samples of 4 or 5 s. If the participant responded with a smile during the last 2 s of the sample or the 4 s that followed it, the computer system presented the corresponding stimulus for 20 s. Following a brief pause from the participant's lack of responding to a sample or the end of a stimulus event, the system presented the next sample and this continued, according to the same conditions, until all samples available for the session had been presented. During the 98 and 124 intervention sessions, the participants responded to 70 or 75 % of the samples of the preferred stimuli and 10 % or less of the samples of the non-preferred stimuli. A camera-based microswitch was used for monitoring the smiling response. It might be worthwhile to underline that the successful choice outcome obtained with the smile response and the camera-based microswitch was in clear contrast with the choice failure obtained with a control response (i.e., vocal emission), which was in the participants' repertoire, but appeared less immediate (i.e., less amenable for use in a time-sensitive task situation such as the choice context).

Lancioni et al. (2011c) assessed a microswitch-aided choice program with two adults of 34 and 31 years of age whose general conditions and assessment reports were similar to those described in the previous studies. The computer system included a set of 16 stimuli at each session. Twelve stimuli were considered to be positive/preferred (e.g., music and familiar stories and voices), while the other four were considered negative/non-preferred (e.g., distorted sounds). The system presented the sample of each stimulus for about 5 s. If the participants made an affirmative/selection response within 6 s from the end of the sample, the computer system presented the corresponding stimulus for 20 s. A new response within 6 s from the end of a 20-s stimulus event led the system to repeat the same stimulus or the next 20 s of it. The response consisted of a slight hand closure, which was recorded through a pressure microswitch attached to the palm of their hand. Abstention from the affirmative/selection response after a stimulus sample or the end of a stimulus event led the system to have a brief pause and then present the next stimulus sample of the set available for the session. During the 304 and 129 intervention sessions, the mean frequencies of positive stimuli chosen per session were about eight and seven for the two participants, respectively. Their mean frequencies of responses per session were 74 and 39, respectively. That meant that they had means of about 9 and 5.5 responses per stimulus selected. Their responding to the negative stimuli was largely sporadic. Observations about their mood during the study indicated that the mean percentages of intervals with indices of happiness were about or above 40 during the intervention sessions and near zero outside of those sessions.

Microswitch-Aided Programs for Promoting Positive Responding (and Stimulus Control) and Reducing Problem Behavior or Posture

The basic concern with persons with extensive intellectual and multiple disabilities is their limited range of adaptive responses and their failure to engage with their environment to enrich their input and/or increase their adaptive behavior (Lancioni et al., 2013a; Zucker, Perras, Perner, & Murdick, 2013). The studies reviewed above represented an attempt to provide an answer to such concern. Another concern with a number of these persons may be related to problem behavior (e.g., hand mouthing and eye poking) and problem postures (e.g., head forward bending). Conventional intervention approaches have generally focused on the two types of concerns in a separate way, that is, with programs aimed at promoting positive responding (and independent access to environmental stimulation) and with programs aimed at curbing problem postures and behavior (Lancioni, Singh, O'Reilly, & Sigafoos, 2009c). Over the last decade, successful evidence has been reported about the possibility of targeting both types of concerns within a single approach that combines microswitches for monitoring the positive/adaptive responding and the problem posture/behavior (Lancioni et al. 2007e, 2008c, 2013a, 2013b, 2013e).

For example, Lancioni et al. (2007e) reported a program using combinations of microswitches (i.e., microswitch clusters) for two children of about 8 and 12 years of age, who were considered to function in the profound intellectual disability range and were affected by visual impairment or blindness and spastic tetraparesis. The adaptive responses targeted for the two participants involved manipulating or moving/knocking objects. The problem behavior consisted of hand mouthing and object mouthing. The first response was detected via a wobble microswitch or a vibration-sensitive microswitch. The problem behavior was detected via an optic microswitch held below the chin or to the side of the face. Data recording concerned the frequencies of the adaptive responses and the percentages of session time with the presence of the problem behavior. During the first intervention phase, the participants received positive stimulation for each adaptive response. During the second intervention phase, the participants received stimulation for their adaptive responses performed in the absence of the problem behavior. In addition, the stimulation that followed the adaptive responses free from the problem behavior lasted the scheduled time only if such behavior did not appear during the stimulation interval. Whenever it did, the stimulation was interrupted prematurely, and the participants needed a new adaptive response free from the problem behavior to restart it. Initial baseline data showed low frequencies of adaptive responses and high percentages of session time with the presence of the problem behavior. During the first intervention phase, the participants' performance improved in terms of frequency of adaptive responses. During the second intervention phase, the improvement also involved a drastic decline of the problem behavior. These results, which were then maintained with both participants, emphasize their self-determination and self-management skills (i.e., their ability to refrain from the performance of the problem behavior in order to obtain the preferred stimulation available for the adaptive responses) (see Carter, Owens, Trainor, Sun, & Swedeen, 2009; Carter et al., 2013; McDougall, Evans, & Baldwin, 2010).

Lancioni et al. (2008c) carried out a program based on microswitch clusters to promote adaptive responses and reduce problem head posture in two children and an adolescent who were affected by severe/profound intellectual disabilities as well as motor and sensory impairments. The participants' adaptive responses consisted of foot lifting or hand stroking; their problem posture consisted of head forward bending. The adaptive responses were monitored via tilt or touch and pressure microswitches. The inappropriate posture was monitored via a tilt microswitch fixed to a headband that the participants wore during the sessions. As in all studies in this area, the first intervention phase served to increase the frequency of the adaptive responses. This was followed by brief periods of preferred stimulation regardless of the participants' head posture. During the second intervention phase, the adaptive responses were followed by the preferred stimulation provided that they occurred in the absence of the problem posture (i.e., head forward bending). If the problem posture was present, the adaptive responses were ignored by the computer system. The preferred stimulation that followed the adaptive responses performed in the absence of the problem posture lasted for the scheduled time only if the problem posture did not appear during that time. The design of the study ensured that the second intervention phase was replaced by a new baseline and then a replication period (i.e., a new intervention period identical to the second phase). Initial baseline data showed minimal levels of adaptive responding and high percentages of problem posture. The second intervention phase allowed the achievement of both objectives of the study, that is, the frequency of adaptive responses was fairly high and the percentages of problem posture was low for all three participants. These data remained consistent (i.e., were maintained) during the replication period.

Lancioni et al. (2013a) reported two single-case studies. In the first study, the participant was a man of 19 years of age who presented with motor impairment (i.e., he was on a wheelchair), severe/profound intellectual disabilities, unspecified visual impairment, and lack of communication and self-help skills. The adaptive response selected for him was that of pointing to visual cues appearing on a computer screen in front of him. The problem behavior was hand mouthing. A touch screen applied to the computer monitor acted as a microswitch for accurate pointing responses. An optic microswitch close to his neck was used for detecting the problem behavior. Throughout all sessions of the study (which were 5-min long), the computer system employed in connection with the microswitches recorded the frequency of adaptive responses and the session time with the presence of the problem behavior. During the first intervention phase, the participant received 10 s of positive stimulation after each adaptive response. The stimulation involved, among others, video clips and music. During the second intervention phase, the adaptive responses were followed by positive stimulation only if they occurred in the absence of the problem behavior. Moreover, any stimulation occasion lasted the scheduled 10-s period only if the problem behavior did not appear during that interval. If it appeared, the stimulation was interrupted. This phase was followed by a new baseline phase and a replication (i.e., an identical phase). The baseline showed that adaptive responses were sporadic, and about 40 % of the session time saw the presence of the problem behavior. During the first intervention phase, the frequency of adaptive responses increased, but the session time with the problem behavior remained quite high. During the second intervention phase, the frequency of adaptive responses was high and the session time with the problem behavior declined below 10 %. These data were maintained and even improved during the intervention replication phase.

In the second study, the participant was a woman of 20 years of age, who presented with severe motor impairment, severe/profound intellectual disabilities, lack of communication and self-help skills, and drooling. The adaptive response was mouth wiping through a special napkin. The problem behavior was hand mouthing. The adaptive response was recorded through pressure sensors placed inside the napkin. The hand mouthing was recorded as in the previous study. Data recording concerned the frequency of hand wiping responses, the percentage of session time with the presence of the problem behavior, and the percentage of observation intervals with the presence of drooling. During the first intervention phase, the participant received 20 s of preferred stimulation after each adaptive response. This was subsequently increased to 25 s (i.e., 13 s at normal intensity and 12 s at lower intensity). During the second intervention phase, the positive stimulation was provided if the adaptive response occurred in the absence of the problem behavior and continued for the scheduled time only if such behavior did not appear during such time (i.e., as in the first study). Initial baseline data showed a virtual absence of the adaptive response, high percentages of session time with the problem behavior, and high percentages of observation intervals with the presence of drooling. The first intervention phase improved the situation in terms of adaptive responses and, partially, in terms of percentages of intervals with drooling. The second intervention phase improved the previous two measures and drastically reduced the problem behavior. These results were then maintained.

Lancioni et al. (2013e) carried out two programs involving microswitch clusters. The first program was directed at a child of 10 years of age who was affected by multiple disabilities and needed to increase his constructive hand engagement (i.e., interaction with his surrounding) and reduce a problem head posture. The hand engagement selected for the study consisted of touching objects attached to a bar in front of the child. The problem posture to be reduced was head forward bending. Tilt and optic microswitches were connected to the objects in front of the child to monitor his adaptive touching/manipulation responses. An optic microswitch attached to the wheelchair's headrest was used to monitor the head posture. A problem posture was recorded when the child kept his head more than 10 cm away from the headrest and thus failed to activate the optic microswitch. The procedural sequence was the same as that used in previous studies. Once the child had increased the frequency of his adaptive responses (i.e., first intervention phase), such responses were followed by positive stimulation only when they occurred in the absence of the problem posture (i.e., second intervention phase). Moreover, stimulation would be interrupted if the problem posture appeared during its presentation. The program's outcome was largely satisfactory. In fact, the child had a large increase in the frequency of adaptive responses and a critical reduction of the session time with the presence of the problem posture (i.e., indicating that he had learned to control such posture in order to get the environmental stimulation available for his adaptive responses).

The second program was directed at a man of 27 years of age who presented with spastic tetraparesis and, reportedly, severe intellectual disability. He did not possess speech but could understand simple verbal instructions and could make requests concerning his daily activities and his personal interests and needs through pictorial means. The first intervention phase was aimed at establishing an adaptive response (i.e., mouth cleaning) that served to reduce the man's problem behavior (i.e., drooling). The occurrence of the adaptive response led to the delivery of preferred stimulation (i.e., music presented via an earplug). The microswitch was a light-dependent resistor fixed under the man's chin, which was activated by the mouth cleaning response (i.e., by the cleaning cloth covering the light-dependent area of the resistor). During the second intervention phase, the cleaning response produced stimulation only if the man had carried out another adaptive (object-assembling) response prior to it. This response was monitored through optic microswitches attached to the containers used for the assembling response. In practice, the cluster system would allow a stimulation output after the activation of the light-resistor microswitch only if its activation had been preceded by the activation of the optic microswitches monitoring the assembling response. Data were largely satisfactory with the man acquiring the cleaning response, virtually eliminating the drooling problem, and, eventually, preceding any cleaning response with a vocationally relevant object-assembling response.

Programs with a Microswitch and a Speech-Generating Device (SGD) to Allow Stimulation Control and Requests of Caregiver Attention

The largely successful use of single and multiple microswitches, as reviewed above, provides encouraging evidence about the potential of these technological resources in allowing stimulation control and choice (including also the ability to refrain from problem postures/behavior to obtain preferred stimulation) to persons with intellectual and multiple disabilities. The use of these resources may be considered a critical extension/enrichment of any rehabilitation context. Indeed, they can be instrumental in helping the participants develop forms of independent activity and self-determination capable of improving their social status and quality of life (Brown et al., 2009; Carter et al., 2013; McDougall et al., 2010; Petry, Maes, & Vlaskamp, 2009; Rigby, Ryan, & Campbell, 2011). In this way, the microswitches are also essential to promoting learning and consolidation of specific responses that become meaningful for the participants (i.e., functional within their context), extend their behavior repertoire, and empower them (i.e., by correcting the conventional passivity, dependence, and helplessness that characterize most of these persons) (Holburn et al., 2004; Lancioni et al., 2008b). In practical terms, the use of those resources could be envisaged as an indispensable supplement to the direct intervention of the rehabilitation and care staff.

Having underlined the extremely important functions of microswitch technology does not mean that the use of such technology can be extended without any precaution. Indeed, one may easily argue that the microswitches do not really afford the participants the option of contacting their caregivers. Yet, this might be an important option, particularly if the participants (a) are provided with the microswitches for rather extended periods of the day and (b) are considered likely to enjoy and/or need interactions with the caregivers during those periods (Lancioni et al., 2008a, 2008b, 2009a). A plausible solution to envisage for those situations might involve the combination of conventional microswitch technology with speech-generating devices (SGDs) also known as voice output communication aids (VOCAs). The microswitch technology would ensure that the participant continues to access environmental stimuli independently. The SGD/VOCA would enable the participant to ask for caregiver contact whenever he or she desires to have such a contact. Two studies combining the use of microswitch and SGD technology will be summarized here to illustrate the relevance of this approach and the procedural conditions for implementing it.

For example, Lancioni et al. (2009a) carried out a study involving 11 participants with multiple disabilities whose ages ranged from about 5 to 18 (with a mean of almost 11) years of age. The responses selected for activating microswitches and thus accessing environmental stimulation independently included, among others, hand and head movements, foot lifting, and vocalization. The microswitches used for monitoring these responses included pressure sensors, tilt devices, optic sensors, and throat microphones. The responses selected for activating the SGD devices were similar to those mentioned for the microswitches. Yet, an effort was made to clearly differentiate the microswitch response from the SGD response for each participant. The SGDs consisted of vocal output devices which could be activated by sensors similar to the aforementioned microswitches. Activation of the SGD did not cause a period of preferred stimulation but the emission of a verbal message requesting for caregiver attention. After an initial baseline, the intervention focused on teaching the participants the microswitch response. The emission of such a response was followed by a brief period of preferred stimulation (e.g., music, video clips, audio recording of familiar voices, and vibratory inputs). Once the microswitch response was consolidated, the intervention concentrated on the SGD response. The request of caregiver attention that followed each of the SGD responses caused (a) the activation of a joyful sentence (that could be accompanied by events such as hand clapping and sound of kisses) or (b) the combination of the above with physical gestures involving, among others, caressing, embracing, and kissing. Normally, the combined form of attention was available for every third SGD response. Eventually the microswitch and the SGD-related sensors were simultaneously available during the sessions, and the participants could use either one at their will. Data showed that all participants had a large increase in the frequency of their microswitch responses. Six participants also had a large increase in the frequency of SGD responses. Such an increase, however, was moderate for the other participants. During the final section of the program (i.e., when the participants could perform either response), most participants had higher frequencies of microswitch responses. All of them also continued to display SGD responses and thus maintained systematic interaction with the caregiver. A social validation assessment carried out at the end of the study with the involvement of 110 university psychology students as raters showed that the students favored the combination of a microswitch and an SGD (a) over the use of a microswitch or SGD alone and (b) over the hypothetical use of combinations of microswitches or combinations of SGDs.

Lancioni et al. (2009b) carried out a second study in the area, which served to verify the generality of the data obtained with the first study (i.e., the one just reviewed). Eight participants were involved in the latter study. Their characteristics and ages were similar to those of the participants of the previous study. Two responses were selected for each of the participants (i.e., one response for a microswitch device and another response for an SGD device). The responses included hand pushing, eye and mouth opening, head turning or lifting, and arm/hand lifting or stroking. The microswitches consisted of pressure, tilt, and optic devices. The sensors linked to the SGD devices for the request of caregiver attention were similar to the microswitches. Again, care was taken that a participant's microswitch response and SGD response clearly differed from each other. As in the previous study, the initial intervention phase focused on establishing the microswitch response, which entitled the participants to access brief periods of preferred stimulation on their own (i.e., directly). The second intervention phase focused on teaching the SGD response, which was followed by conditions identical or similar to those described for the previous study. The last intervention period provided the participants the opportunity to perform either response (as they wanted) and receive the consequences available. Data showed that the intervention phases were effective to establish the microswitch responses as well as the SGD responses. During the last part of the intervention (i.e., when either response could be emitted), the participants showed satisfactory performance, with a general preference for the microswitch response. A social validation assessment yielded results in line with those reported for the previous study.

SGDs for Active Communication

SGDs, also known as VOCAs, are assistive technology resources that enable persons without functional speech abilities to produce verbal messages (i.e., requests and statements) that the environment can easily decode. These devices can be used in combination with microswitches or alone (i.e., totally by themselves). In the latter case, the basic (exclusive) reason for their use is to allow an effective form of active communication, essentially to provide the person the opportunity to make requests. The persons that can most immediately and extensively benefit from this technology are those who do not possess effective communication within their context because they (a) have failed to develop any speech abilities or produce only unintelligible speech and (b) do not have effective/specific nonverbal means of communication (Lancioni et al. 2011e, 2013b; Sigafoos et al., 2009, 2013, 2014a, Van der Meer et al., 2012a).

The first prerequisite for a successful use of SGDs for persons with intellectual and multiple disabilities is that the persons have an interest in their environment and the stimuli that it contains (i.e., want to obtain/reach some of the stimuli and need help to do so; Gevarter et al., 2013a; Kagohara et al., 2013). The second prerequisite concerns the skills for the use of the device. In other words, persons can realistically use a device if they have the motor skills that allow them to reliably/effectively and inexpensively (i.e., without excessive effort) activate the device. Persons who have adequate fine motor skills may activate the device by direct selection of the panels/cells of the SGD concerned with the request objectives (i.e., using pointing, pressing, or touching responses). Persons without adequate motor skills may need to activate the device by using simple, single sensors/microswitches connected to voice output instruments (i.e., sensors that can be activated via minimal responses) (Lancioni et al., 2013b). The third prerequisite for a successful use of SGD devices is the availability of a communicative partner (e.g., staff, parent, or general caregiver) who responds to the communication messages that the persons with disabilities activate through the device. These persons will be motivated to reproduce their use of the device and send their communication messages (and maintain and extend them over time) only if the messages find consistent and satisfactory responses (Kagohara et al., 2013; Lancioni et al. 2008b, 2008c; Sigafoos et al., 2009, 2014a, 2014b).

Although a plurality of instruments exist and multiple ways of using them have been reported (Gevarter et al., 2013b; Mullennix & Stern, 2010), persons with intellectual and multiple disabilities may be taught to rely on relative simple technology and programs that can be easier for them to use for their communication (which mostly consists of requests to access to preferred objects or activities) (Gevarter et al., 2013a, 2013b). Four studies reporting the use of SGD technology will be summarized here to illustrate technological solutions and procedural conditions in this intervention area.

Lancioni et al. (2011e) used a commercial SGD (Go Talk 9; Special Needs Products of Random Acts Inc., USA) to enable a woman who presented with intellectual disabilities, respiratory problems, and absence of speech, to make requests about various activities. In relation to each request, the caregiver (a) provided material for the activity the participant wanted to carry out and (b) offered the participant a choice between different material options. The SGD was a tablet-like tool, which included nine cells. Only five of those cells were used during the program, given the fact that the participant normally requested five activities, which were of interest to her. On each of the five cells, the participant found the pictorial representation of one of the activities. The response required for making a request about a specific activity consisted of producing a light pressure on the cell showing the representation of such activity. The pressure activated the underlying key area and triggered the verbalization of the request message. The message consisted of calling the caregiver and asking for the opportunity to carry out one of the activities (i.e., the one selected on SGD device). The five activities involved listening to music/songs, watching videos, using ornamental material, watching picture cards and completing drawings, and using makeup material. The first intervention phase subsequent to the initial baseline focused on introducing the five pictorial representations used to indicate the activities available, one at a time. The following intervention phase involved the presence of all five representations on the SGD device and the possibility of requesting any of them. An activity was generally allowed for about 2 min. The participant's request performance during the baseline periods was very limited. Moreover, caregivers and staff could not always understand what the participant really wanted. During the intervention with the SGD device and all five activities available, she had an average of about eight requests per 20–25 min session.

Van der Meer et al. (2012a) assessed the use of SGD technology and manual signs with four children of 5–10 years of age who had a diagnosis of intellectual/developmental disabilities and autism spectrum disorder. The children were taught to request for their preferred stimuli which involved snacks and toys. The SGD consisted of an Apple iPod touch with Proloquo2Go software. The iPod was configured to show three graphic symbols representing requests for snacks, play, and social interaction. Touching a symbol activated the corresponding synthetic speech output. Only one of the symbols (i.e., the snack or play) represented the target request being taught. The other two symbols represented distracters. All participants acquired the use of the SGD, and only three of them acquired manual signs. Moreover, three of the participants preferred the SGD above the manual signs.

Van der Meer et al. (2012b) compared the use of an SGD with two other alternative communication strategies (i.e., picture exchange and manual signs) with four children of 4–11 years of age who had a diagnosis of autism spectrum disorder and possessed limited or no communication skills. Indeed, they had age equivalencies below 2.5 years in the expressive communication subdomain of the Vineland Adaptive Behavior Scales (Sparrow, Cicchetti, & Balla, 2005). The children possessed sufficient motor skills to handle the communication requirements within the three strategies used and were not reported to have auditory and visual disabilities. Each child was taught to make four requests with each of the three strategies, which were used according to an alternating treatments design. Each session included 12 trials, three per each requested item. The SGD consisted of an Apple iPod touch or an Apple iPad with Proloquo2Go software. The iPod and iPad were configured to show four graphic symbols (i.e., photos) representing requests for specific snacks and toys. At each trial, the experimenter would offer the participant an item, and the participant was to touch the matching symbol on the iPod or iPad (i.e., SGD condition), give the experimenter the corresponding picture (i.e., picture exchange condition), or make the matching sign (i.e., manual signs condition). The results showed that (a) one child reached the learning criterion rather rapidly within all three conditions, (b) one child reached the learning criterion only within the SGD condition, (c) one child reached the learning criterion quite rapidly within the SGD and picture exchange conditions and very slowly with the manual signs, and (d) the last child did not reach the learning criterion within any of the conditions.

The participants' preferences for the communication conditions varied. Only two children showed a strong preference for the SGD device.

Sigafoos et al. (2013) carried out a study with two children of 4 and 5 years of age, who had a diagnosis of autism spectrum disorder and displayed marked developmental delays with poor adaptive and communication behaviors. The program consisted of teaching the two children to request continuation of toy play via an Apple iPad device with Proloquo2Go software. The iPad was configured with a single graphic symbol, which was in the upper left quadrant (with the other three quadrants being blank). The children were provided with 3–10 requesting opportunities within each intervention session. Each trial started with the child selecting a toy and playing with it and continued with the experimenter gently taking the toy away. The child was to touch the symbol on the iPad to request the opportunity to continue playing with the toy. Any request led the experimenter to deliver the toy back so that the child could continue to play with it. Data showed that both children learned to request the toy very rapidly and, concomitant with their learning, they got rid of behaviors such as hitting the person and reaching for the object, which were displayed during the baseline period. The children maintained their request ability over time and generalized it to other stimuli.

Technology-Aided Programs for Promoting Functional Activities

Constructive (functional) activity engagement is an important goal of programs for persons with intellectual and multiple disabilities who do not present with main motor impairment that would prevent them from using objects (Ramdoss et al., 2012; Taylor & Hodapp, 2012). While activity engagement is a widely agreed objective and a way to help the persons acquire a positive role with beneficial effects in terms of general stimulation, social status, and acceptability, the achievement of such an objective may be difficult with many of those persons. Memory problems (i.e., difficulties to remember the sequence of steps involved in the activities) may often be the obstacle that interferes with the possibility of achieving the objective. The dimensions of such an obstacle may largely increase (a) when the activities are rather lengthy and (b) when the participants' level of functioning is relatively low (Ramdoss et al., 2012). Another aspect that may also be critical for the outcome of the intervention with these persons is motivation (Didden et al., 2006). Indeed, for some of these persons, the completion of an activity is not sufficiently motivating (reinforcing) so as to increase and/or maintain their willingness to engage in the activity with continuity and determination (Harr, Dunn, & Price, 2011). The overall agreement about the importance of functional activity engagement and the problems that may interfere with its achievement has encouraged a number of research efforts directed at finding plausible intervention solutions (Ayres & Cihak, 2010; Davies, Stock, & Wehmeyer, 2002).

Early efforts seemed strongly focused on developing computer-aided programs capable of regulating the presentation of step-related instructions and ensure reinforcing events (Furniss et al., 2001; Lancioni, O'Reilly, Seedhouse, Furniss, & Cunha, 2000). The instructions were pictorial representations that the participants did not need to manipulate as required, for example, with the use of booklets or picture arrays (thus avoiding the risk of skipping or mixing them with negative implications for their performance; Lancioni et al., 2000). Other efforts made in the area have assessed computer-aided programs with verbal instructions and with video prompts (i.e., video clips showing the actions/operations required for each step of the activity) (Banda et al., 2011; Cannella-Malone et al., 2006, 2011; Lancioni et al., 2011d; Mechling & Gustafson, 2009; Sigafoos et al., 2007). Recently, studies were carried out directed at guiding persons with multiple disabilities (i.e., through auditory or visual cues) in assembling complex objects with potentially positive consequences for the vocational perspective of the persons involved (Lancioni et al. 2013b, 2014a). The five studies summarized below provide an illustration of each of the approaches mentioned above, of the technology required for their implementation, and of their applicability and strengths within daily contexts (e.g., residential or day centers, rehabilitation programs, and vocational places).

Lancioni et al. (2000) reported one of several evaluations of computer-aided pictorial instructions for functional activities. They also compared the effects of such instructions with instructions provided via cards presented in a booklet format. The study included six participants who were between 23 and 47 years of age, possessed ambulatory skills and some verbal communication abilities, and were rated to function within the severe intellectual disability range. All of them were able to discriminate simple pictorial representations and could identify the objects reported within those representations. The computer-aided instructions appeared on the color screen of a palmtop computer, which contained a large key that the participants were to operate/press in order to move to the first/next instruction of the sequence. The computer was supplemented with an electronic circuitry, which ensured that it (a) would ignore erroneous/repeated key-press responses at any given point and (b) would send out a prompt if the participants did not seek a new instruction (i.e., did not make a new key-press response) within a maximum programmed time from the occurrence of the previous instruction (i.e., previous key press). Each task included 25–31 instructions (i.e., simple color representations) indicating the task steps. These step-related representations were interspersed with 4–6 other representations (i.e., smiling faces), which indicated reinforcing occasions. The instructions presented through the booklets (i.e., comparison condition) were arranged in the same way as those presented through the computer system. In essence, they consisted of color representations dealing with the task steps and color representations dealing with reinforcing occasions. Each participant was taught eight tasks, four via the computer system and four with the booklets. A partial crossover procedure was used before the end of the study to switch the tasks with poorer performance level to the system, which had produced higher levels of correct responding. Data showed that all participants had higher percentages of correct performance on the tasks taught via the computer system. When the tasks taught with the booklets were switched to the computer system (i.e., toward the end of the study), improvements were regularly recorded. For the three participants with the highest percentages of correct performance, it also was possible to combine many instructions in groups of two presented in quick sequence without declines in their performance.

Lancioni et al. (2011d) carried out a study to assess the effectiveness of a computer-aided program with verbal instructions to help three adults whose age equivalencies on the Vineland Adaptive Behavior Scales were of 6 or 5 years with regard to communication and 5 years or somewhat lower on daily living skills. Two participants also presented with visual impairments, while one was blind and affected by motor disabilities. Four tasks, including between 47 and 52 steps, were available for each participant. The new technology evaluated in this study consisted of a computer system linked to (a) optic sensors available at the two tables used by the participants (i.e., one containing the task items that the participants were to collect and the other serving for the use of those items and thus to carry out the task) and (b) an amplified MP3 that served for presenting the verbal instructions. A session started with the MP3 presenting the first instruction (e.g., take a tray). In taking that item, the participant broke the light beam of the optic sensors available at the first table. As soon as he or she freed those beams (i.e., moved back), the MP3 presented the second instruction (e.g., put the tray on the other table). As soon as he or she completed the response freeing the light beams of the optic sensors available on the second table, the MP3 presented the third instruction (i.e., concerning an item that the participant was to collect at the first table). The procedure continued in the same way until all task instructions were presented. Some of the instructions (never more than five) could be preceded by one-word encouragement or praise. Data showed that (a) all three participants learned to carry out the tasks, with high levels of accuracy, and (b) their performance with the new system (i.e., the one described above) was better than their performance with a computer-aided system which did not include the optic sensors, and thus the participants were to seek the instructions on their own.

Cannella-Malone et al. (2011) conducted a study with seven school children, who were between 11 and 13 years of age and were diagnosed with moderate to severe intellectual disabilities. Six of them also had a diagnosis of autism. The study compared the effectiveness of video prompting with that of video modeling in teaching daily living tasks, that is, starting a load of laundry and hand-washing a plate, a spoon, and a cup. The two tasks contained the same number of steps (i.e., 18) and were rated as comparable in terms of difficulty. For the video prompting condition, 18 video clips were prepared with regard to each of the tasks. Every clip represented the action (motion and objects) required for one specific step of the task. For the video modeling condition, a single video was made, which provided a representation of all the steps of the task, without specific emphasis on any of them or breaks between them. During intervention sessions with video prompting, the participants were shown one instruction at a time and allowed 30 s to perform the corresponding step. If they failed in their performance, the research assistant could intervene with various levels of prompts. During intervention sessions with video modeling, the participants were first shown the video of the entire task and then told to carry out the task. They had 30 s to start the first step and 2.5 min to perform the following steps of the task. The results indicated that for six participants, video prompting was more effective than video modeling, which proved largely ineffective. For one participant, neither strategy was effective. Yet, he was able to learn when in vivo instructions were provided.

Lancioni et al. (2013c) carried out a study aimed at assessing a computer-aided program to support two men of 31 and 33 years of age, with multiple disabilities (including blindness), to carry out an object-assembly task. Both participants were able to carry out small daily activities, such as assembling two-piece objects and transporting them. They could also follow a few verbal instructions concerning recurring daily events. The task targeted for the men was the assembling of five-piece wheels (i.e., a task that was considered relevant for vocational and social reasons). Given the men's inability to follow the correct sequence in the assembly process as well as their tendency to pause during their performance, a technology package was arranged for the intervention. This included (a) five small tables, each of which had a container with several exemplars of the same component of the wheel, (b) a sixth table with a carton where the men had to put each completed wheel, (c) a prompt and praise box and an optic sensor at each of the first five tables, (d) a prompt and praise plus music box and an optic sensor at the carton, and (e) a remote computer-aided control device which was linked to all the aforementioned boxes. At the beginning of a session, the control system activated the box on the first table, which called the man involved at intervals of about 8 s until he reached the table and found the container, thus activating the optic sensor available there. At that point, the box verbalized a praise statement and encouraged the man to take an object. After an interval of a few seconds, the box of the second table started to call him. The procedure for the second table and the following ones was virtually identical to that just described. Once the participant reached the cartoon, the box provided praise, encouraged him to drop the wheel, and turned on a preferred song for 30 or 45 s. At the end of the song, the box of the first table called him and the sequence started all over again. Data showed that both men were successful with the computer-aided program, while they failed to perform the task efficiently without technology support. By the last phase of the study, they were capable of assembling eight or nine wheels per 25-min session. About 95 % of the wheels were assembled correctly.

Lancioni et al. (2014a) carried out a study with three adults of 36–44 years of age who had multiple disabilities (including severe visual impairment and deafness). The participants were taught an assembly task through the support of a new technology package, which presented similarities and differences compared with that used by Lancioni et al. (2013c). The new package included (a) five tables each displaying several exemplars of one of the five components of a water pipe to be assembled, (b) a sixth table with a carton where each completed water pipe was to be placed, (c) a box with strobe lights and an optic sensor at each of the six tables, (d) a vibration device with flickering lights inside the carton (for one participant) and a chair with a back massage device next to the carton (for the other two participants), and (e) a remote control device connected to the boxes, the optic sensors, and the vibration devices. At the start of a session, the lights at the first table were on until the participant reached the object component available on that table, thus activating the optic sensor present there. This led to the activation of the box and lights at the next table. When the participant reached the object component available at that table and thus activated the optic sensor available there, the lights at the third table were switched on. The procedure continued the same way through the other tables. Once the participants dropped a completed water pipe inside the carton, the reinforcing stimulation (i.e., the vibrator and flickering lights in the carton or the back massage device at the chair) was automatically switched on for 20 s. Once that period was over, the control device turned off the reinforcing stimulation and switched on the box with the lights of the first table so that a new sequence started. All three participants displayed successful performance with the assistance of the technology package. After the initial part of the intervention, they became capable of assembling mean frequencies of 17 or 18 water pipes per 20- or 25-min session.

Considerations on the Technological Resources and Intervention Outcomes Reviewed

Microswitch-Aided Programs

Intervention programs with microswitches may be very helpful for enabling participants with intellectual and multiple disabilities to (a) control environmental stimulation, (b) develop assisted ambulation, (c) have the chance of making choices, and (d) strengthen adaptive responding and stimulation access and, concurrently, curb problem postures/behavior. Microswitches can also be combined with SGDs so as to allow participants to manage independent engagement and control of environmental stimulation and also request for caregiver attention. The results of the studies conducted in relation to each of the objectives just mentioned seemed to be very encouraging, thus emphasizing the positive impact of microswitch-aided programs.

A first consideration one can make about microswitch-aided programs concerns the fact that they can be applied successfully only when two essential conditions are met. The first condition is the selection of an appropriate adaptive response (i.e., a response that is in the person's repertoire and simple to perform or not yet present but easy to prompt and not particularly tiring). Obviously, the most suitable response for the person may frequently correspond to a minimal behavior that needs to be monitored through new microswitch technology rather than with conventional microswitches (e.g., pressure and tilt devices) (Lancioni et al., 2007a, 2007b, 2014b). During the last 10 years, much attention has been devoted to developing new microswitch resources that could reliably detect responses, such as eyelid movements, vocal emissions, mouth opening, and smiles (Lancioni et al., 2013b, 2014b, 2014c; Lui et al., 2012). The second condition is ensuring that the adaptive response is critical for accessing motivating/reinforcing environmental stimulation (i.e., stimulation that the participants want to reach and enjoy) (Catania, 2012; Kazdin, 2001; Lancioni et al., 2013b). Absence of relevant stimulation events is most likely to preclude any increase in the participant's responding and thus any positive change.

A second consideration is that a successful microswitch-aided program that allows the person to acquire control of positive environmental stimulation (i.e., regardless of whether this occurs through a minimal motor behavior or through an extensive type of response, such as step movements) can have beneficial effects also on mood and, possibly, quality of life (Dillon & Carr, 2007; Lancioni, Singh, O'Reilly, Oliva, & Basili, 2005d; Petry, Maes, & Vlaskamp, 2005, Petry et al., 2009). A number of studies have documented an increase in indices of happiness during intervention sessions in which microswitch activation allows the person access to the preferred stimulation (Lancioni et al. 2005d, 2007c, 2013b). This type of benefit can be considered as important as (or even more important than) the development of adaptive responding per se (Szymanski, 2000).

A third consideration concerns the beneficial effects of the programs for the social perception of the person (i.e., for the way the person is perceived and rated within his or her context). Indeed, persons who show an active role and independent engagement provide a more positive image of themselves than persons who are passive and rely on others for stimulation input. In turn, programs that facilitate the persons' active engagement are considered useful and desirable. Evidence of the aforementioned points can be found in social validation studies in which social raters are employed to assess (a) the persons' general behavior within program sessions and outside of the sessions and (b) the possible relevance of the program in the persons' daily context (Lancioni et al. 2005b, 2006a, 2013b).

A fourth consideration concerns the acquisition of choice and the possibility of increasing adaptive responding and curbing problem postures/behavior independently. The question of choice is relevant also in light of the fact that the general approach to persons with severe/profound and multiple disabilities is concerned with environmental enrichment more than with individual involvement and possible selection of the more attracting/preferred stimuli (Mitchell, 2012; Tullis et al., 2011). Microswitch-aided programs may be the only way to allow the persons to operate a decision (i.e., a stimulation selection) based on individual preferences (Lancioni et al. 2006b, 2013b). The possibility of helping many of these persons to reduce problem postures/behavior amounts to helping them develop a clear form of self-control that frees them from outside restrictions and makes them look much more responsible and mature (McDougall et al., 2010; Singh et al., 2008a, 2008b).

A final consideration about microswitch-aided programs concerns the issue of costs and the need of upgrading (Borg et al., 2011; Kagohara et al., 2013; Hubbard Winkler et al., 2010; Lui et al., 2012). With regard to costs, one can argue that microswitch-aided programs may be considered affordable within school and rehabilitation settings. Most of the microswitch devices would cost less than 200 US dollars that should be added to the cost of a portable computer, interfaces, and basic software required for the complete program. With the notion of upgrading, one stresses the importance (necessity) of finding/providing satisfactory alternative designs for the available microswitches or developing new forms of microswitches so as to create intervention options also for persons that would be unlikely to benefit from the currently available microswitch technology.

SGD Technology and Communication

The literature has shown that SGDs can be combined with microswitches and can be used as single intervention solutions. The combination of SGD and microswitch devices may be considered an interesting approach in any type of education/rehabilitation and care environment, particularly in conditions in which a consistent caregiver presence is not ensured for periods of time. The first beneficial consequence of such combination is that it would avoid any risks of isolation for the participants. Such risks might be considered real in microswitch-aided programs implemented over rather extended sessions (Lancioni et al. 2014b). The possibility to intersperse an active engagement in seeking environmental stimulation through microswitch activations with requests of caregiver attention could be considered a reassuring opportunity for the persons involved in the programs as well as for the persons in charge of those programs (Lancioni et al., 2009a, 2009b). The second beneficial consequence would seem to be strictly practical, that is, directly related to the caregiver commitment. Given the way the programs reported were arranged (i.e., with the microswitch responses allowing systematic stimulation access and the SGD response allowing verbal/auditory responses intermittently accompanied by physical contact), the request of caregiver attention did not appear to be excessively frequent and to require consistent levels of caregiver physical involvement. This condition could be considered mostly reconcilable with the supervising and management duties of many caregivers employed within education/rehabilitation or care contexts.

As single solutions, SGD devices can be highly useful in a variety of daily situations in which the participants are expected to learn to communicate their requests successfully (i.e., in a way that is easily understandable to any communication partner). Only successful communication can allow immediate access to events that are reinforcing and motivating for them. For example, one can envisage this kind of approach in snack situations as well as in play or occupational situations (Sigafoos et al., 2009, 2013, 2014a, 2014b; Van der Meer et al., 2012a, 2012b). Obviously, the devices used and the number of requests involved in the communication exchanges need to match the characteristics of the persons involved in the programs (e.g., Van der Meer et al., 2012a; Lancioni et al., 2011d). New research will need to clarify how programs can proceed (a) from single requests to multiple requests and (b) from specific communication/request sessions to the possibility of exercising communication/request during most part of the day. The technology and procedural conditions used may also need to be reconsidered. For example, one could envisage a context containing several SGD devices so that the person would have one of the devices almost always visible, with the possibility that this could promote/facilitate his or her communication initiatives. The investigation of the motivating/reinforcing potential of larger (nonconventional) arrays of stimuli may also be necessary so as to have a request interest also for those persons who seem minimally attracted by daily events (Davies, Chand, Yu, Martin, & Martin, 2013; Li, Bahn, Nam, & Lee, 2014).

Technology-Aided Programs for Functional Activity

Programs aimed at helping persons with intellectual and multiple disabilities to perform functional/vocational activities can be considered critical to provide those persons (a) a relevant role within their domestic and education/rehabilitation environment and (b) a possible chance to enter a work environment (Lancioni et al., 2014a). The studies reviewed indicate that different technology solutions may be envisaged for helping these people achieve their activity goal. The different solutions need to be carefully matched to the characteristics of the persons involved and the type of activity goals that are targeted. For example, a computer-aided program based on pictorial instructions and involving reinforcing events and prompt opportunities may prove largely effective with people with severe intellectual or multiple disabilities. Indeed, pictorial instructions may be or become rapidly clear to these people and provide the information they need for each step of the activities targeted. The reinforcing events may ensure the motivation for them to continue their involvement and accuracy. The prompt opportunities may be an important resource to solve possible breaks in performance. A system's self-protection mechanism to deal with repeated key presses may be a guarantee in case of motor disabilities (Lancioni et al., 2010a, 2010b, 2013b).

The use of video prompting may be an alternative to static pictorial representations with potential advantages on such representations for persons with moderate/severe intellectual and multiple disabilities. In theory, the dynamic presentation of the actions required for the single activity steps may be considered more illustrative and thus more effective than static pictorial representations. With regard to this point, there is evidence favoring the video prompting approach (Banda et al., 2011; Mechling & Gustafson, 2009) and evidence indicating a general equivalence of the approaches (Perilli et al., 2013). Indeed, the final outcome of a program may not only depend on the types of instructions used but also on other variables, such as the responses required to access the instructions, the motivation ingredients available, and other mechanisms (e.g., prompting or self-protection) involved in the program package (see Lancioni et al., 2000, 2013b).

Programs using verbal instructions can only be used with persons capable of discriminating/understanding simple sentences and responding to them properly. This kind of ability may be rare in persons with severe intellectual disabilities or multiple disabilities including auditory impairment. As in the case of programs relying on pictorial instructions and video prompting, the final outcome of a program with verbal instructions may be largely affected by the technology package used and the motivation and prompting variables included. In the study by Lancioni et al. (2011d), for example, the program in which the verbal instructions were automatically presented by the system in relation to the performance of the participants produced better results than the control program in which the participants were to seek the same verbal instructions on their own.

Programs with auditory or visual cues to guide persons with multiple disabilities through the steps of assembly tasks may be considered a relevant resource. In fact, they may represent the only opportunity for these persons to develop and maintain functional work skills that could help them expand their perspectives within occupation day centers or even work contexts (Vornholt, Uitdewillingen, & Nijhuis, 2013). The same programs may also help the participants increase their mobility and physical activity (i.e., as they are required to repeatedly walk through the workstations used for the task), thus countering the sedentariness that characterizes their days (Cannella-Malone, Mizrachi, Sabielny, & Jimenez, 2013; Frey, 2004; Van Naarden Braun, Yeargin-Allsopp, & Lollar, 2009).

Conclusions

The studies reviewed and the considerations formulated above can be taken as positive evidence that emphasizes the possibility of relying on various forms of technology-aided programs to help persons with intellectual and multiple disabilities pursue functional objectives. Microswitch-aided programs have been widely used with the aim of reaching different goals. Data show that they can be a valuable resource for a large range of cases, varying from those who have a minimal behavioral repertoire and need help to access environmental stimulation on their own (i.e., with their minimal resources) to those who need to learn combinations of adaptive responding (to access environmental stimulation) and self-control (i.e., to refrain from their problem postures/behavior) (Lancioni et al., 2013a, 2013b, 2013e; O'Reilly et al., 2008). Research has evaluated a number of microswitch devices suitable for cases with minimal behavior and indicated that additional efforts are required to help all those persons who are still considered unable to benefit from current microswitch-aided programs, due to the incompatibility between the technology resources available and their characteristics (Lancioni et al. 2013b, 2013d, 2014b, 2014c; Leung & Chau, 2010; Lui et al., 2012).

SGD technology has shown to be a highly valuable resource when used alone as a way for the person to communicate (i.e., generally to make requests about environmental stimuli/events that are relevant and motivating for him or her) as well as when used in combination with microswitches (Sigafoos et al., 2014a, 2014b). The first type of application can be further investigated to assess ways of making the technology consistently available and the communication of the person involved in the program plausible throughout the day. The second type of application (i.e., in combination with microswitches) may be seen as a form of guarantee against the risk of isolation for persons involved in microswitch-aided programs for relatively extended times of the day. In fact, the presence of the SGD option allows the person to seek caregiver attention anytime he or she may desire/need such attention (Lancioni et al. 2009a, 2013b). Obviously, new research may help to diversify this type of approach for different persons. In some cases (i.e., those with more severe disabilities), it might be more practical (or even necessary) to alternate sessions with the microswitch with sessions with the SGD option.

Instruction systems for promoting functional activities can vary largely across individuals and situations, and the choice of one system or another should be decided based on the characteristics of the participants and the objective pursued with them. For practical purposes, one could state that systems relying on pictorial instructions can be suitable for persons with severe intellectual and multiple disabilities, provided that the technology available ensures reinforcing occasions, deals with possible breaks in performance, and prevents handling errors (Furniss et al., 2001; Lancioni et al. 2000, 2013b). Video prompting could probably be used with participants of similar levels of functioning (i.e., moderate and severe intellectual and multiple disabilities). As indicated above, it might be critical that the technology available to regulate the presentation of the instructions is easily usable, ensures motivation, and prevents operation errors. The use of verbal instructions cannot really be an option for many persons with severe and multiple disabilities (who are unlikely to have sufficient receptive language skills) but may serve well persons with moderate intellectual disabilities. Finally, systems using auditory and visual cues and separate workstations may be highly suited to guide persons with severe/profound intellectual and multiple disabilities through the different steps of object-assembly tasks. This arrangement may also be helpful in increasing the level of motor activity in a group of persons who tend to be sedentary (Cannella-Malone et al., 2013; Frey, 2004; Van Naarden Braun et al., 2009).

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Positive Behavior Support

15

Kelsey R. Morris and Robert H. Horner

Introduction

Positive behavior support (PBS) is emerging as a primary approach for addressing problem behavior within educational, disability, and community support settings (Odom, Horner, Snell, & Blacher, 2007). Frequent and severe problem behaviors are a major cause of isolation and exclusion for people with disabilities (Koegel et al., 1996; Lehr & Brown, 1996; National Institutes of Health, 1989; Reichle, 1990). Between 10 and 40 % of children with disabilities display frequent and severe problem behaviors (Durand, 2015; Einfeld, Tonge, & Rees, 2001; Lowe et al., 2007), and current epidemiological estimates suggest 15–20 % of individuals with intellectual disabilities exhibit one or more types of problem behavior (Emerson et al., 2001; Lowe et al., 2007; Reichle & Moore, 2014). Moreover, problem behaviors are increasingly more likely among individuals who experience severe and multiple developmental disabilities (Harvey, Boer, Meyer, & Evans, 2009; Reichle & Moore, 2014).

Problem behaviors such as self-injury, aggression, property destruction, defiance, tantrums, and disruption are highly prevalent among children and adults with a variety of developmental disorders (Durand, 2015). Such behaviors prove to be major barriers to the social, vocational, educational, and physical success of the individual (Carr et al., 1999a, 1999b). Fundamental life elements such as family dynamics (Cole & Meyer, 1989), education (Koegel & Covert, 1972), and employment (Hayes, 1987) are significantly strained by the presence of problem behaviors.

In the absence of effective supports, individuals with disabilities who exhibit problem behaviors are susceptible to exclusion from regular educational settings, community environments, and employment opportunities; increased medical risks; isolation from social relationships; and exposure to highly intrusive forms of treatment (Horner, 1999; Horner, Diemer, & Brazeau, 1992; Knitzer, 1993; Sailor & Skrtic, 1995). Likewise, families are challenged and parental stress is shown to increase when caring for a child with problem behavior (Brown, MacAdam-Crisp, Wang, & Iarocci, 2006; Malick-Seltzer & Krauss, 2001; Mugno, Ruta, D'Arrigo, & Mazzone, 2007; Werner et al., 2009).

Behavioral support for individuals with disabilities has undergone dramatic advances in recent decades and improved the ability of educators, families, and community clinicians to

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support students with severe disabilities and problem behaviors (Horner & Carr, 1997). These advances have occurred in part due to the careful construction of effective intervention procedures and in part due to a recasting of the focus of behavioral support. Behavioral support has shifted from a punishment-based logic to an approach emphasizing teaching of desired behavior, rewarding desired behavior, and systematically withholding rewards for problem behavior. To a very great extent, effective behavioral support in the twenty-first century is about engineering settings (schools, homes, workplaces) so that problem behaviors become less likely and desired behaviors become more likely.

PBS is a general term referring to the application of interventions and systems to achieve socially important behavior change (Sugai et al., 1999). PBS includes skills that increase the likelihood of success and personal satisfaction in normative academic, work, social, recreational, community, and family settings (Carr et al., 2002). PBS involves the assessment and reengineering of environments so people with problem behaviors experience reductions in their problem behaviors and increased social, personal, and professional quality in their lives (Horner, 1999). The technology represents application of behavior analysis to the social challenges resulting from behaviors such as self-injury, aggression, property destruction, defiance, tantrums, and disruption.

Though the origins of the PBS technology are in providing an alternative to aversive interventions used with students with significant disabilities who engaged in extreme forms of self-injury and aggression, PBS has demonstrated success in its application with wide ranges of individuals and contexts. PBS is an approach that blends values about the rights of people with disabilities with a practical science about how learning and behavior change occur. What was once an intervention approach for individuals is now an evidence-based approach for entire systems (Sugai et al., 1999).

PBS is neither a new intervention package nor a new theory of behavior. It is the application of a behaviorally based systems approach for enhancing the capacity of schools, families, and communities to design effective environments that improve the fit or link between research-validated practices and the environments in which teaching and learning occur. Attention is focused on creating and sustaining environments that improve lifestyle results (personal, health, social, family, work, recreation, etc.) for all individuals by making problem behavior less effective, efficient, and relevant and desired behavior more functional (Sugai et al., 1999). Improved lifestyle results equate to an improved quality of life (QOL). The emergence of PBS as a field is due in large part to the technology's focus on improving the QOL of individuals with disabilities (Dunlap, Sailor, Horner, & Sugai, 2009).

The purpose of this chapter is to offer a perspective on the development of PBS beginnings in the late 1980s to its current, strong and healthy state. We begin with a clear understanding of PBS by identifying the context of its development and describing its defining characteristics. Next, we review the current role of PBS in the support of individuals with disabilities and its application to larger social systems. Finally, we describe the future of PBS and its implications for social systems, professional development, data analysis, as well as policy design and implementation.

PBS: Where Did It Come from and Why Was It Created?

PBS combines behavioral science, organizational theory, and social values. Understanding the content and application of PBS requires appreciation of the social standards that guide the use of the technology.

Deinstitutionalization and Normalization

The 1980s bore great change to how services for persons with disabilities should be conceptualized, organized, and provided. The disability rights movement of the time was spurred by the immense national discontent with the large congregate settings such as state institutions for people with developmental disabilities (then referred to as “mentally retarded”; Lucyshyn, Dunlap, & Freeman, 2015). The resulting deinstitutionalization movement demonstrated intense conviction to expose the abject, warehouse-like conditions persons with disabilities were subjected to. Blatt and Kaplan’s (1966) *Christmas in Purgatory* exposed the conditions of New York’s Willowbrook Institution, and the Gannett News Services’ exposé entitled Oklahoma Shame (Dubill, 1982) revealed conditions of Hissom and other large institutions in Oklahoma.

The outcome of such revelations was the normalization movement that sought the right to community living and an enhanced quality of life for persons with developmental disabilities (Wolfensberger, 1972). The movement was characterized by the support for people with disabilities to achieve a life as culturally normative as possible, through means that were as culturally normative as possible (Lucyshyn et al., 2015). Normalization advocates sought rights to employment and independent living. Based on the concept that persons with intellectual and/or developmental disabilities who have been socially devalued should be allowed to acquire socially valued roles in typical community environments, normalization supplied a rationale for transitioning people out of large, segregated institutions and into community settings (Nirje, 1994; Singer & Wang, 2009). These values extended to all people, including people who engaged in problem behavior. The normalization movement both established the standard that any intervention technology should be functional for all people and the expectation that an effective intervention technology not only decreased undesirable events but actively established lifestyle outcomes that were substantive, durable, and self-determined.

A History of Aversive Punishers

In addition, the technology of positive behavioral support emerged in contrast to restrictive and punitive behavior management technologies that were promoted during the 1970s and 1980s. Researchers reported success using behavior management technologies reliant on the systematic application of contingent punishment. Punishments included the application of physical pain (i.e., slapping, pinching, electric stimulation) or the use of dehumanizing punishments (i.e., shaving cream in mouth; Lucyshyn et al., 2015). Examples include developmentally disabled individuals being subjected to a device that administered automatic electric shocks (Linscheid, Iwata, Ricketts, Williams, & Griffiths, 1990) and people with autism being forced to wear helmets that emit white noise and spray water in the face (Butterfield, 1985; Linscheid et al., 1990; Singer & Wang, 2009). Such technologies originated in the insulated environments of institutions where early behavior research with people with severe disabilities was conducted. Later known as “aversives,” these punishment procedures represented an ideology founded upon the elimination of problem behavior through the delivery of pain, withholding of basic human needs, or social humiliation.

Despite the reported successes associated with the use of such techniques, the techniques themselves were challenged as being unethical. Pinching, slapping, spraying water in face, or providing electric shocks were not viewed as acceptable in community settings and not related to achieving larger lifestyle goals. Given the disability rights movement of the era and the focus on deinstitutionalization and normalization, the use of such aversive procedures in community settings or public education was discouraged. A case in point, public schools in the 1980s were occupied with imposing state-mandated bans on corporal punishment. Administering physically or psychologically painful punishments to students with disabilities was out of the question. Federal lawsuits such as Beard v. Hissom in Oklahoma were confirmatory (Dunlap et al., 2009).

Contentious dissension marred the scientific community of behavior research and the professional community of practice (Repp & Singh, 1990). Behaviorists grappled with how to apply effective and proven behavioral practices in school, work, and community contexts. Freagon (1990) proposed the question of how the use of highly aversive stimuli to punish unwanted behavior could ever be accepted as a functional technology for reducing problem behavior in community contexts. Meanwhile, there was groundswell continuing to form in support of nonaversive behavior management and committed to the belief that persons with severe disabilities exhibiting challenging behaviors should receive the same respect and dignity as all other members of the community (LaVigna & Donnellan, 1986; Meyer & Evans, 1989).

The strain within the field precipitated a need for research and development on new technologies that (a) could address the same population of individuals (students in schools or adults in community-based facilities), (b) would be socially appropriate and socially acceptable, and (c) would be durable, efficient, and effective (Dunlap et al., 2009).

Toward Nonaversive Behavioral Support

During this time of sweeping reform of services for people with disabilities, the field of behavior management experienced a significant need for a technology of nonaversive behavior intervention that was grounded in science. In 1987, the US Department of Education provided funding for a national research and technical assistance center on the topic of nonaversive behavior management. The faculty of the center published an article detailing the emergence of nonaversive behavioral support technologies that focused on positive, educative procedures that foster the development of adaptive repertoires, as opposed to emphasizing behavioral suppression through aversive contingencies. The faculty introduced the term "positive behavior support" as a successor to nonaversive behavior management (Carr & Durand, 1985; LaVigna & Donnellan, 1986; Meyer & Evans, 1989). PBS became the name associated with the research and practice dedicated to the development of this technology.

PBS is founded in applied behavior analysis (ABA), a social science tradition encompassing almost 50 years of research (Baer, Wolf, & Risley, 1987; Cooper, Heron, & Heward, 2007; Singer & Wang, 2009). Both ABA and PBS are founded upon the belief that human behavior can change. At conception, PBS differed from ABA in that (a) it was established upon the belief that effective positive alternatives to aversive treatments do exist and therefore it is unethical to use harsher procedures (Singer, Gert, & Koegel, 1999) and (b) it demonstrated a commitment to using behavioral interventions for both changing distinct target behaviors and also having a more robust and positive influence on the intervention recipient's quality of life (Singer & Wang, 2009).

From a functional point of view, both ABA and PBS make the assumption that behavior is defined and understood in a context (Singer & Wang, 2009). Indeed, both assume that all lasting behavior is caused and enabled by the environment as)opposed to intra-psychological variables. ABA and PBS conceptualize the environment as the independent variable and the person's behavior as the dependent variable. Within any behavior, there is a functional relationship that exists between the person and repeated patterns of environmental variables. Typically, the environment in question is the social environment, comprised of microsocial interactions between the change agent and person demonstrating the inappropriate behavior (Singer & Wang, 2009). Like ABA, PBS conjectures that recurrent behavior is the composition of antecedent events or variables and reinforcing consequences. PBS believes that the relationship between behavior and environment can be structured according to setting events, established operations, discriminative stimuli, as well as positive and negative reinforcement. Moreover, PBS believes that it is possible to predict and control many targeted problem behaviors once a functional relationship between the behaviors and their relative antecedents and consequences are identified (Singer & Wang, 2009).

PBS is an empirical approach that relies on valid and reliable data to support its practices.

The foundations of PBS interventions are reinforcement and contingency management, functional assessment and functional analysis, shaping and fading, and manipulations of stimulus control and established operations (Dunlap, Carr, Horner, Zarcone, & Schwartz, 2008). The scientific underpinnings of PBS can overshadow its deep commitment to present-day utility for people with problems in behavioral adaptation. PBS emphasizes the generation of immediately applicable knowledge (Dunlap et al., 2008).

A major focus of PBS research is the integration of research with practice, including the analysis and application of factors characteristic of complex social environments (Carr, 1997). PBS is distinct in that it endeavors to make behavior intervention strategies more effective in complex settings and at multiple levels as well as larger scales of implementation. Within PBS, the unit of analysis is homes, schools, workplaces, and other complex naturalistic settings. The concept emphasizes intervention on a broad scale and looks beyond the immediate environment to classroom, group, and systems-level contingencies that may impact behavior. PBS exemplifies an equal focus on preventive strategies and intervention strategies for problem behavior reduction (Dunlap et al., 2008). In addition, PBS proactively promotes replacement behaviors and submits that behavior interventions relying on aversive and exclusionary discipline practices and which ignore the expansion of positive behavior are usually ineffective and possibly inhumane (Solomon, Klein, Hintze, Cressey, & Peller, 2012).

Within the science of behavior, PBS assumes its own identity, an identity strongly influenced by the realities of conducting research and intervention in natural community settings—realities that necessitate changes in assessment methods, intervention strategies, and the definition of what constitutes a successful outcome (Carr et al., 2002).

PBS emerged when it did because of two challenges facing the field of behavior support. The first was how to provide support to individuals with intensive support needs without using painful and aversive stimuli. The use of electric shock, spanking, noxious sprays, and similar “consequences” for problem behavior could be defended from an analysis of animal research, but these approaches offended the values of the field and were found to too often carry deleterious side effects for both those receiving the intervention and those implementing the intervention. PBS was challenged first to become a technology that could reduce dangerous and damaging behaviors without requiring the delivery of pain.

The second, and synonymous, challenge to the field was to move from “management” of behavior to “support” of behavior. The recognition was that behavior support must move beyond a research endeavor where change across time segments was documented to an applied technology to where support resulted in change that included improved quality of life and improved positive behavior as well as reduction in problem behavior. This second challenge was more complex, more important, and more instrumental than many understood at the time. The call was to make the technology of behavioral intervention responsive to the values of individuals and their families/advocates. When the disability field made behavioral intervention a “values-first” technology, it launched positive behavior support. In many ways, the last 25 years have been spent building, validating, and documenting the practices needed to meet this challenge.

Defining Characteristics of PBS

From its origin, PBS focused on intervention strategies feasible for community, home, and school settings to address problem behavior and improve quality of life, without using aversive or stigmatizing procedures. PBS is characterized by its proactive approach, and emphasis on teaching new skills, and manipulating the antecedent conditions in a setting as much as on the consequences for behavior (Dunlap et al., 2010).

The first formal iteration of PBS involved persons with severe disabilities who had previously been subjected to official and unofficial mistreatment through aversive interventions (LaVigna &

Donnellan, 1986; Meyer & Evans, 1989; Singer & Wang, 2009). The technology was comprised of functional behavior analysis, antecedent manipulations based on assessment, teaching strategies, and the altering of contingent reinforcement to emphasize the positive and reduce or remove the aversive. Built upon previous ABA research, these foundational components were assembled purposefully to emphasize ecological and social validity, quality of life, and a pervasive respect for dignity (Dunlap et al., 2009). Previously denied the common benefits and pleasures of community life, the recipients of the original PBS technology were the beneficiaries of a commitment to improve the quality of life of vulnerable persons (Singer & Wang, 2009).

As previously noted, PBS is proactive in nature. It is emblematic of a prevention paradigm. Key messages from the science of behavior denote that much of human behavior is learned and affected by environmental factors and, therefore, can be changed as an environment is changed. The more we understand the multiple facets of a problem behavior, the better positioned we are to teach prosocial, functionally equivalent replacement behaviors. The technology of PBS is grounded in the science of human behavior and, although various techniques are applied at different levels, the essential elements of behavior are unvarying (Sugai et al., 1999). The technology's practices and procedures represent an attempt to remedy the symbiotic relationship between maladaptive behavior and their inadequate environments for the purpose of preventing recurrent problem behavior.

There are a number of features that are important to consider when defining PBS and appreciating its role in the landscape of behavioral science and practice. Carr et al. (2002) describe PBS as a highly pragmatic, problem-solving approach that is receptive to input from multiple perspectives, with the ultimate standard being that such inputs are subject to empirical accountability and validation, as well that they are aligned with the supreme PBS goals of decreasing problem behavior and increasing quality of life. In defining PBS, there are seven common themes worthy of acknowledgment and encouragement.

Values Driven

PBS is a technology for changing behavior. Unlike many behavior change technologies, however, PBS starts with the values of the person receiving support, his or her advocates, and those who will deliver support. The science informs behavior change, but it is ultimately our values that define what is worth changing. The core of the PBS technology is not simply the reduction of problem behavior but the improvement of people's lives (Carr et al., 1999a, 1999b; Koegel, Koegel, & Dunlap, 1996; National Institutes of Health, 1991).

In contrast, PBS includes increasing the likelihood of successful opportunities in education, employment, and the community, as well as improved health and social well-being of the individual and his or her stakeholders. The supports necessary to foster such success and improvement include instructional methodologies for teaching, strengthening, and expanding prosocial behavior repertories. The primary goal of PBS is to help an individual change his or her lifestyle in such a way that all relevant stakeholders (i.e., educators, employers, family, friends, the individual himself or herself) are afforded the opportunity to perceive and enjoy an improved quality of life (Carr et al., 2002).

Within the science of behavior, PBS represents a position from the high moral ground—a position that challenges the design of effective technology. PBS balances scientific technology with person-centered values by evaluating all strategies with respect to efficacy as well as ability to enhance personal dignity and opportunities for choice (Carr et al., 2002). Support strategies are focused on producing durable, generalized behavior change in order to achieve greater access to community settings, improved social contact, and a wider array of preferred events (Horner et al., 1990). The hypothesis of the technology is that if an individual's needs are met, then quality of life will improve and behavior will be reduced or eliminated (Carr et al., 2002).

At the heart of PBS is the focus on defining the technology that affords individuals the opportunity to live a personally satisfying, enviable life. Quality of life (QOL) is a complex concept. Dunlap et al. (2010) identified six domains from the literature including material well-being, health and safety, social well-being, emotional/affective well-being, leisure and recreation, and personal well-being.

Behavior Based

PBS owes more to applied behavior analysis (ABA) than any other conceptual foundation. Behavior is a function of understood principles. Effective support should be guided by practices that are empirically documented to work. Evaluating the antecedent and consequences associated with a behavior has a long been advocated in ABA (Baer, Wolf, & Risley, 1968; Bandura, 1969; Kanfer & Saslow, 1969). PBS is an approach based on valid science. The technology focuses on efficient processes for identifying when problem behaviors are likely to occur and what events are likely to maintain the recurrence (Horner et al., 1990).

Central among the practices used in PBS is the use of functional behavioral assessment (FBA). Functional behavioral assessment is the process of identifying variables that reliably predict and maintain problem behaviors (Horner, 1999). FBA serves to definitively identify how inappropriate, challenging, or problem behaviors function for the person exhibiting them. The underlying assumption is that every behavior serves a purpose. Understanding the functional relation between problem behavior and consequences (i.e., purpose, motivation, intent) does not serve to rationalize the inappropriate behavior but does serve to make it understandable (Singer & Wang, 2009).

Instead of interpreting problem behavior as the product of indiscernible, active forces within the individual, PBS supports that behavior is the product of challenging social situations for which the problem behavior is the individual's attempt at a solution. Revealed is a focus on environmental variables including antecedents (i.e., events that trigger the behavior), setting events (i.e., the larger context that influences the likelihood that problem behavior will be triggered), and consequences (i.e., the purpose, intent, function, motivation; Horner & Carr, 1997). Functional behavioral assessment serves the intention to identify the very conditions in which problem behavior is likely to occur so that environments can be modified and rearranged to reduce recurrences of problem behavior and foster the teaching and encouragement of replacement behaviors (Sugai et al., 1999).

The role of functional behavioral assessment, however, is only the start of the contribution that behavior analysis has made to PBS; the conceptual understanding of human behavior provided through behavior analysis permeates PBS. The technology emphasizes establishing a direct connection between the results of an FBA and the actual intervention program developed.

Comprehensive in Scope

Because the values guiding PBS require attention to both prosocial replacement behaviors and problem behaviors, behavior throughout an entire day, and behavior across many days, it is highly unlikely that a single intervention strategy will be adequate. From conception, PBS was challenged to define a support technology for not simply solving the problems of a dramatic moment but preventing that moment, teaching skills to redirect that moment, defusing the moment, preventing the moment from repeating, and most importantly defining the data system that would make all this understandable to people who both deeply cared about the valued outcomes and care enough to be technically competent. To meet this challenge, PBS became much more complete as a support technology. The result was the emergence of technology of support incorporating multiple elements and multiple outcomes.

The daily application of positive behavior support requires the application of multiple procedures. Therefore, interventions must be comprehensive in scope, format, and function. Because behavior support is about lifestyle change as well as behavior change, there must be an expansion in the structure and scope of interventions. A focus on person-centered values necessitates complex, multicomponent interventions designed to improve the living options of the individual as well as reduce the occurrence of problem behavior. Specifically, comprehensive interventions aid in increasing positive behavior while simultaneously decreasing undesirable behavior (Horner et al., 1990; Horner & Carr, 1997; Koegel & Koegel, 1988).

The chief objective of a comprehensive intervention is to yield a lasting, general reduction in problem behaviors within a short time frame while improving the individual's quality of life in home, community, educational, or professional settings. Comprehensive interventions are exemplified by five essential elements (Horner, 1999). (1) Comprehensive interventions target all inappropriate or challenging behaviors performed by the individual. A behavior support plan is inefficient and ineffective if it targets some behaviors and ignores others. (2) Comprehensive interventions are powered by a functional behavioral assessment. There is now wide and compelling literature documenting that if behavior support is consistent with functional assessment, the effectiveness of the intervention increases (Carr et al., 1994, 1999a, 1999b). (3) Comprehensive interventions are applied throughout the entire day. (4) Comprehensive interventions combine multiple procedures to target the different problem behaviors, different motivations, different antecedents, and different setting events. The purpose is not to create unintelligible, elaborate, complicated behavior supports but rather to better comprehend how the traditional, single-strategy approach is insufficient. (5) Comprehensive interventions must exemplify a contextual fit. Comprehensive positive behavior support incorporates methodology that is aligned with the values, skills, and resources of the implementers (Horner & Carr, 1997). As well, it must work for all individuals in the context where support occurs. If support benefits the individual with disabilities but inhibits life for other individuals in the environment or impedes the success of implementers due to complex and difficult support plans, then the support will either not be provided at all or will be cast aside as soon as the behavioral crisis is past.

There is no standardized template for designing comprehensive interventions. Functional behavioral assessment provides great insight for developing interventions. However, the assessment results will never detail specific intervention strategies or methodologies. Within PBS, it is likely that numerous intervention combinations could be implemented with acceptability and produce valid results. The goal is to select complementary procedures (i.e., antecedent manipulations, consequence modifications, setting event redesign) that are both aligned with the functional assessment and realistic given the resources of the setting (Albin, Lucyshyn, Horner, & Flannery, 1996).

Educative

When Carr and Durand (1985) defined functional communication training and the design of interventions that competed with problem behavior, there was an immediate recognition that too often behavior support had missed the important role of building adaptive skills. PBS includes teaching adaptive skills, but through the use of FBA, these skills include those positive behaviors that can replace problem behaviors.

Individuals with challenging behaviors sometimes develop maladaptive behaviors; they possess a deficient skill set for coping with their contexts. One of the most significant aspects of PBS is instruction of new skills for navigating current and future environments (Lee, Wood, & Browder, 2015). Within a nonaversive approach to behavior management, great attention is given to directly teaching individuals prosocial, adaptive ways of obtaining the very outcomes that are currently achieved through maladaptive, challenging behavior (Carr, 1988; Evans & Meyer, 1985; LaVigna & Donnellan, 1986).

To teach replacement behaviors, the behavioral function of the challenging behaviors must first be identified. What is the consequence (i.e., purpose, intent, function, motivation) of the inappropriate behavior? By attending to the function of a challenging behavior, clinicians and practitioners are better able to distinguish deficient behavior repertoires. Carr et al. (1999a) noted that behavior repertoires are deficient to the extent that communication skills, self-management, social skills, and other constructive behaviors are underdeveloped or absent.

A principal objective of PBS is to assist an individual in achieving his or her goals in a socially acceptable manner, thereby removing all relevancy and effectiveness of problem behavior and fundamentally reducing or eliminating problem behavior episodes (Carr et al., 2002). As evidenced through Carr and Durand's (1985) work on functional communication training, the educative component of PBS involves teaching individuals a specific set of replacement behaviors that are (a) socially acceptable, (b) produce the same effect (i.e., obtain desired items/activities or avoid aversive situations) as the problem behavior, and (c) are more efficient than the problem behavior (i.e., requires less time, effort, or repetitions; Carr & Durand, 1985). Focusing on the cultivation and development of replacement behaviors and behavior repertoires is an effective and efficient approach to decreasing challenging behaviors without the use of invasive or overly disruptive interventions (Horner et al., 1990).

Focus on Effective Environmental Design

An unexpected result of PBS development was a recognition that drew directly from ABA: problem behavior is less likely in effective environments. The goal of effective support was not just what to do around an individual in a situation. The goal became to make home, community, educational, or professional settings more behaviorally constructive. Too often clinicians were being asked to develop highly intensive interventions to control behavior that was occurring in a larger context that was inadvertently shaping occurrence of the behavior. PBS grew from an approach to deal with individuals who performed difficult behavior, to incorporate specific settings for larger features of home, school, work, and community settings.

In addition to ABA, PBS draws greatly from the interrelated fields of systems analysis, ecological psychology, environmental psychology, and community psychology. Conceptually, PBS parallels such ecological paradigms in numerous ways: (1) the technology deals with units of analysis larger than the individual and seeks to focus on systemic change; (2) ecological validity is paramount with typical intervention agents (i.e., parents, teachers, job coaches) supporting individuals in typical settings (i.e., home, community, school, workplace) for extended periods of time in all relevant venues; and (3) research is viewed as a collaborative process between researchers, practitioners, and stakeholders (Carr et al., 2002). Essentially, the aforementioned fields converge in PBS with the understanding that because individuals in community settings are interdependent, then significant change must exist in the larger social system and not only in the individual. Conceptually aligned with Bronfenbrenner's (1989) ecological systems theory, PBS technology focuses intervention on the problem context as well as the problem behavior.

A defining characteristic of PBS is that intervention efforts should be focused on fixing deficient environments (i.e., problem contexts), not problem behavior. Durable behavior change requires more than the application of distinct techniques to particular challenges (Carr et al., 2002). An uncooperative or disorganized context will defeat the best technologies and methods every time.

Designing effective environments is synonymous with effortful systems change. Within PBS, it is essential to understand that problem behavior remediation is the outcome of the remediation of deficient contexts. It is worth noting that there are two types of deficiencies: environmental deficiencies and behavior repertoire deficiencies. The latter is detailed in the previous section. Carr et al. (1999a) noted that deficient environments exist to the degree that lack of choice, inadequate instructional methods, limited access to activities, and unsatisfactory daily routines are present, in addition to a host of other proximal and distal stimuli.

Historically, behavioral theory has incorporated manipulation of ecological and setting events into support methodologies. Drawing from ABA, behavior management has traditionally involved manipulating the variables that reliably predict and maintain problem behavior. Horner and Carr (1997) noted that environmental events such as antecedents (i.e., the cues that trigger the target behavior), consequences (i.e., the events immediately following the targeted behavior), and setting events (i.e., the broad context that influences the likelihood that a specific cue will trigger the target behavior; Bijou & Baer, 1978) are all manipulable.

It follows logically that by analyzing antecedents and setting events, one can reliably predict when behavior is most and least likely (Bijou & Baer, 1961; Thompson & Grabowski, 1972; Carr, 1977). The increased use of functional behavioral assessment within PBS allows for practitioners to modify antecedent events so that items or events in a setting which trigger target behaviors are reduced or removed (Touchette, MacDonald, & Langer, 1985) while simultaneously adding items or events that are likely to prompt the use of the replacement behavior (Horner & Albin, 1988; O'Neill et al., 1997).

For a prosocial, appropriate, functional behavior to thrive, there must be a supportive host environment. By manipulating independent variables such as altering environmental conditions (i.e., antecedents, setting events), there is greater promise for practitioners and stakeholders to see positive, durable behavior change. PBS technology is more than the selection of an intervention. It is representative of behavioral support with a greater focus on comprehensive supports that include teaching of replacement behaviors that make the problem behavior inefficient, manipulation of consequences to ensure appropriate behaviors are more satisfying, and design of effective environments to make problem behaviors irrelevant (Carr et al., 1999a, 1999b).

Accountability

Similar to ABA, PBS is an empirical approach that relies on valid and reliable data to support its practices. Due in large part to its roots in behavior analysis, PBS has always advocated for high accountability. This advocacy is most evident in that PBS technology includes the collection and use of publicly interpretable data as part of individual application (Dunlap et al., 2008).

This attention to accountability is evident in the collection of functional assessment data. Data collected on (a) the context and triggers that covary with a problem behavior, (b) the intensity duration and form of the problem behavior, and (c) the events that follow (and presumably maintain) the problem behavior is extremely valuable. This data allows for the development of hypotheses about when, where, and why the problem behavior occurs, hypotheses that can be used to devise effective and efficient interventions (Horner & Carr, 1997).

Accountability is also exhibited in evaluation systems. Evaluation systems include collection, reporting, and use of data for decision making. Sugai et al. (2010) noted that evaluation systems are a critical component of behavior support. Within the PBS technology, various data sources (i.e., frequency of problem behavior, frequency of replacement behavior) are collected through a range of methods (i.e., archival review, interview, direct observation) and involve multiple stakeholders (i.e., supported individual, family, educators, community members). The data collected are analyzed to determine not only the individual's current level of functioning but also to identify the impact of the intervention on the target behavior as well as improvements in the individual's quality of life. Effective evaluation systems include regular structures for stakeholders to meet, make decisions based upon data, and prioritize implementation items (i.e., action plan; Todd et al., 2011). The incorporation of an evaluation system and regular data collection allows for implementers to make timely programmatic decisions based upon data and adjust support plans accordingly (Sugai et al., 1999).

In addition to documentation of support plan effectiveness, an evaluation system is the more recent and evolving theme of accountability as seen through fidelity of implementation (Newton, Horner, Algozzine, Todd, & Algozzine, 2009). While evaluation systems provide documentation of whether a support plan has been effective, comprehensive evaluation systems allow for assessment of both plan effectiveness (i.e., individual outcomes, progress toward goals) as well as assessment of fidelity of implementation. Conceptualized as the extent to which implementers actualize support plans as designed, fidelity of implementation is an essential element of PBS technology because of its utility in predicting the degree to which an intervention will be successful (Domitrovich et al., 2008; Gresham, 1989). PBS implementers should incorporate fidelity of implementation data as a measure of accountability for the enhancement of supports provided. Advances in computer technology are making assessment of implementation fidelity more feasible and universally possible.

Safety

PBS is a practical technology with intended use by typical intervention agents in typical settings. Be that as it may, there will always be occurrences of problem behavior. Any ethical and practical approach to support should plan for the occurrence of behavior that has been performed in the past. This results in clearly defined plans to protect the safety of all involved. The caveat is that safety procedures are not the plan but are part of the plan.

There is an expressed need in PBS to distinguish emergency procedures from proactive programming. Any effective behavior support technology for individuals with severe problem behavior must include specific response strategies for relevant stakeholders (i.e., practitioners, family). Problem behaviors such as self-injury, aggression, property destruction, defiance, tantrums, and disruption are highly prevalent among children and adults with a variety of developmental disorders (Durand, 2015), and many of these behaviors pose severe social or physical risk to the individual with the disability as well as others within proximity. A support plan which details avoidance or ignoring of undesirable behaviors is insufficient and unethical.

As important as it is to identify specific response strategies, it is equally important to understand that there will be instances where the preferred, most appropriate response is to control the situation as opposed to using an intervention strategy. In dangerous situations, the objective is to provide adequate control in the moment to ensure the safety of the individual and those in close proximity (Horner et al., 1990). Effective use of the PBS technology incorporates detailed procedures for providing support in emergency situations where the supported individual's crisis poses danger to self and others.

Nonetheless, it is imperative that the difference between crisis intervention strategies for infrequent use in emergency situations and ongoing proactive programming designed to produce substantive positive change is unambiguous and explicit. It is crucial that crisis intervention procedures not be allowed to evolve into ongoing restraint or be substituted for effective programming (Horner et al., 1990).

Current Role of PBS

PBS is a multifaceted approach that builds from functional behavioral assessment of problem behavior and generates a support plan that is both comprehensive and educative. The PBS process is characterized by an iterative, data-based process as opposed to a fixed, invariable intervention or program. Within a comparatively brief time span, PBS has amassed a compelling database demonstrating the validity of function-based assessment and comprehensive intervention.

Numerous studies have established that comprehensive, multicomponent PBS interventions are linked to reductions in problem behavior and increases in replacement behaviors. Several analyses have included individuals with developmental disabilities who have a recorded history of challenging behavior, and a number of these studies have demonstrated positive, sustained, protracted outcomes (e.g., Carr et al., 1999a, 1999b). A case in point is the Feldman, Condillac, Tough, Hunt, and Griffiths (2002) study of multicomponent, assessment-based PBS implemented with 20 participants with developmental disabilities and challenging behaviors (i.e., self-injury, aggression, property destruction).

The Feldman et al. (2002) study was designed to include a diverse set of participants whose life experiences were compromised as a result of serious and chronic behavior problems. The multiyear study included participants ranging in age from 3 to 39 years with various diagnostic characteristics and living in geographically diverse regions of Canada. The study involved collection of baseline data, initial assessment, and implementation of PBS, plus continual support. Prior to PBS implementation, researchers established support teams for each participant comprised of relevant stakeholders (i.e., family, friends, caregiver, employer, educator, participant). Support teams then engaged in the process of person-centered planning (consensus of person's strengths, needs, short- and long-term goals; Kincaid & Fox, 2002) and researchers conducted a functional behavioral assessment (FBA) of the participant's problem behaviors. Resulting FBA data allowed for target behavior to be operationally defined and for the identification of (a) the function of each target behavior, (b) antecedent and setting variables that control each behavior, and (c) appropriate replacement behaviors.

Support teams utilized resulting FBA data to design specific PBS plans for each targeted behavior and relevant setting. PBS plans included explicit instructions replete with definitions of target behaviors as well as precise procedural descriptions for (a) developing replacement behaviors, (b) appropriately reinforcing displays of replacement behaviors, (c) redesigning the antecedent environment to prevent occurrences of problem behavior, (d) appropriately responding to displays of problem behavior, and (e) collecting evaluation data to plan effectiveness and implementation fidelity. The intention of the study was to demonstrate PBS implementation by natural intervention agents; thus researchers never served as primary interventionists in any setting.

Data from the study were indicative, relative to baseline, of decreases in problem behavior, increases in replacement behaviors, improvements to quality of life (QOL) for the vast majority of participants, and up to 3 years post-intervention maintenance. Moreover, data demonstrated that natural intervention agents implemented PBS plans with fidelity. The Feldman et al. (2002) study highlighted that the application of comprehensive PBS, consisting of multicomponent interventions delivered by natural intervention agents across all relevant settings and for long durations to time, is associated with reliable decreases in problem behavior as well as enhancements in QOL.

In another study, Carr et al. (1999b) utilized a comprehensive PBS approach to deal with the problem behaviors of three group-home residents. The experimental, multiple-baseline study included detailed FBAs, verification of hypotheses, and the implementation of a five-component intervention package consisting of building rapport, providing functional communication training, building tolerance for delay of reinforcement, providing choices, and embedding problem behavior stimuli among replacement behavior stimuli (also referred to as behavioral momentum). Results of the study established beneficial outcomes for task engagement and problem behavior and demonstrated maintenance up to 2.5 years. Moreover, the authors illustrated the dynamic qualities of PBS in the needed follow-up assessments and intervention plan modifications as a result of changes in life situations (i.e., residential status, employment status, recreational opportunities) and the passing of time. One significant aspect of the study is the authors' discussion of how dealing with problem behavior across settings, intervention agents, and tasks can beneficially impact a person's quality of life, enabling access to an increased amount of community activities.

There is evidentiary support that a complete and detailed application of essential PBS elements results in valuable quality of life enhancements for individuals with developmental disabilities (Carr et al., 2002; Dunlap & Carr, 2007). As such, PBS is increasingly expected to be the standard for behavior support within the area of developmental disabilities and is also being extended to many other disciplines (i.e., emotional behavioral disorders, mental health, etc.).

While PBS continues to be expanded to other disciplines and use of the framework's components grows, the units of analysis and focus continue to increase in scope. As such, it is worth discussing PBS as it relates to employment, family support, early-intervention systems, and schoolwide systems.

Employment

Contemporary conversations regarding PBS for adults with developmental disabilities are incomplete without examining the relationship between employment and quality of life (QOL). Dunlap et al. (2010) identified and defined, with specificity, six domains of QOL including material well-being, health and safety, social well-being and interpersonal confidence, emotional/affective well-being, leisure and recreation, and personal well-being. An individual's employment status has the potential to impact QOL domains in a myriad of ways.

Employment increases opportunities for a person to have a social network. Relevant to the QOL domain of social well-being and interpersonal confidence, an employed person has more opportunities for social interaction, thus enhancing capability for engaging in social relationships. The social interactions and social networks that result from employment allow for individuals with developmental disabilities to develop and enhance skills for communication, social interplay, and behavioral adaptation in social contexts. Social networks allow an individual to feel a sense of belonging and to be a part of the workplace culture and community life (Dunlap et al., 2010; Mank, 2007). The alternative to social networks is a diminished potential for friendship and connectedness, along with an increased probability of isolation.

A result of employment is the accumulation of discretionary income. For all persons, with or without developmental disabilities, meaningful choices and improved quality of life are more achievable with discretionary income. More often than not, discretionary income is the result of employment. Discretionary income is relevant to the QOL domain of material well-being. The domain is concerned with access to preferred materials or activities that may enhance a person's pleasure or functional abilities (Dunlap et al., 2010). A person's discretionary income allows them to access the tangible items they value. Additionally, discretionary income enhances a person's access to leisure activities (i.e., hobbies, games, reading) and recreational activities (i.e., sports, travel, arts, and entertainment) that are found to be pleasurable and directly related to the QOL domain of leisure and recreation. As well, a noteworthy association is that of employment and the QOL domain of personal well-being. Employment provides the opportunity to become more self-sufficient, self-determined, and independent. For all persons, employment and the resulting income allow for choice—choice in relationships, belongings, activities, and life decisions.

Research and implementation strategies indicate that individuals with disabilities can be successful in the workplace with appropriate and individualized supports (Mank, 2007). However, gainful employment and the choices of everyday life are often limited. From the early 1980s to the early 2000s, the number of people with developmental disabilities employed in community settings grew from a few thousand to 150,000 (Wehman, Revell, & Brooke, 2003). Still, despite the increase over the years, fewer than 30 % of people with developmental disabilities are employed in community settings and even fewer are working full time. There is a reality of unemployment and underemployment that stands in contrast with the capabilities of people with developmental disabilities and the PBS supports known to be effective.

During the 1990s, research studies demonstrated the effectiveness of natural supports in the workplace for people with developmental disabilities. Studies indicated the capacity for coworkers and supervisors to serve as natural, everyday supports. Other studies identified leadership qualities relative to employers hiring people with developmental disabilities. Taken together, the studies substantiate that barriers to employment are expected to be the result of funding and systems, as opposed to an individual's assumed inability (Mank, 2007).

Other studies of the era exemplified that the training and assistance provided to coworkers and the attention given to placing individuals in jobs that align with their interests, skills, and talents were positively related to a person with disabilities' opportunities to earn higher wages and be more fully integrated within the workplace's social culture (Fillary & Pernice, 2006; Jordan de Urries, Verdugo, Jenaro, Crespo, & Caballo, 2005; Mank, Cioffi, & Yovanoff, 1998, 2000; Nisbet & Callahan, 1987; Storey, 2002). The evolving research on people with developmental disabilities in the workplace continues to show that people with developmental disabilities, regardless of severity, can be productive both independently and collaboratively, be supported in the work environment, earn a significant wage, and be integrated into the environment's social network (Mank, 2007).

Families

For many individuals with developmental disabilities, the most reliable source of support throughout life is the family unit (Kim & Morningstar, 2005). Family support begins at an early age and can profoundly impact a child's development trajectory. The younger a child, the less access they have to the level of social networks adults do. The family unit assumes a greater distinction and importance when children experience disabilities or display problem behaviors that limit the variety and depth of social activities and interactions (Dunlap & Fox, 2009).

Developmental disabilities and challenging behaviors can have a negative impact on the QOL for persons with developmental disabilities and their families. In that regard, research demonstrates that support of the family is very significant when supporting individuals with histories of challenging behaviors (Dunlap & Fox, 2009). Within the PBS framework, the concept of family support aims to involve and empower families by building on family strengths, acquiring and developing new skill repertoires needed to support the child's development, and improving the family's unity and quality of life (Lucyshyn, Dunlap, & Albin, 2002).

Family-centered PBS refers to the application of PBS within the family environment through the partnering of the family with support professionals. In this approach, the family collaborates with professionals on the design and implementation of PBS plans. As well, this approach positions the family as the primary beneficiary and decision maker. This views both the support professional and the family as expert. The support professional is the expert on PBS and technical assistance. The family is the expert on the person being supported, the person's behavior history, the family unit, and all relevant implementation contexts (Dunlap & Fox, 2009).

Recent years have seen significant developments and refinements to the family-centered PBS approach. Research completed with families of children with autism (Dunlap & Fox, 1999) as well as families with young persons with challenging behavior regardless of disability (Fox, Dunlap, & Powell, 2002) has helped to elucidate a process designed to focus on the family as principal intervention agent with the support of professionals well versed in strategies of assessment and intervention such as child development and early-intervention as well as family systems and dynamics.

Complementary to most PBS models, Dunlap and Fox (2009) detailed a family-centered PBS approach that incorporates a five-component intervention package. The approach begins with the establishment of a support team comprised of the support professional(s) and the family. Trust and vulnerability are integral to this process because a close and harmonious relationship between team members is necessary for success and for the identification of supported person's strengths and needs as well as short- and long-term goals (i.e., person-centered planning).

Once both teams and goals are established, support professionals complete a functional behavioral assessment (FBA) of the supported person's problem behaviors. FBA data allows the team to operationally define the targeted problem behaviors and identify (a) the function of each target behavior from the supported person's perspective and (b) antecedent and setting variables that increase and/or decrease the likelihood of the supported person demonstrating the problem behavior. Support teams then utilize information gathered in the FBA to create PBS plans tailored to the individual. Plans are comprehensive in scope including strategies and techniques focused on prevention of the problem behavior, procedures for teaching replacement behaviors aligned with the function of behavior, and methods for reinforcing desired behavior as well as appropriately responding to problem behavior.

Following plan design, families begin implementation. Families serve as chief interventionists and must live with a plan's procedures and outcomes. As a matter of practice, support professionals never serve as interventionists except when modeling strategies and techniques. Support professionals provide ongoing coaching and support to families so that they may effectively use procedures indicated in the PBS plan. As with all PBS plans, data-based decision making is integrated. Data collected in regard to the supported person's performance (i.e., outcomes) and implementation fidelity are used to evaluate plan effectiveness and to determine any necessary refinements and modifications.

Early Intervention

For families of infants and toddlers with developmental disabilities, prominence is placed on increasing and reinforcing parents' capacity to nurture their children's development. In order to achieve the greatest developmental outcomes possible for infants and toddlers with disabilities, it is imperative to intervene early and provide supplemental experiences to positively influence the early development of the child. As a concept, early intervention is characterized by families and primary caregivers of infants and toddlers with developmental disabilities providing supplemental experiences for the purpose of fostering the development of the child's prosocial behavioral skills (Dunst, 2007).

Within early intervention, four classes of practices exemplify methods which positively influence the learning and development of infants and toddlers with developmental disabilities: (1) response-contingent learning, (2) parent responsiveness to child behavior, (3) everyday natural learning opportunities, and (4) capacity-building help-giving practices (Dunst, 2000).

Response-contingent learning refers to a child's behavior increasing in frequency or strength as a result of having recognized the relationship between what they do and what happens in response (Hulsebus, 1973; Watson, 1966). Whether manufactured or occurring naturally, response-contingent learning opportunities provide the occasion for parents and caregivers to positively reinforce child behavior. Lancioni (1980) detailed that children with disabilities are capable of identifying the relationship between their behavior and the resulting outcomes and that learning opportunities which foster these realizations serve as effective intervention practices. Response-contingent learning promotes the development of child's skill repertoires for achieving desired outcomes.

Directly related to response-contingent learning is the class of practices known as parent responsiveness. Parent responsiveness serves as a contingency to child behavior and is connected to enhanced child development. When interacting with their child, a parent or caregiver's sensitivity and responsiveness to the child's behavior has profound implications on the child's development (Shonkoff & Phillips, 2000). As such, coaching and supporting parents to use a responsive instructional approach with their children is recognized as an early-intervention practice and has been so for more than 25 years (Affleck, McGrade, McQueeney, & Allen, 1982); Marfo, 1988). Kassow and Dunst (2004) noted that a parent's awareness and mindfulness of the communicative intent of a child's behavior as well as their timeliness and appropriateness of response to behavior positively impacts subsequent behavior. Parent responsiveness fosters a supportive, dependable, nurturing relationship between parent and child of which an outcome is environmental conditions optimal for learning.

The class of natural learning opportunities demonstrates a powerful context for child growth and development and, when taken advantage of, has been shown to positively impact the development of children with disabilities as well as the abilities of parents and caregivers. Routine, customary activities and experiences provide natural learning environments for children with disabilities and their families to develop prosocial behavior and relevant skill repertoires necessary for social well-being (Dunst, Hamby, Trivette, Raab, & Bruder, 2000). However, infants and toddlers with disabilities are typically afforded fewer opportunities to participate in everyday activities and benefit from the resulting natural learning opportunities in comparison to their typically developing counterparts (Dunst, 2007). This discrepancy is lesser related to their specific disabilities and is more related to parental value and appreciation of natural learning opportunities in everyday contexts (Trivette, Dunst, & Hamby, 2004). Studies indicate that parental use of natural learning opportunities results in positive outcomes for parent and child well-being, parent self-efficacy, and parental competence while early-intervention practitioner use of natural learning opportunities had no such effect (Dunst, Bruder, Trivette, & Hamby, 2006; Dunst, Trivette, Hamby, & Bruder, 2006).

Capacity-giving help-giving practices constitute the fourth class of evidence-based, early-intervention practices. Parental appreciation of their own parenting abilities is viewed as determining factor in the types of learning opportunities their children are afforded (Dunst, Trivette, & Hamby, 2006). Capacity-giving help-giving practices serve to increase parent competence and confidence in carrying out their role and responsibilities and increase enjoyment in interacting with their child. Practices involving active listening and empathy, which promote parent decision making and action and which foster collaboration between parent and practitioner, all serve to support parents. Practitioners who employ capacity-giving help-giving practices with families encourage and support parental involvement so as to provide parents with ability to effectively provide their child with beneficial learning opportunities (Dunst, 2007).

As noted in the aforementioned evidence-based practices, early-intervention positions the family as primary interventionist and views parental support and capacity as a determining factor of a child's social–emotional growth and well-being. In that regard, Dunst (2007) outlined three fundamental assumptions which shape the framework of early intervention. First and foremost, it is accepted that the supplemental experiences provided to infants and toddlers with disabilities are designed to promote the child's self-directed learning. The target is the child acquiring prosocial behavior skill repertoires and appropriately using the skills to yield desired outcomes.

As well, since early intervention is comprised of parent-mediated child learning, the second assumption is that early-intervention efforts are effective only to the extent that they increase parental ability and confidence to offer experiences that enhance learning and development. As in most fields, the likelihood for implementation increases when implementers understand the value of their role. When parents and caregivers of infants and toddlers with disabilities identify their importance in determining their child's growth and development, the probability of appropriate supplemental experiences being offered increases.

The third assumption is that early-intervention practitioners serve to support parents and caregivers so that they may, in turn, support the child. Early-intervention practitioners have two main goals: (1) expand parental capacity to acquire skills necessary for child development and (2) refine and strengthen the use of skills parents already possess. As a matter of practice, direct intervention with a child occurs only to model for parents the use of evidence-based practices and strategies. As a result of the coaching and support early-intervention practitioners provide, parents and caregivers are better poised to offer the supplemental experiences necessary.

In addition to the applications of PBS previously described with individual persons, PBS continues to be expanded to larger systems and units of analysis. One such expansion is early intervention in the area of child-care and early childhood education settings.

There is an increased awareness of the problem behaviors displayed by young children as a result of the disconcerting pervasiveness of such behaviors revealed in contemporary research. Studies approximate that 10–15 % of young children demonstrate significant problem behavior (i.e., prolonged tantrums, physical and verbal aggression, propter destruction, noncompliance, etc.) and that equivalent proportions of children entering kindergarten display such behaviors (Campbell, 1995; West, Denton, & Germino-Hausken, 2000). Other studies, using broader identification criteria, indicated that up to 20 % of preschool children have a quantifiable social–emotional disorder. Prevalence figures are considered to be associated and increased with risk factors such as prenatal exposure to toxic substances, exposure to violence, poverty, and developmental disabilities (Dunlap & Fox, 2009). In addition to prevalence rates is the understanding that problem behaviors do not simply disappear. In many cases, they pose harmful influence to child development and social–emotional growth for years to come (Arnold et al., 1999).

With this heightened awareness of young children's challenging behavior comes a public sense of duty for an enhanced programmatic approach to the social–emotional learning and development of young children and for concentrated endeavors to prevent the development of problem behaviors as well as intervene with present challenging behaviors (US Public Health Service, 2000).

Positive behavior support as it relates to early intervention and early childhood education settings is best viewed through the lens of prevention. Applications of PBS involving larger populations and units of analysis generally involve a multi-tiered model of prevention akin to the public health tiered model comprised of three tiers of populations. The universal tier relates to all members of a population who may possibly contract the problem (i.e., problem behavior) and involves primary prevention strategies focused on reducing the probability of problem occurrences. The second tier is comprised of groups of the population who are considered to be at risk for contracting the problem and incorporates frequent secondary prevention strategies of greater intensity. The third tier is comprised of those members of the population who have already contracted the problem and are in need of intensive, individualized supports (Sugai et al., 1999; Walker et al., 1996). The tiered model of prevention provides an organized system of prevention and intervention matched to level of need.

Fox, Dunlap, Hemmeter, Joseph, and Strain (2003) described the application of a tiered prevention model for early childhood education that aligns with the tiered model derived from public health. The teaching pyramid consists of four levels and represents a continuum of supports and services provided to enhance the social–emotional learning and growth of young children and prevent problem behaviors. The first two levels of the pyramid incorporate primary/universal strategies appropriate for all children. The primary/universal levels of the pyramid pertain to the quality of relationships established between child and parents, educators, and child-care professionals. As well, the primary/universal level focuses on adult–child interactions, guidance, modeling of empathy, assistance with problem solving, and establishment of predictable and stimulating environments.

The third level of the teaching pyramid matches secondary prevention and intervention practices to children who have life experiences and risk factors recognized as increasing the likelihood of social–emotional disorders and enhancing the development of problem behaviors. The top level of the teaching pyramid relates to the small number of children who presently demonstrate patterns of chronic problem behavior and who necessitate intensive, individualized intervention efforts.

Application of PBS in early childhood education settings typically involves the five-component intervention package previously described: (1) teaming and goal setting, (2) functional behavioral assessment, (3) construction of a behavior support plan based upon data assessment data, (4) implementation, and (5) evaluation and refinement. The literature base chronicling empirical support of PBS in early childhood settings is rapidly increasing. A study by Gettinger and Stoiber (2006) compared classrooms implementing PBS through school-based teams to classrooms not implementing PBS. Those classrooms implementing a PBS process comprised of functional assessments and collaboration between expert and educator, and evidence-based interventions demonstrated higher-quality outcomes when compared to the non-implementing classrooms in regard to frequencies of appropriate and problem behaviors. The study also concluded that children's behavioral improvements were positively correlated with the level of fidelity for PBS implementation.

Schoolwide Positive Behavior Interventions and Supports (SWPBIS)

PBS originated as an intervention for persons with developmental disabilities and challenging behavior. Over time, the essential elements of PBS such as its focus on behavior-based education, environmental redesign, and accountability have expanded to larger units of analysis in more comprehensive and preventive models. School/facility systems are the most recent recipients of the PBS technology.

In today's society, schools and educational facilities have the principal goals of increasing the academic achievement and social–emotional learning of all learners. In order to realize these goals, it is necessary for schools/facilities to focus on the abilities of individual students. However, in order to maximize the potential of all students, it is imperative to adopt a systems perspective. Focusing on the overall culture of a school is vital for establishing an environment conducive to achieving school/facilities' societal goals (Sugai & Horner, 2009).

Schoolwide Positive Behavior Interventions and Supports (SWPBIS) is a framework that has developed in recent years as an alternative to punitive and exclusionary forms of schoolwide discipline (Solomon et al., 2012). SWPBIS uses a systems approach focused on the creation of safe, effective, predictable learning environments for all students through the establishment of a positive social culture and necessary individualized behavior supports (Sugai & Horner, 2009). Use of SWPBIS is growing widely within the USA with more than 30 states reporting the creation of statewide SWPBIS leadership teams and almost 8000 schools reporting adoption (Spaulding, Horner, May, & Vincent, 2008). As well, SWPBIS has been adopted internationally and is widely used in Canada, Norway, Denmark, the Netherlands, Australia, and New Zealand.

Similar to PBS technology for individuals with disabilities that seeks to positively enhance behavioral skill repertoires, SWPBIS aims to create systems that prevent undesirable, problem behaviors while promoting positive, prosocial behaviors. Unlike other efforts aimed at school-/facility-wide reform, SWPBIS is not a packaged curriculum or scripted intervention. SWPBIS is a framework that incorporates evidence-based practices from PBS, practices of universal behavioral prevention, and an educative emphasis on positive, prosocial behaviors (Horner et al., 1990, 2009; Sugai et al., 1999; Walker et al., 1996). SWPBS facilitates the adoption, implementation, and use of evidence-based practices regarding behavior, classroom management, and schoolwide discipline systems.

SWPBIS was designed to strengthen and reinforce teaching and learning environments of the school as well as provide for the social behavior development of all students. Despite the fact that application of SWPBIS varies by school and context, each application is based upon five essential elements. First and foremost is the inclusion of behavioral theory and behavior analysis. This behavior-based foundation accentuation underscores a person's observable behavior as being indicative of what he has learned and/or how he has been conditioned to conduct himself. As well, SWPBIS accepts that behavior is learned and influenced by environmental factors, thus making it possible to identify when behavior is likely to occur and what alternative behaviors can be taught (Sugai & Horner, 2009).

Second, SWPBIS focuses on prevention. It is this element that is both a hallmark of the approach and a noteworthy distinguisher from PBS technology for individuals. Within SWPBIS, prevention is operationalized through the establishment of a continuum of behavior support and intervention designed to prevent the development of new problem behaviors, the triggering of current problem behavior, or the worsening of existing problem behavior (Sugai & Horner, 2009). To efficiently organize a continuum of support and intervention for a large population such as a school, SWPBIS borrows the three-tier prevention logic from community health and disease prevention in which the primary tier provides universal behavioral support for all students across all settings, the secondary tier provides more intensive behavioral support for students whose behaviors were unresponsive to primary-tier supports, and the tertiary tier provides intensive, individualized supports for students whose behaviors were unresponsive to primary- or secondary-tier supports (Kutash, Duchnowski, & Lynn, 2006; Walker et al., 1996).

Third, SWPBIS is educative and includes both instruction and intervention to enhance students' behavior skill repertoires. At the universal primary-tier level, a small number (3–5) of positively stated core expectations are selected for the entire school. These expectations (i.e., be safe, be respectful, be responsible) serve as explicit, simple, and consistent rules for student behavior. School staff explicitly define each expectation in regard to target behaviors for various school settings (i.e., cafeteria, playground, hallways, classroom). Defined expectations are then taught in the applicable context/environment to students at the beginning of the school year and reviewed at key times throughout the year (Solomon et al., 2012). Education of schoolwide expectations creates a common language for all students, staff, and families. At the secondary tier, instruction is focused on establishing fluency of prosocial behavior skills by incorporating specific, targeted social skill-learning opportunities on a more frequent basis. At the tertiary tier, instruction is intensified and individualized integrating information about antecedent factors that elicit problem behavior, consequences that maintain problem behavior, and function of behavior. This information is utilized to create an individualized behavior support plan focusing on the instruction of more efficient, effective, relevant replacement behaviors (Horner, 1994).

Fourth, evidence-based interventions are part of the SWPBIS infrastructure to increase effectiveness of behavior education and generalization of learned skills. High priority is given to the selection, adoption, and use of evidence-based practices for (a) acknowledging and reinforcing appropriate behavior and (b) establishing consequences for problem behavior (Alberto & Troutman, 2006).

Fifth, a defining feature of SWPBIS is its systems orientation focused on using existing school resources and structures for instilling the SWPBIS approach within the culture and practices of the school (Solomon et al., 2012; Sugai & Horner, 2009). The SWPBIS perspective emphasizes establishing local capacity and expertise for effective and sustained implementation. Majority agreements and commitments among staff and faculty create a common mission and collegial accountability. As well, high standards for implementation readiness, implementation fidelity, and the continuous evaluation of implementation and outcomes contribute to systemic quality improvement (Sugai et al., 2010).

Finally, a hallmark of SWPBIS is the collection and use of data for active decision making (Horner, Sugai, & Todd, 2001). Office discipline referrals (ODRs), suspensions/expulsions, and other records of student behavior problems are considered outcome measures that can be collected, summarized, and used by a SWPBIS leadership team for formative intervention planning (i.e., increase active supervision in the cafeteria, reteach expected hallway behavior). The Schoolwide Information System (SWIS) is a web-based application commonly used by schools to both collect behavior data and summarize it in detail by student, grade level, time of day, location, and problem behavior. Facilities using the SWIS application are also presented the opportunity to analyze data based upon preferred filters (antecedent factors) to identify behavior motivation or function of behavior (May et al., 2015). In addition, SWPBIS emphasizes the collection, summarization, and analysis of implementation data to identify the extent to which elements and practices are being implemented with fidelity. Together, implementation and outcome data are used by administrators, faculty, and school-based teams to improve the SWPBIS continuum of behavior supports and services (Sugai & Horner, 2009).

As previously stated, SWPBIS serves to strengthen and reinforce teaching and learning environments of the school for optimal academic outcomes as well as provide for the social behavior development of all students through the establishment of a positive school culture. Generally, SWPBIS practices are organized within the aforementioned three-tier model of prevention and support. Each tier has distinctive practices and interventions that characterize SWPBIS.

At universal, primary-tier SWPBIS, interventions are not single, isolated strategies or practices, but rather they are compilations and sets of interventions that enhance the development of a comprehensive and positive social culture for all students, staff, and community members in all areas of the school (Colvin, Kameenui, & Sugai, 1993). SWPBIS interventions are intended to be contextually and culturally relevant. That is, they are created with the needs and characteristics of the school culture in mind for the purposes of successfully influencing and supporting students (Walker et al., 1996).

Commonly, primary-tier SWPBIS embodies six critical characteristics. First, majority agreements among staff and faculty are made to create a common method of discipline that is positive, comprehensive, formal, and continuous. As well, staff and faculty are committed to the use of evidence-based practices for behavior instruction that are both contextually and culturally relevant (Sugai & Horner, 2009). Second, relevant stakeholders of the school (i.e., students, staff, community members) select a small set of positively stated schoolwide expectations that are applicable to all students and staff across all settings and that promote academic and behavioral success (i.e., safe, respectful, responsible or achievement, respect, responsibility). Third, the selected schoolwide expectations are operationally defined in terms of appropriate, expected behaviors and are directly taught to students in a manner akin to academic instruction (i.e., define, model, practice, provide corrective/reinforcing feedback, encourage use for skill fluency). Typically, schools establish a teaching matrix that specifies the appropriate behavior for a location relative to the schooled expectation (Sugai & Horner, 2009).

The fourth characteristic essential to primary-tier SWPBIS is the provision of frequent positive feedback or acknowledgment for displays of expected behavior. It is imperative that students receive such feedback regularly in order for the newly taught behavioral expectations and acquired skills to be strengthened and maintained over time. Fifth, common, formal procedures for responding to problem behavior are necessary for effective error correction. When problem behavior is displayed, a continuum of consequences for responding to rule violations serves to inform and teach distinctions of behaviors that do not meet the schoolwide expectations. Finally, the systems that support SWPBIS practices are supported by ongoing data collection to evaluate the extent to which practices are being implemented with fidelity and the impact implementation is having on student outcomes. In order for SWPBIS to have a positive impact, leadership teams must have access to accurate information, when needed, in an interpretable format for easy data analysis. SWPBIS promotes structures that facilitate data collection routines as well as data analysis routines and procedures (Sugai & Horner, 2009).

As students demonstrate behavior that indicates nonresponsiveness to primary-tier interventions, secondary-tier supports are accessed. Interventions at this tier are aligned with the schoolwide systems established in the previous tier, and efforts are made to integrate secondary supports within the universal system. At the secondary tier, implementation is guided by an intervention team who coordinate the logistics, provision, and implementation of secondary-tier interventions. The intervention team is responsible for regularly identifying student candidates for secondary-tier supports based upon screening data or other data decision rules (i.e., quantity of office referrals). The secondary-tier interventions and supports that students receive are aligned with the schoolwide, universal system of positive expectations and feedback/acknowledgment systems.

However, the social skill instruction received at this tier is more targeted and based upon the behavior skill deficits demonstrated by the student. This targeted skill instruction incorporates frequent evaluations (i.e., daily, hourly, etc.) of student behavior in relation to a goal for the purpose of providing higher rates of feedback and positive reinforcement to help the student build fluency with positive behavior skills. Additionally, data-based decisions are made on a regular basis to make programmatic modifications for individual students. Such modifications include changing a student's percentage used to indicate success, adjusting the frequency of behavior evaluation, or modifying the reinforcement system to enhance sustainment (Sugai & Horner, 2009). As well, a programmatic adjustment may be transitioning a student to the tertiary tier for more intensive, individualized support.

As student behavior demonstrates unresponsiveness to primary- and secondary-tier interventions implemented with fidelity, it is necessary to consider tertiary-tier supports that are more specialized. Because supports at this tier are more individualized to the student and the specific context of problem behavior(s), tertiary-tier systems are less connected to the schoolwide, universal system.

Definitive characteristics of tertiary-tier interventions are that they are function based and team driven (Crone & Horner, 2003; O'Neill et al., 1997). As a student is identified as an appropriate candidate for tertiary-tier supports, an FBA is conducted to identify the antecedent events that elicit problem behavior, the consequences and environmental outcomes of the problem behavior, and the function/purpose of the problem behavior. A uniquely constructed student support team comprised of relevant stakeholders (i.e., teacher, administrator, family, behavior support specialist) uses the information resulting from the FBA to design an individualized behavior intervention plan comparable to those previously described in applications of the PBS technology for individuals (Sugai & Horner, 2009).

In circumstances with the most severe behavior disorders, tertiary-tier supports provide for the inclusion of community-based supports such as mental health, juvenile justice, child and family welfare, etc. A comprehensive support plan is created accounting for collaboration and interaction among school staff and community resources/agencies to provide supports that are comprehensive and that wrap around the student and the family (Sugai & Horner, 2009).

Future of PBS

With ongoing advances in the conceptual and procedural elements of PBS, we can expect increased diversity in the array of implementation contexts. The field of PBS is witnessing the emergence of successful application in and with school systems (Sugai & Simonsen, 2012) and in school-based bully prevention (Ross & Horner, 2009), families (Binnendyk & Lucyshyn, 2009), early childhood (Fox, Carta, Strain, Dunlap, & Hemmeter, 2010), residential support, communities (Nelson, Jolivette, Leone, & Mathur, 2010), juvenile justice systems (Gagnon & Barber, 2010), and mental health (Bradshaw et al., 2012).

Advances over the next decades will require efforts to collaborate and integrate without losing focus on the core features that define PBS. Currently, PBS advocates and developers are collaborating across disciplines in the effort to improve the quality of life for young persons at risk for or experiencing emotional and behavioral challenges, as well as the quality of life for all youth. The fields of mental health, juvenile justice, and early intervention are working jointly, sharing unique knowledge and insight, to develop the interconnected systems framework (ISF) to effectively link school mental health (SMH) and positive behavioral interventions and supports (PBIS). In doing so, the strengths of each of the respective processes can be leveraged and result in enhanced teaching and learning environments.

It is worth noting that advancement, collaboration, and integration should not result in the loss of core features. To sustain PBS, it is necessary to emphasize the conceptual logic and core features that are related to behavior change. Sustained development and implementation depend upon PBS being conceptualized as a problem-solving framework that embodies research-based practices. In doing so, the essential elements and critical components of PBS continue to endure while individual practices, applications, populations, and contexts change. As we look to the future, the work is not to develop a new framework. Instead, it is about perfecting and improving the systems, data, and practices we currently used and doing so in alignment with the core features of PBS.

One such feature is the incorporation of environmental redesign to promote positive behavior. It is necessary to examine applications of PBS across individuals and settings to better understand future directions and potential. Applications of PBS across school, home, and community settings illustrate the ability to adapt to context. Future research directions include identifying the features of effective environments. For families and caregivers, how can the field help in the effort to avoid not just the development of self-injurious behavior but also the emergence of depression, defiance, and social withdrawal? For community mental health agencies, how can PBS aid in the promotion of mental health and well-being? As implementation is scaled up in schools and facilities, how can we create systems that simultaneously make more effective learning environments and create settings where bullying, harassment, and intimidation are not supported?

As the field continues expand, use of data will be essential. Data not only guides the clinical implementation but also guides the science. More than ever before, we now have the ability to provide policy makers, clinicians, advocates, and individuals with problem behavior with useful data. A danger is that we now have access to more data than we know how to use. We anticipate that improved data sources (e.g., school information systems) will need to be linked to better training on how to use data for effective decision making. Preliminary evidence suggests that, with a modest investment in training, school teams can become much more effective in using data to identify problems, build solutions, and achieve valued outcomes (Newton, Horner, Algozzine, Todd & Algozzine, 2012).

There remains much we do not know about human behavior and about how to both avoid the development of dangerous behavior and facilitate reduction when such behaviors are present. The need for research on basic principles of behavior remains paramount. PBS implementation has resulted in improved quality of life outcomes for many individuals. Despite improved quality of life being championed as the intended, principal outcome for many years (Carr et al., 2002), it continues to be a challenge. More information is needed profiling individuals with challenging behavior living quality lives based on their own interests, talents, and personalities. Such information serves to illustrate how the critical components of PBS can be successfully applied across lifestyles.

As PBS research and implementation grows, so does its status. The field of PBS has transitioned from being a type or variety of behavior management to becoming a widely accepted science applied across a broad spectrum of social systems. In light of such growth and expansion, it is important to stay mindful that public policy has direct implications for sustainability. Proposed federal legislation in the USA includes PBS by name and language specific to the field. As such proposals become law, we will enter into a new era in which PBS is no longer an evidence- and research-based concept but the de facto standard in social service systems such as public education.

Thus, it is imperative that leaders, lawmakers, those in power, and those responsible for states, cities, municipalities, schools, and facilities should be knowledgeable about PBS.

The field of PBS has an evidenced history and an unlimited future. It now represents more than a technology to change problem behavior. It is the technology for building quality of life throughout our society.

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Staff Training in Positive Behavior Support

16

Anne MacDonald

Introduction

Challenging behavior is prevalent in people with intellectual disabilities (Emerson et al., 2001) and has been demonstrated to have a number of negative effects on services, staff and service users (Allen, 2009), including abuse (Emerson, McGill, & Mansell, 1994), placement breakdown (Allen, 1989), and high staff turnover (Felce, Lowe, & Beswick, 1993). Positive Behavior Support (PBS) has been shown to be successful in addressing issues of challenging behavior and of achieving behavior change for individuals (Carr et al., 1999; La Vigna & Willis, 2012; Lucyshyn, Horner, Dunlap, Albin, & Ben, 2002). PBS is an approach that has gained widespread acceptance over the past 20 years as an effective and appropriate response to challenging behavior in individuals with intellectual disabilities (Carr et al., 1999; Koegel, Koegel, & Dunlap, 1996; La Vigna & Willis, 2012; Lucyshyn et al., 2002). It came to the fore in the 1980s and 1990s, and is widely regarded as emerging from the debate in this period about the use of aversive techniques. In this context, aversive techniques came to mean more than the technical behavioral meaning of aversive, but became synonymous with approaches that involved punishment, pain or extremely unpleasant events. PBS was also a reflection of the development of values-based approaches to supporting people with intellectual disabilities such as normalization and the inclusion movement (Allen, 2009; Dunlap & Carr, 2009). Their principles and values-base increased the momentum to publicize alternative behavior management approaches that did not use aversive techniques.

Some controversy remains about the definition of PBS and whether it is in fact a separate discipline from Applied Behavior Analysis (ABA). For example, Carr et al. (2002) defined it as “an applied science that uses educational and systems change methods to enhance quality of life and minimize problem behavior” (p. 4), and Horner, Sugai, Todd, and Lewis-Palmer (2000) as “an approach that blends values about the rights of people with disabilities with a practical science about how learning and behavior change occur” (p. 97). However, others have questioned this definition and queried whether PBS is indeed a science and, in particular, whether it is separate from ABA. Wacker and Berg (2002) stated, for example, “we are not sure that any definition of science could be used to categorize PBS as an applied science that is distinguishable from the scientific methods from which it is derived” (p. 25). Johnston, Foxx, Jacobson, Green, and Mulick (2006) concluded in their examination of PBS that “it is difficult to characterize PBS in ways that will not invite disagreement” (p. 69).

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Horner et al. (1990) published what is the first clear definition of PBS, although at that time they called it "non-aversive behavioral support." They emphasized nine main characteristics: an emphasis on lifestyle change; based on functional analysis; utilizes multi-element support; focuses on ecological changes; emphasizes antecedent control; teaches new skills; uses contingent and non-contingent reinforcement; minimizes use of aversive approaches; utilizes proactive and reactive approaches. Although this was the first time that an attempt had been made at a definition of PBS, earlier work had also referred to many of these nine characteristics (Carr, 1988; Emerson & McGill, 1989; La Vigna & Donnellan, 1986; La Vigna, Willis, & Donnellan, 1989).

At this point, many of these characteristics could also be said to be true of ABA. Aside from the emphasis on lifestyle changes and the clear statement about avoiding aversives and instead using socially valid approaches, ABA could be said to meet the remaining criteria in Horner et al.'s definition (J. Carr & Sidener, 2002; Johnston et al., 2006). However, throughout the 1990s, the differences between PBS and ABA became more clearly defined. For example, Anderson, Albin, Mesaros, Dunlap, and Morelli-Robbins's (1993) description of PBS training indicated that PBS was evolving. Their description of PBS included a move away from more specialist-led approaches and a movement towards approaches such as person-centered planning (Kincaid, 1996) which involved a range of stakeholders in the process of developing behavior support plans for individuals. This included family, friends, direct care staff and other professionals, as well as potentially the person themselves, and was a clear move away from the more "expert-based" approaches of ABA.

One of the results of this inclusion of stakeholders is that functional assessment was widened out to be something undertaken by staff teams and those closest to the individual, rather than by external specialists; assessment also moved from controlled settings such as the laboratory to more ordinary settings in the community. Logically there was also less of an emphasis on carrying out actual functional analysis, but rather using staff report, direct observation and other more flexible methods.

These developments in PBS and its increasing distinctiveness from ABA were reflected in a variety of publications over the next few years (Anderson & Freeman, 2000; Carr et al., 1999; La Vigna & Willis, 1996). Anderson and Freeman (2000) compared PBS with ABA and referred to PBS as "expanding the application of ABA." Their summary of the development taking place is that "ABA provides the technology with which to teach skills, whereas PBS suggests the areas in which the technology should be applied" (p. 91), and this theme of PBS being a development or evolution from ABA, is referred to by many authors (Allen, James, Evans, Hawkins, & Jenkins, 2005; Carr et al., 2002; J. Carr & Sidener, 2002; La Vigna, Christian, & Willis, 2005; La Vigna & Willis, 1996).

However, it was not until the seminal article by Carr et al. (2002) that the additional characteristics of PBS were spelled out and defined. These additional characteristics were defined as: lifespan perspective or a long-term focus; stakeholder participation; systems change; flexibility with respect to scientific practices and willingness to utilize other theoretical perspectives. These additional definition standards moved PBS into a more obviously separate category from ABA.

After Carr et al. (2002), the majority of PBS writings reflect these definitions, with some small exceptions. For example, Allen et al. (2005) and Allen (2009) did not include "flexibility in scientific practice" as part of their definition. Another exception is Carr (Carr, 2007; Carr et al., 1999, 2002), whose writings on PBS make little reference to reactive strategies. The emphasis in his descriptions of PBS is very much on proactive approaches, so much so that he stated, "The proactive nature of PBS stands in sharp contrast to traditional approaches" (Carr et al., 2002, p. 9). La Vigna and colleagues (La Vigna et al., 1989; La Vigna & Willis 2005a), on the other hand, emphasize the need for reactive as well as proactive approaches in their multi-element model, as do Allen et al. (2005) and Allen (2009). Despite these small differences, on the whole, there is widespread agreement in the literature about the key features of PBS.

Despite the apparent effectiveness of PBS in addressing challenging behavior (Carr et al., 1999), its use remains limited in services for people with intellectual and developmental disabilities (IDD). In a study of 500 people with IDD living in residential support in the UK, only 15 % were recipients of any kind of behavior programs (Emerson et al., 2000). It is not clear from this study if these programs were PBS-based; however, the findings indicated the low use of any kind of behavioral program. Allen et al. (2005) proposed a number of possible reasons for the low level of PBS use: the labor-intensive nature of interventions; a bias against ABA-type approaches in community care settings; lack of specialist staff trained in PBS; and no statutory requirement within community care settings for PBS to be provided for individuals with challenging behavior. A further reason for low level of use could be the lack of care staff skills in implementing PBS.

Training of staff teams to use PBS is therefore important for a number of reasons. First, despite the effectiveness of PBS, restrictive and aversive practices continue to be used (Deveau & McGill, 2014; Emerson et al., 2000). The risks associated with restrictive physical intervention are clear (e.g., Leadbetter, 2002). Studies have also indicated a potential over-dependence on psychotropic medication to manage behavior. For example, in one study service users were three times more likely to receive anti-psychotic medication than behavior support (Emerson et al., 2000), despite a lack of evidence for its effectiveness (Tyrer et al., 2008). In comparison, PBS is non-intrusive and likely to be regarded as least restrictive.

Second, creating skilled and confident staff teams that can implement PBS plans with accuracy and consistency may enable individuals with challenging behavior to be supported in ordinary community care settings and therefore minimize the need for expensive, often out-of-area, specialist placements. It is likely that these models of support do not allow for the building of skills and competencies within the individual's home environment and by the primary caregiver, most likely either a social care provider or family (Department of Health, 1993).

Third, creating skilled local staff teams is likely to be a positive alternative to relying on external specialist support teams. These specialist support teams who typically provide assessment and intervention input to individuals within their own environment are one alternative to specialist residential placements. These have been shown to be effective (Hassiotis et al., 2009) and are recommended in the UK government's good practice guidance (Department of Health, 1993). However, there are also limitations to the resources of specialist teams. For example, McClean et al. (2005) reported that only 48 % of people with severe challenging behavior are on team caseloads. The number of specialist teams required to provide PBS to all individuals who might benefit from it is not likely to be available (Sprague, Flannery, O'Neill, & Baker, 1996). Training service providers' direct care staff in PBS may therefore address issues of coverage.

This chapter summarizes the published literature in the last 20 years regarding outcomes of PBS staff training in relation to either children or adults with IDD. Studies which include either outcomes for staff (e.g., changes in knowledge or skills) and/or outcomes for service users (e.g., changes in rate or severity of challenging behavior, impact on quality of life, reductions in use of restraint) are discussed.

Models of Positive Behavior Support Training

Just as it has become necessary to define PBS and to specify some essential elements of the approach, so also it is necessary to define what constitutes PBS training, particularly as the term becomes more commonly used, and there may be a watering down of what is actually involved. There are a number of studies that have outlined the content of PBS training in some detail, either from a theoretical standpoint or to describe the training they have delivered. Generally, these have described PBS training in relation to the training objectives and the format of the training. Considering how each of the studies addresses these two key features will help towards a definition of what constitutes PBS training.

Model 1

The training model presented by Anderson et al. (1993) and further described in Anderson, Russo, Dunlap, and Albin (1996) proposed that PBS training, because it required the transmission of a new value base, as well as learning new skills and processes in practice, had to reach beyond traditional brief training and must be delivered in a specific way. They emphasized a case study approach, which would allow implementation of the learning through practical application in the workplace. This longitudinal training had a focus on long-term change in the person's life and behavior. Rather than just reducing problem behaviors, it aimed to teach the person new, more adaptive behaviors in addition to introducing a range of quality of life changes, designed to support them to live a fuller and more ordinary life in the community.

Training Objectives

Anderson et al. (1993) noted the foundation of PBS is that "behavior changes occur in the context of a rich lifestyle, not as a prerequisite to a rich lifestyle" (p. 364), thus specifying at the outset a key feature of PBS—that lifestyle enhancement or quality of life approaches are not just an outcome but are a technique; they are not an optional extra, but an essential element of PBS. They noted that training must be delivered in a way that promotes generalization and maintenance, so that PBS skills learned can be used in a variety of contexts over a period of time. Specific objectives are to achieve positive impact on: (a) lives of service users (improved lifestyles as well as reduced behavior); (b) on skills and knowledge of staff (focus on proactive strategies, shift from single to multi-component approaches, sees behavior change in context of a good life, recognizes need for long-term support, not quick fixes); and (c) on agencies and systems (PBS to be adopted into organizational policies; training to be prioritized proactively rather than crisis-led; resulting in flexible support options for individuals involving inter-agency and family collaboration).

Training Format

Their description of how the training is to be delivered is very detailed and strategic in its aim to develop local expertise and to change systems. This includes: (a) ensure sustainability and developing local expertise via a trainer for trainer model, with good support to new trainers; (b) target multiple audiences—training should be useful to a wide range of participants and should seek to create systems of comprehensive support across all of the individual's environment; (c) use a case-study approach; (d) intersperse teaching with supported application via longitudinal training which is combined with periods of practice in the service setting, along with coaching and mentoring; (e) provide a comprehensive curriculum (including values, functional analysis, PBS planning, skill building, reinforcement, emergency management, evaluation and systems issues); and (f) facilitate the development of PBS communities via ongoing implementation of PBS at a local level, and multiple levels of training, dependent on roles.

Model 2

Dunlap and Hieneman (2000) refined and extended the definition of PBS training and their description of training objectives and format have considerable overlap with that of Anderson et al. (1993, 1996).

Training Objectives

These include: (a) building enduring capacity to provide effective PBS; (b) lifestyle changes for individuals with challenging behaviors; (c) systems change and enhancing systems to promote PBS; and (d) collaborative working including community building and networking.

Training Format

These include: (a) collaboration between multidisciplinary participants, all of whom are involved in supporting the individual in a range of settings; (b) case study format—participants are brought together to apply their learning to an actual person; (c) dynamic training process—practical application interspersed with formal learning; and (d) comprehensive training which addresses a broad range of topics (e.g., collective goals, building teams, functional assessment, designing PBS plans, implementing strategies, evaluation, and infusing PBS into systems).

Model 3

La Vigna, Christian, Liberman, Camacho, and Willis (2002) outlined their intensive PBS training program based on a multi-element model they had developed earlier (La Vigna et al., 1989; La Vigna & Willis, 1996).

Training Objectives

The include; (a) to train participants to provide competency-based assessment, including the —development of multi-element support plans, designed to achieve valued outcomes in cost effective ways; (b) to provide participants with the skills, materials and procedures to continue delivering PBS in their workplaces; (c) to teach participants to use PBS interventions with consistency and accuracy, and to utilize ongoing quality improvement systems; and (d) via the training for participants to be able to support individuals with intellectual disabilities and severe challenging behaviors to integrate into ordinary work and living; and to be able to achieve durability and generalization of effect for individuals.

Training Format

These include: (a) 2 weeks of intensive training and practice; (b) hands-on implementation of PBS, with supervised field-based practice assignments, practice exercises, writing assignments —and feedback sessions; (c) carry out functional analysis and develop multi-element plans with both proactive and reactive strategies; (d) implement person-centered, community-based behavior analysis approaches; and (e) learn about evaluation and ongoing quality assurance systems.

Model 4

In addition to presenting the definition and development of PBS, Carr et al. (2002) also articulated a vision for how it should continue to develop and what PBS training should entail.

Training Objectives

These include; (a) training a range of stakeholders, not just professionals; (b) movement away from experts—more collaboration, with stakeholders and also between agencies; (c) not simply a transfer of information from expert to provider, but involving capacity building and leading to system change.

Training Format

These include: (a) creative use of technology; (b) more on-site education and less use of lecture format and formal training; (c) real-life problem solving, in context, within sufficient time duration; (d) not based on a list of intervention techniques, but learning how to use interventions within systems and how to integrate these with broader infrastructures and networks.

From a review of the relevant literature, which has described PBS training, it is suggested that there are a number of defining aspects to PBS training which can be summarized into these four key features:

Function-Based, with Multi-Element Support Planning

PBS training teaches that all support strategies must be based on functional assessment and an understanding of why behavior occurs in specific contexts and environments. This leads to a range of proactive and reactive strategies, with the major focus on proactive strategies. Within the proactive, there must be a focus on both stimulus-based intervention (changing the physical and social environment, e.g., manipulation of setting events) and reinforcement-based interventions (addressing behavioral deficiencies via skills teaching, e.g., functional communication, and reinforcement plans, which more strongly reinforce appropriate behaviors than challenging behaviors).

Person-Specific with a Long-Term Focus on Improving Quality of Life

PBS is a practical approach, which emphasizes application rather than theory, therefore through PBS training participants are supported to apply PBS in practice and are encouraged to carry out the training with a specific individual in mind. The training has a long-term focus and is comprised of more than one session; it is modular, with breaks in between sessions to apply the learning in practice. It is through this process that the training can best be truly person-focused and multi-element, and trainees can most effectively develop PBS skills in practice. It also has a wider focus than just behavior: PBS has a clear focus on improving quality of life for individuals in addition to reducing severity and frequency of challenging behavior, and therefore this must be a fundamental element of PBS training also.

Involvement of Stakeholders

Within the definition of PBS, involvement of stakeholders is important, and so it also is within the training model. PBS training should not be focused solely on professionals or specialists. Training is the primary means to make PBS more widespread in natural settings, therefore family carers and direct care staff are the essential groups to receive the training. PBS training is not intended to be a scientific-focused demonstration of techniques, rather it is intended to support trainees to understand and participate in a collaborative process that fits with their values and makes sense to their life experience. It is not only about learning skills but also about learning how to implement PBS in real life settings with individuals known to the trainees.

A further aspect of stakeholder involvement is that of "contextual fit," that is, the congruence between the PBS interventions and the context in which they will be implemented (Albin, Lucyshyn, Horner, & Flannery, 1996). If those who implement PBS interventions find the plans to be a good fit with their own values, a good match for their goals, suited to their skills and resources, and congruent with the needs and demands of the environments in which they live and work, it is anticipated that they will be more likely to implement them. Involving stakeholders in the development of these plans through a person-focused training model is therefore likely to increase contextual fit and therefore may also increase implementation. There is some evidence of this. Carr et al.'s (1999) meta-analysis of PBS interventions found that natural settings and carers demonstrated better outcomes than external intervention agents in controlled settings, with a success rate in 61 % of cases as opposed to 44 %. Carr et al. (2002) went even further and stated, "the primary goal of PBS is to help an individual change his or her lifestyle in a direction that gives all relevant stakeholders … the opportunity … to enjoy an improved quality of life," thus putting the needs of the individual, family, friends, staff, and employers as equally central to the outcomes of PBS.

Systems Changes and Organizational Focus

PBS is a whole-systems approach and is most effective when not seen in isolation from the rest of the organization. Therefore, when introducing PBS to a service or organization, it must reach further than just behavioral changes. PBS training must address this issue, particularly if participants are to leave the training and implement what they have learnt. This issue is so central to PBS that Carr (2007) suggested "the central independent variable in PBS is systems change" (p. 4) and a range of other studies have shown associations between implementing a whole-system approach to PBS and improved outcomes for service users both in terms of challenging behavior and quality of life (Allen, 2011; Allen, Kaye, Horwood, Gray, & Mines, 2012; Perry, Felce, Allen, & Meek, 2011). Allen et al. (2013) proposed that for PBS to be successful, behavioral intervention skills at the service user level needs to be supplemented by organizational changes in order to ensure whole system commitment and widespread implementation. La Vigna, Willis, Shaull, Abedi, and Sweitzet (1994) suggested a model for this—Periodic Service Review—which is a quality assurance system that can be used to support the implementation of PBS. A number of studies have reported positively on the use of this system (Lowe et al., 2010; McKenzie, Sharp, Paxton, & Murray, 2002).

Positive Behavior Support Training Outcomes

PBS training should address two key sets of outcomes: those for service users and those for staff. Service user outcomes focus on reduction in both severity and frequency of challenging behavior, as well as quality of life outcomes (e.g., increase in adaptive skills, greater use of community, increased participation, enhanced relationships, and better experience of support). Staff outcomes focus on changes in actual staff behavior (e.g., improved behavioral de-escalation strategies; more use of person-specific communication techniques; improved use of active support) and also in other less tangible changes such as increased knowledge, better understanding of behavior, more confidence in dealing with challenging behavior and more emotional strength in stressful and challenging situations. In addition, we would hope to find some evidence of both generalization and maintenance, that is, new skills and behavior changes can be transferred to a variety of contexts and can be maintained over time.

Although there is extensive research on generic challenging behavior training available, there is a limited published literature regarding outcomes of PBS training; 15 studies have been identified as meeting the criteria outlined above. There are other studies available that self-identify as PBS (e.g., Browning-Wright et al., 2007; Kraemer, Cook, Browning-Wright, Mayer, & Wallace, 2008; Rose, Gallivan, Wright, & Blake, 2014), but as these are all 1-day training sessions which cannot therefore meet the criteria of "person-specific, with a long-term focus on improving quality of life" they will not be discussed.

The 15 studies that do meet the PBS training criteria are summarized in Table 16.1 with details of participants, sample size, design, outcome measures, reliability, and results Table 16.2 shows the length, format, and content of the training. Seven of these studies focused on only staff outcomes, four on only service user outcomes and four on both. In order to consider the studies and their outcomes in more detail, the 15 studies have been split into those including outcomes for staff and those including outcomes for service users.

Outcomes for Staff

In terms of design, only one of the 11 studies considering staff outcomes used a control group (Reid et al., 2003). Five studies included reliability data (Baker, 1998; Crates & Spicer, 2012; Lowe et al., 2007; McGill et al., 2007; Reid et al., 2003). Eight studies used a repeated measures design (Baker, 1998; Freeman et al., 2005; Gore & Umizawa, 2011; Lowe et al., 2007; McGill et al., 2007; Reid et al., 2003; Wardale, Davis, Carroll, et al., 2014; Wardale, Davis, & Dalton, 2014; Wills et al., 2013), with one of these studies having three data collection points (McGill et al., 2007). Two studies used a post-training evaluation only for their staff measures (Crates & Spicer, 2012; Dench, 2005). Participants in these 11 studies included staff from a residential and vocational support unit; staff from community services, including residential, day-support and specialist; direct-care staff; students undertaking a university diploma; students undertaking a distance learning course; nurses; behavior specialists, teachers; allied health professionals; service managers; staff from a forensic secure unit and unregistered staff from a specialist health resources.

Outcome measures used in each study to evaluate different variables were identified and are described below (see Table 16.3).

Attitudes

One study looked specifically at staff attitudes. Wardale, Davis, Carroll, et al. (2014) used the Evidence Based Practice Attitude Scale (Aarons et al., 2012), which evaluates attitudes towards evidence-based practice. They found significant differences for 2 of the 12 subscales (i.e., Openness and Fit).

Table 16.1 Details of PBS Training

Author(s)	Year	Country	Participants	Sample size	Design and data collection	Outcome measures	Reliability	Results
Baker[a]	1998	US	Managerial and direct care staff from residential and vocational support unit	At least 16 staff	Repeated measures design; review of FA and Behavior Support Plan (BSP) pre and post training; incident reports completed pre and post training, during a 2-month period	FA and BSP were reviewed against 'critical elements' (4 for FA and 6 for BSP)	Coding was checked for 50 % of FA and BSP (93–96 % agreement)	The number of FA and BSP with at least 4 critical elements significantly increased
			Service users on whom training was focused	5 service users		Incident reports	CB reliability was assessed via comparison with house logs (100 % agreement)	In 2 months post training, CB for 2 service users reduced to 0; others reduced to between 11 and 28 % of baseline
Reid et al.[b]	2003	US	Supervisors of direct care staff	Experimental 12	Repeated measures within and between groups design	Observation of role-play demonstration of 2 supervisory skills	Inter-observer agreement checks on 46 % of observations (95 % agreement)	Pre-training 0–33 % met criteria; post training 100 %
				Implementation 386	Post training evaluation of skill	Paper exercise evaluation (17 modules); role-play evaluation (9 modules); and on-the-job checks (6 modules)	None reported	85 % completed all training and achieved mastery level
Freeman et al.[b]	2005	US	Professionals working in human services with bachelor's degree	11	Repeated measures design; PBS experts score BSP pre and post training	37-item PBS Checklist (based on Horner et al., 2000)	None reported	10 PCP and 9 BSP produced; scores on both checklists increased from 48 % pre training to 73 % post training

McClean et al.[c]	2005	Ireland	Service users whose staff were on the training course	138	Repeated measures design; staff recordings of target behavior at 3 time points, baseline, intervention and follow-up (between 4 and 8 week periods)	Behavior recordings	Inter-rater reliability checks for 1 week during baseline only for 21 cases (92 % agreement)	Significant improvement in 77 %, at average follow-up of 22 months (3 months–5.5 years)
Dench[a]	2005	Ireland	Students undertaking the course	38 staff	Post training assessment of FA and BSP	Behavior Assessment Report and Intervention Plan Evaluation Instrument (Willis & La Vigna, 1990)	None reported	91.7 % scored across all 7 categories on the Evaluation Instrument
			Service users—focus person for the course	25 service users	Staff recording of target behavior at baseline and post training; pre and post questionnaire re quality of life	Behavior recordings; Quality of Life Questionnaire (Schalock & Keith, 1993)		CB reduced to less than 30 % of baseline within 3 months for 56 %; questionnaire did not demonstrate changes in quality of life;
McGill et al.[b]	2007	UK	University Diploma students	79	Repeated measures design; questionnaires completed at 3 time points, beginning middle and end of course	Self-Injury Questionnaire (SIBUQ) (Oliver, Hall, Hales, & Head, 1996); Challenging Behavior Attributions scale (CHABA) (Hastings, 1997); Emotional Reactions to Challenging Behavior scale (ERCB) (Mitchell & Hastings, 1998); vignettes	5 % of data repeated entry to check reliability (95 % agreement) Independent rating of 15–23 % of vignettes (91 % agreement)	Knowledge significantly increased; negative emotional responses reduced; SIBUQ very significant increase of correct attributions; CHABA no change

(continued)

Table 16.1 (continued)

Lowe et al.[b]	2007	UK	Registered and non-registered staff in specialist health services	275	Repeated measures design; self report questionnaire and knowledge test pre and post training and at 1 year follow-up	ERCB; CHABA; Challenging Behavior Staff Perceptions Questionnaire (CBSPQ) (Hastings & Brown, 2002); Confidence in Coping with Patient Aggression (CCPA) (Thackery, 1987); knowledge questions	Inter-assessor reliability for 25 % (86 % agreement)	Significant increase in knowledge for both groups; initial changes in attributions after training reverted to baseline over time; lasting increases occurred in confidence for both group; limited impact on fear/ anxiety or depression/anger scale
Grey and McClean[c]	2007	Ireland	Service users whose staff were on the training course	60	Non-randomized matched control group, repeated measures design; CCB completed by 1 staff member pre and post training; staff completion of behavior observation records for target group only, pre and post training	Behavior observation recordings (target group only); Checklist for Challenging Behavior (CCB) (Harris, Humphreys, & Thomson, 1994); prescription of psychotropic medication	43 % of CCB were completed by 2 staff to check inter-rater reliability (correlation co-efficient range 0.8–0.92)	Significant differences between the groups post-training in frequency, management difficult and severity of behavior (on CCB)
								For 66 % of the target group the frequency of CB reduced to below 30 % of baseline after 3 months post implementation (behavior recordings)
								No significant reduction in units of medication prescribed for either group

Gore and Umizawa[a]	2011	UK	Teaching staff	33 staff	Repeated measures design; all measures completed by participants pre and post training; CCB post data collection was 1 month after training	CHABA; ERCB; CCB	None reported	CHABA—no significant differences; ERCB—significant decrease on fear/anxiety scale, no other significant differences
[d]see note below				37 children				CCB—1 month after training significant decrease in frequency but not in severity or management difficulty for staff (difference between staff and family carer results)
Reynolds et al.[c]	2011	Canada	Children whose parents and staff attended training	33	Repeated measures design, pre and post training	Aberrant Behavior Checklist (ABC) (Aman & Singh, 1986)	None reported	Significant improvements reported by staff in the total ABC score
[d]see note below								
McClean and Grey[c]	2012	Ireland	Service users whose staff were on the training course	61	Repeated measures design; 3 data collection points—baseline, post training and follow-up (average 26 month follow-up)	Challenging Behavior Rating Scale (CBRS) (based on Checklist for Challenging Behavior, Harris et al., 1994); behavior recordings	CBRS completed by 2 staff at baseline and post training (Pearson's correlation coefficient range 0.8–0.9)	Significant reduction in frequency, management difficulty and severity in the CBRS; behavior records showed an average decrease of 61 % at 3 months

(continued)

Table 16.1 (continued)

Crates and Spicer[a]	2012	Australia	Professionals working in disability services and the service users that they completed the training for	32 staff	Post training evaluation of assessment; repeated measures design for behavior; 2 data collection points—baseline and 3 months post-training	Assessment and Intervention Plan Evaluation Instrument (AIEI) (La Vigna, Christian, et al., 2005)	Inter-rater reliability checks for marking of 62 % of reports—85 %; mean reliability for behavior occurrence and severity was at least 84 %	Mean score on AIEI was 79.85 %
				32 service users				Reduction in occurrence of behavior at 3 months for 29/32 (mean change was 49.6 % of baseline); 27/30 showed reduction in severity at 3 months (mean change was −30.8 % of baseline)
Wills et al.[b]	2013	UK	Care staff from residential and day services	38	Repeated measures design, pre and post training	Revised Causal Dimension Scale II (McAuley, Duncan, & Russell, 1992); Helping Behavior Scale (Jones & Hastings, 2003); emotional responses to challenging behavior questionnaire (based on Rose & Rose, 2005); Optimism Pessimism Scale (Mores & Grant, 1976); PBS multiple choice questionnaire	None reported	Significant increase in PBS knowledge; significant decrease in controllability in causal attributions; significant increase in proactive helping; significant increase in optimism

Wardale et al.[b]	2014	Australia	Health professionals; direct support workers; managers; team leaders	234	Repeated measures design, pre and post training, except for BSP-QE only used post training	Knowledge acquisition test (based on O'Neill et al., 1997); CHABA; Evidence Based Practice Attitude Scale (EBPAS-50) (Aarons, Cafri, Lugo, & Sawitzky, 2012); Behavior Support Plan Quality Evaluation Guide (BSP-QE) (Browning-Wright, Mayer, & Saren, 2003) used to score each BSP	None reported	Significant increase in PBS knowledge; significant differences for all CHABA subscales except for Emotional; significant differences for 2 of the EBPAS-50 subscales (Openness and Fit increased); participants produced PBS plans with mean score of 13.73
Wardale et al.[b]	2014	Australia	Care staff from a secure facility for offenders with learning disabilities	6	Repeated measures design, pre and post training, except for BSP-QE only used post training	Knowledge acquisition test (based on O'Neill et al., 1997); BSP-QE	None reported	Participant knowledge increased (significance not reported); participants produced PBS plans with scores of 18–20 (*good*)

[a] Both staff and service user outcomes

[b] Staff outcomes only

[c] Service user outcomes only

[d] A variety of measures were used in relation to family carers, but these are not reported here, as this review only considers outcomes for staff and service users

Table 16.2 Length, content and format of training

Study	Length and format of training	Content
Baker (1998)	3× 3-h sessions 1 month apart; inter-session assignments	Completing FA; developing and implementing Behavior Support Plan (BSP) for focus person
Reid et al. (2003)	Experimental group: length not specified; role-play teaching for specific skills	Experimental: 2 modules (teaching staff a PBS-related skill and carrying out a staff observation)
	Implementation group: 5 days over 5 weeks (day 4 was on-the-job training)	Implementation: Skills related to PBS; 26 module curriculum
Freeman et al. (2005)	10 h/week over 1 year; online and monthly classes; online and practice-based assignments; portfolio	Person-centered planning (PCP), FA and BSP for focus person
McClean et al. (2005)	9 days over 6 months in 5 blocks; 4 inter-session assignments	Person-focused training in multi-element PBS; completing FA and implementing BSP and Periodic Service Review (PSR)
Dench (2005)	9 days over 9 months in 6 blocks; 5 inter-session assignments	Person-focused multi-element PBS; completing FA and implementing BSP for focus person and PSR
McGill et al. (2007)	57 days over 2 years; part-time University Diploma; practice-based assignments to implement in workplace	ABA: Active Support (AS); FA; multi-element PBS
Lowe et al. (2007)	80 h teaching over 10 consecutive days: portfolio; mentored by unit managers; 5 on-the-job observations	AS; PBS
Grey and McClean (2007)	9 days over 6 months in 5 blocks; 4 inter-session assignments	Person-focused training in multi-element PBS; completing FA and implementing BSP and PSR
Gore and Umizawa (2011)	2× 4-h sessions; session 1 repeated twice, delivered separately to staff and family carers; session 2 was joint	Functions of behavior; communication; recording behavior; developing proactive and reactive strategies
Reynolds et al. (2011)	3 full days and 2 half-days training over 7 weeks; training took place in teams of staff and family carers, focused round 1 child	Behavioral theory; functional assessment; designing BSP; data collection; crisis intervention
McClean and Grey (2012)	9 days over 6 months in 5 blocks; 4 inter-session assignments	Person-focused training in multi-element PBS; completing FA and implementing BSP and PSR
Crates and Spicer (2012)	4 consecutive days then an additional 9 days over 9 months involving 3 practice-based assignments	Multi-element model; functional assessment; positive programming; focussed support; reactive strategies
Wills et al. (2013)	5 half-days per week for 5 consecutive weeks	Understanding challenging behavior; challenging environments; environmental change; positive programming; secondary prevention
Wardale, Davis, Carroll, et al. (2014)	4 days over 6–8 weeks	PCP; FA (informant and observation methods and hypotheses); developing and implementing PBS plans; reactive strategies
Wardale, Davis, and Dalton (2014)	3 days across 5 weeks	PCP; FA (informant and observation methods and hypotheses); developing and implementing PBS plans; reactive strategies

Table 16.3 Staff outcome measures

Variable measured	Outcome measures	Studies reporting
Attitudes	Evidence Based Practice Attitude Scale (Aarons et al., 2012)	Wardale, Davis, Carroll, et al. (2014)
Attributions	Challenging Behavior Attributions questionnaire (CHABA) (Hastings, 1997)	Lowe et al. (2007), McGill et al. (2007), Gore and Umizawa (2011), Wardale, Davis, Carroll, et al. (2014)
	Revised Causal Dimension Scale II (McAuley et al., 1992)	Wills et al. (2013)
Confidence	Confidence in Coping with Patient Aggression Instrument (CCPAI) (Thackery, 1987)	Lowe et al. (2007)
	Challenging Behavior Staff Perceptions Questionnaire Self-efficacy (CBSPQ) (Hastings & Brown, 2002)	Lowe et al. (2007)
Emotions	Emotional Reactions to Challenging Behavior scale (ERCB) (Mitchell & Hastings, 1998)	Lowe et al. (2007) & McGill et al. (2007), Gore and Umizawa (2011)
	Emotional responses to challenging behavior questionnaire (based on Rose & Rose, 2005)	Wills et al. (2013)
Helping	Helping Behavior Scale (Jones & Hastings, 2003)	Wills et al. (2013)
Knowledge	Knowledge-based questionnaire	Lowe et al. (2007), Wills et al. (2013), Wardale, Davis, Carroll, et al. (2014), Wardale, Davis, and Dalton (2014)
	Vignettes on behavioral function	McGill et al. (2007)
	Self Injury Understanding (SIBUQ) (Oliver et al., 1996)	McGill et al. (2007)
Optimism	Optimism Pessimism Scale (Mores & Grant, 1976)	Wills et al. (2013)
Skills	Completion of FA and implementation of BSP	Baker (1998), Freeman et al. (2005), Dench (2005), Crates and Spicer (2012)
	Carolina Curriculum on Positive Behavior Support	Reid et al. (2003)
	Behavior Support Plan Quality Evaluation Guide (BSP-QE) (Browning-Wright et al., 2003)	Wardale, Davis, Carroll, et al. (2014), Wardale, Davis, and Dalton (2014)

Attributions

Five studies considered changes in attributions, four of these using the CHABA (Hastings, 1997). Lowe et al. (2007) reported initial changes in attribution after training reverted to baseline over time, and McGill et al. (2007) found varied change across measures. Gore and Umizawa (2011) found no significant differences, and Wardale, Davis, Carroll, et al. (2014) found significant differences for all the subscales except Emotional. Wills et al. (2013) used the Revised Causal Dimension Scale II (McAuley et al., 1992) and adapted this to refer to a case study describing a service user with intellectual disabilities and challenging behavior. They reported little change in mean scores on the internality and stability dimensions, but the mean controllability score decreased significantly.

Confidence

Lowe et al. (2007) measured confidence via the CCPA (Thackery, 1987) and also used the CBSPQ (Hastings & Brown, 2002). Both of these studies reported significant increases in confidence.

Emotions

Four studies looked at this area, three of them utilizing the ERCB (Mitchell & Hastings, 1998). Lowe et al. (2007) reported little lasting effect on emotions, McGill et al. (2007) reported that Depression/Anger scores were significantly reduced, and Gore and Umizawa (2011) found a significant decrease in the Fear/Anxiety scores. Wills et al. (2013) also considered emotions using a questionnaire based on Rose and Rose (2005). Following training, negative emotions reduced by one point on the scale and empathy increased by nearly one point. There was little change in mean scores of positive emotion.

Helping

One study (Wills et al., 2013) evaluated changes in helping behavior from staff, using the Helping Behavior Scale (Jones & Hastings, 2003), which looks at the help offered by staff to service users engaging in self-injurious behavior. This was adapted to include help in relation to aggressive behavior also. Following training, they found a significant increase in proactive helping and a significant decrease in unhelpful behavior.

Knowledge

This was measured in a number of different ways in different studies. Four studies used a PBS knowledge questionnaire. Lowe et al. (2007) used a questionnaire based on the course work that covered policy, PBS strategies, PCP and Active Support. This study demonstrated significant increases in knowledge, both immediately after the training and over time. Wills et al. (2013) used a multiple choice questionnaire and found significant increase in knowledge, and Wardale et al. (Wardale, Davis, Carroll, et al., 2014; Wardale, Davis, & Dalton, 2014) used a test based on O'Neill et al. (1997). They noted an increase in scores although they did not report significance figures. McGill et al. (2007) used the SIBUQ (Oliver et al., 1996) and showed a highly significant increase in correct attributions, demonstrating increased knowledge regarding self-injury. This study also used vignettes on behavioral function, where responses are rated as correct, partially correct or incorrect. At post-training, the trainees demonstrated more correct analysis with regard to the scenario with an attention function, but not with the escape/avoidance function.

Optimism

One study considered changes in staff optimism, using the Optimism Pessimism Scale (Mores & Grant, 1976), which measures how optimistic staff are about the possibility of reducing a service user's likelihood of engaging in challenging behavior. Wills et al. (2013) found a significant increase in optimism following training.

Skills

There are a number of different ways of assessing skills gained in PBS. The most common method used in extant studies was production and/or evaluation of functional assessments (FA) or behavior support plans (BSP). Baker (1998) reported on FA and BSP that were produced following three, 3-h, training sessions. Although the quality of these was not formally assessed, each was reviewed to ensure that they met a number of criteria. Baker's (1998) definition was that FA should contain: description of problem behavior; predictors of the behaviors; testable explanations for the function; direct observation to confirm this explanation and the BSP should contain at least four of six elements: definition of the behavior; link to FA; emphasizing lifestyle change; including interventions addressing setting events; including interventions addressing consequences; and emergency or reactive strategies. All three groups receiving training produced FA and BSPs that met these criteria.

Dench (2005) measured FA and BSP produced by students against an adapted version of the Assessment Report and Intervention Plan Evaluation Instrument (Willis & La Vigna, 1990), which lists 49 separate competencies, under seven headings. Students achieved an average of 91.7 % across all units, with one area, principles of skill teaching, being lower than the others. Crates and Spicer (2012) also evaluated FA and BSP via a version of the same instrument, the Assessment and Intervention Plan Evaluation Instrument (AIEI) (La Vigna, Christian, et al., 2005) which has 140 criteria in 12 content areas of. They reported a mean score of 79.85 % over the two training sessions evaluated using the AIEI.

Freeman et al. (2005) reported on a statewide plan in Kansas for embedding PBS into social care organizations, via a longitudinal course and although data were still being ,collected at time of report, nine BSPs had been produced and had been assessed via a tool based on that devised by Horner et al. (2000). This tool contains 37 items that are scored (in place, partially in place, and not in place). Average scores moved from 48.31 % pre-training, to 72.79 % post-training.

Wardale et al. (Wardale, Davis, Carroll, et al., 2014; Wardale, Davis, & Dalton, 2014) reported on improvements in writing BSPs as a result of training. They used the Behavior Support Plan Quality Evaluation Guide (BSP-QE) (Browning-Wright et al., 2003) to evaluate this. This tool is described as being based on six key concepts of PBS including behavior function and changing behavior via changing environmental features. Participants in the first study developed PBS plans scoring a mean total 13.73, which is rated "under-developed" and likely to require modification., However, they noted that this score needed to be seen in context of the fact that some items were not taught to the participants. The second study reported scores of 18–20, indicating a rating of "good" and likely to be helpful in effecting changes in behavior.

Reid et al. (2003) reported outcomes in relation to trainees developing an understanding of PBS and of the skills associated with it, rather than actually producing FA or BSP. They reported, on training for supervisors of direct care staff where evaluation was carried out via paper exercise, role-play and on-the-job checks. About 85 % (328) supervisors completed the training successfully and performed all on-the-job skills at mastery criteria.

Service User Studies

Participant numbers for the eight studies that included service user outcomes, ranged from 5 to 138. In terms of design, only one study used a control group (Grey & McClean, 2007), and three studies included reliability data (Baker, 1998; Grey & McClean, 2007; McClean et al., 2005). Six studies used a repeated measure,s design, pre and post training (Baker, 1998; Crates & Spicer, 2012; Dench, 2005; Gore & Umizawa, 2011; Grey & McClean, 2007; Reynolds et al., 2011). In addition, McClean et al. (2005) and McClean and Grey (2012) had a third data collection at follow-up.

Outcome measures used in each study to evaluate different variables were identified and are described below (see Table 16.4).

Frequency of Behavior

Five studies used real-time behavior recordings. Baker (1998) found that in the 2 months post training, challenging behavior for two service users reduced to zero and for the other three reduced to 11–28 % of baseline. McClean et al. (2005)

Table 16.4 Service user outcome measures

Variable measured	Outcome measures	Studies reporting
Frequency of behavior	Service incident reports	Baker (1998)
	Behavior recordings	McClean et al. (2005), Dench (2005), McClean and Grey (2012), Crates and Spicer (2012)
Severity of behavior	Aberrant Behavior Checklist (Aman & Singh, 1986)	Reynolds et al. (2011)
Frequency, severity and management difficulty of behavior	Checklist for Challenging Behavior (Harris et al., 1994)	Grey and McClean (2007), Gore and Umizawa (2011), McClean and Grey (2012)
Quality of Life	Quality of Life Questionnaire (Schalock & Keith, 1993)	Dench (2005)

reported significant improvement (defined as reduction to 0–30 % of the baseline rate of behavior) in 77 % of the group at an average follow-up of 22 months. Grey and McClean (2007) reported 66 % of the group significantly improved using the same definition, and McClean and Grey (2012) reported an average decrease of 61 % at 3 months. Dench (2005) reported reductions to less than 30 % of baseline within 3 months for 56 % of the group, and Crates and Spicer (2012) reported a mean change for the whole group to 49.6 % of the baseline at 3 months.

Severity of Behavior

Two studies reported specifically on severity outcomes. Reynolds et al. (2011) used the Aberrant Behavior Checklist (Aman & Singh, 1986) and reported significant decrease in the staff scores for this measure. Crates and Spicer (2012) described the use of an episodic severity measure (La Vigna & Willis, et al., 2005b), which was based on the real-time behavior recording, and reported a mean reduction to 30.8 % of the baseline.

Frequency, Severity and Management Difficulty of Behavior

Three studies used the Checklist for Challenging Behavior (CCB) (Harris et al., 1994) which allows for separate scoring on each of these three elements of behavioral measurement. Using this measure, Grey and McClean (2007) reported significant differences between treatment and control group in all three areas. Gore and Umizawa (2011) reported a significant decrease in frequency 1 month after training, but not in severity or management difficulty. McClean and Grey (2012) used the Challenging Behavior Rating Scales, which is drawn from the CCB, and reported significant reduction in each of the three areas.

Quality of Life

Only one study considered the impact of PBS training on the quality of life of service users (Dench, 2005), as rated on the Quality of Life Questionnaire (Schalock & Keith, 1993), but reported no changes.

Quality of PBS Training Studies

There are considerable differences among the 15 studies discussed above. The length of training is a fundamental difference, with a range from 3 half-day sessions to a 2-year University course, including 57 days of training. Comparisons between outcomes from different trainings must therefore be viewed in this light. The studies also varied considerably in their measures; some measured staff outcomes only, some measured service user outcomes only, and some measured both. Studies focusing exclusively on staff outcomes included a range of measures. Some studies focused on cognitive and emotional responses, others on knowledge acquisition, and some on skills acquisition. Despite these differences, however, there are a number of observations that may be made.

A number of studies only considered changes in staff knowledge, attributions, or emotional responses (Gore & Umizawa, 2011; Lowe et al., 2007; McGill et al., 2007; Wills et al., 2013). While there is merit in exploring these variables and significant changes were found following training, changes in staff behavior were not measured. Thus, it is difficult to extrapolate these results to changes in staff practice. It might be logical to assume that changes in staff beliefs about challenging behavior, for example, may lead to changes in providing support to individuals. However, there is little evidence to support this assumption, particularly since associations between staff beliefs and self-reported behavior are weak (Jones & Hastings, 2003). Stokes and Baer (1977) referred to this as a "train and hope" model (i.e., delivering training and hoping that staff will implement positive changes back in the service).

Of the 11 studies focusing on staff outcomes, seven reported on staff skills. Of these, four studies reported on skills applied in practice (i.e., where PBS strategies are implemented and results for service users are reported). The remaining three studies (Freeman et al., 2005; Wardale, Davis, Carroll, et al., 2014; Wardale, Davis, & Dalton, 2014) focused on related skills (i.e., writing BSPs). Of the four studies that focused on skills applied in practice, three supported trainees to write and implement a FA and BSP for an individual (Baker, 1998; Crates & Spicer, 2012; Dench, 2005). In addition, Reid et al. (2003) used on-the-job checks and assessed role-play to teach a range of PBS skills.

It seems likely that skills practiced are more likely to be retained than those that are not. It is likely that research focusing on staff behavior, rather than knowledge, feelings of efficacy, or causal attributions may have more of an impact on actual practice. The literature in relation to active support may be helpful (e.g., Mansell & Beadle-Brown, 2012) as it stresses on-the-job coaching as a necessary element of effective staff training and has demonstrated outcomes in achieving change of practice in staff's own workplace.

In terms of length of training, results are mixed. Some short sessions were shown to have a clear impact on staff skills in developing BSP. For example, Baker (1998) supported staff to write good quality FA and BSP over 3 half-day training sessions. Generally, however, the studies reviewed here are longer and it is likely that training that allowed trainees time and opportunity to practice skills within the workplace, and to complete assignments between formal teaching sessions, was more likely to be effective in achieving real changes in practice and in teaching staff lasting skills (Crates & Spicer, 2012; Dench, 2005; Freeman et al., 2005). However, attributing changes following training to the actual training rather than to other organizational changes is difficult. Specifically, changes in management systems and organizational procedures may have impacted results (e.g., Lowe et al., 2007). Controlled comparison groups may be required in future studies seeking to isolate these variables.

Of the eight studies that included measures of outcomes for service users, four were based on work done in Ireland (Dench, 2005; Grey & McClean, 2007; McClean et al., 2005; McClean & Grey, 2012). All four showed significant reductions in challenging behavior following longitudinal person-focused training that supported staff to design and implement PBS strategies for specific service users. Positive effects were demonstrated both via real-time behavior recordings and by use of the Checklist of Challenging Behavior. In addition, both Baker (1998) and Crates and Spicer (2012) showed considerable reductions in challenging behavior via longitudinal trainings.

Baker (1998) demonstrated a reduction from baseline for five individuals following a 3-session person-focused longitudinal training course. Although this training was shorter than the four Irish studies, each session was a month apart, and follow-up data were taken 2 months after the final training session. Thus, it may reasonably be described as longitudinal training also. Crates and Spicer (2012) utilized a training-for-trainers format based on the La Vigna et al. (La Vigna, Christian, et al., 2005) model and provided a training model similar to those described by the Irish studies. Gore and Umizawa (2011) and Reynolds et al. (2011) delivered training which included both paid staff and family carers, and both reported positive outcomes in terms of challenging behavior, via the Checklist for Challenging Behavior and the Aberrant Behavior Checklist. Although it is difficult to draw firm conclusions given the limited number of studies, it appears likely that when staff skills are improved via longitudinal, person-focused training, positive changes in levels of service user challenging behavior may also occur.

Limited evidence exists with regard to links between PBS training and improvement of support/increased quality of life for service users. Only one of the 15 studies reported directly on quality of life outcomes for service users. Dench (2005) attempted to evaluate outcomes for services users following a longitudinal PBS training course. However, despite positive anecdotal evidence of lifestyle changes, these were not able to be measured and reported. Dench noted that this may have been due to the Quality of Life Questionnaire (Schalock & Keith, 1993) being insufficiently sensitive to measure these changes.

Practice Recommendations

There are a number of implications for research and practice arising from this discussion of PBS training. In terms of looking to the future, there is a need to be creative and innovative in how training is delivered, both to maximize resources and to achieve the coverage of training needed. Use of information technology, e-learning, and video training are measures which have demonstrated some element of success (Macurik, O'Kane, Malanga, & Reid, 2008; Sailor et al., 2000) and may be useful in this context. Further exploration of their use in relation to PBS training would be appropriate.

In addition to creative use of technology, coverage could also be increased by utilizing a training-for-trainers model. Crates and Spicer (2012) demonstrated that "second generation" training could be as effective as that delivered directly (e.g., La Vigna, Christian, et al., 2005). This is an encouraging model in terms of achieving high quality training with reasonable coverage. Rotholz and Ford (2003) also utilized this approach in that trainees who successfully completed the PBS training for supervisors were eligible to enroll in a 2-day trainers' course and were assessed in their training skills. (This study has not been discussed in detail as the data have been already reported by Reid et al., 2003). These elements of training may be useful as a means of furthering an organization's ability to provide PBS training to their staff.

There is a need for more research on the impact of PBS training for service users in terms of frequency and severity of behavior. In addition, considerably more outcome data and research are needed in terms of quality of life outcomes for service users. It would be useful to explore what supports good generalization and maintenance of benefits from PBS training; thus, studies including long-term follow-up would be particularly helpful.

In addition to service user outcomes, research is also needed to examine what makes training effective for staff and service users, e.g., considering issues around organizational environments that promote PBS training and practices. These might include the impact of providing brief PBS training for supervisors of trainees undergoing in-depth PBS training, the impact that good contextual fit (Albin et al., 1996) has on implementation of PBS plans, and how organizational systems, such as the Periodic Service Review (La Vigna et al., 1994) may be used to support implementation.

In all of these areas, it would be ideal to see more use of powerful single case or group experimental designs in order to isolate the influences of different variables and allow clearer conclusions. More of an emphasis on the use of established measures for ensuring the reliability of the data presented would increase the confidence we would have in study results.

Research into the impact of staff training in PBS has focused more on outcomes for staff than service users. The eight studies that considered outcomes for service users demonstrated reductions in challenging behavior. However, improved quality of life for those individuals was not systematically linked to the training. It would be useful for future research to focus on evaluating impact on the lives of service users resulting from staff training in PBS. Although it seems likely that staff training which supports the practice and application of skills within the workplace will be more effective in producing positive changes in the lives of service users, research is needed to support this assumption.

PBS has become more mainstream over recent years, e.g., it is now specified within UK government best practice documents; however, for it to be implemented fully and effectively, it is vital that there is a clear and shared understanding of what constitutes PBS, and what constitutes PBS training. To those responsible for commissioning or developing PBS training, it suggested that training described as PBS be assessed in relation to these four key features and, if it does not meet these, it should not in fact be regarded as true PBS training: (a) function-based, with multi-element support planning; (b) person-specific, with a long-term focus on improving quality of life; (c) involvement of stakeholders; and (d) systems changes and organizational focus.

If training does not support the application of functional assessment and multi-element support to real individuals, if there is no longitudinal approach with opportunity to practice skills and then apply them, if it does not have a commitment to long-term quality of life changes, if there is no involvement of stakeholders and no commitment to organizational change, then it is debatable whether these training packages should indeed be described as PBS. To the degree that training works with real issues in the lives of individuals, engaging with the people who matter to them, attempting to understand the reasons for behaviors and, based on that understanding to develop lifestyle-enhancing support strategies, along with changes to their immediate environment and the systems around them, then it can be regarded as PBS training, and we would expect it to have a significant impact not only on the participants undergoing the training but also on the lives of the individuals they care for and support.

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Parent Training

17

Laura Lee McIntyre and Cameron L. Neece

Introduction

More than 1.5 million children in the USA are estimated to have an intellectual and developmental disability (IDD; Batshaw, Shapiro, & Farber, 2007; Federal Interagency Forum on Child & Family Statistics, 2009). Children with ID are at risk for a variety of poor outcomes, in part because they have cognitive, social, and language deficits (Dosen & Day, 2001). This risk is exacerbated when there is a concomitant behavior problem or mental health disorder (Reiss, 1994). Epidemiological studies suggest a high prevalence of dual diagnosis of ID and behavior/mental health disorder, occurring at a frequency ranging from 10 to 70 %, with most estimates between 30 and 45 % (Emerson, 2003; Nezu, Nezu, & Gill-Weiss, 1992). Thus, more than 500,000 American children have this dual diagnosis. Children and adolescents with ID are nearly 3–4 times more likely to have a diagnosable behavior/mental health disorder than are their typically developing counterparts (Baker, Neece, Fenning, Crnic, & Blacher, 2010; Emerson, 2003). Dual diagnosis places adults at dramatically increased risk for social isolation and vocational and residential difficulties (Borthwick-Duffy & Eyman, 1990). Family members and other caregivers of individuals with ID and co-occurring behavior problems often report higher levels of stress, caregiving burden, and/or depression than do parents of children with ID only (Blacher, Shapiro, Lopez, & Diaz, 1997; Bromley & Blacher, 1991; Herring et al., 2006; McIntyre, Blacher, & Baker, 2002). Few studies have examined the underlying mechanisms of psychopathology in children with ID, although evidence suggests self-regulation and family interactions are potential pathways (Crnic, Baker, Blacher, & Gerstein, under review; Floyd, Harter, Costigan, & MacLean, 2004). Regardless of cause of early behavior problems, children with developmental delay as young as age 3 years already have three times the number of parent-reported behavior problems than do typically developing children (Baker, Blacher, Crnic, & Edelbrock, 2002). These behavior problems remain stable across the preschool years and kindergarten transition and across mother, father, and teacher informants (Baker et al., 2003; McIntyre, Blacher, & Baker, 2006). Because these young children and their families are experiencing problems at such an early age, there is a need for early systematic, preventive efforts

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focused on reducing the risk of future behavioral difficulties and family stress. Left untreated, children with ID are at risk for developing a severe behavior disorder or mental illness, which places significant burden on caregivers and increases the likelihood of out-of-home placement or the need for intensive, costly residential services (Bromley & Blacher, 1991; McIntyre et al., 2002).

Starting at birth, families are children's main socializing agents, and they can influence children's behavior through their actions, attitudes, and behavior (Patterson, 1982). Although care must be taken to not blame families for child problems, positive parenting practices may promote child adjustment and negative or coercive practices may be associated with child problem behavior (Dishion & Stormshak, 2007). Family processes influence the emergence of behavior disorders in young children with and without disabilities (Baumrind, 1989; Bronson, 2000; Floyd et al., 2004; Kumpfer & Alvarado, 2003; Martin, 1981; Russell & Russell, 1996). Patterson and colleagues have suggested that negative, coercive parenting practices place children at risk for behavior problems (Patterson, 1982; Patterson, DeBaryshe, & Ramsey, 1989), and existing behavior problems may be exacerbated by parental stress over time (e.g., Baker et al., 2003; Neece, Green, & Baker, 2012). Furthermore, some evidence suggests that the presence of parental stress influences the emergence and persistence of behavior problems in school-age children with disabilities (Hastings, Daley, Burns, & Beck, 2006). Thus, interventions that address child behavior and parenting stress may be especially important.

Central to the emergence of childhood behavior problems are weak or disorganized family management practices, and coercive parent–child interactions may result. As such, the child's aversive behaviors increase in intensity and frequency and the parent acquiesces, unwittingly reinforcing problem behaviors (Gardner, 1989; Patterson, 1982; Patterson, Reid, & Dishion, 1992; Shaw & Bell, 1993). In turn, the parent dedicates less time and engagement to socialization processes. As the child's behavior becomes increasingly problematic, the parent may either escalate power assertion techniques or begin to avoid conflict with the increasingly coercive young child. It is clear that coercive and rejecting parent–child relationships measured at age 2 are associated with child conflict with peers and teachers at age 6 (Ingoldsby, Shaw, & Garcia, 2001), trajectories of persistent conduct problems from ages 2 to 10 (Shaw, Gilliom, Ingoldsby, & Nagin, 2003; Shaw, Lacourse, & Nagin, 2005; Stormshak, Bierman, McMahon, Lengua, & CPPRG, 2000), and serious problem behavior between ages 11 and 15 (Stormshak et al., 2000). Children with ID and their families may be particularly at risk for these outcomes because of higher levels of parenting stress, parental depression, and contextual risks associated with ID (Baker et al., 2002; Emerson et al., 2010). A recent study has shown that relative to a comparison group of parents of typically developing preschool-age children, parents of children with ID were more detached, more negative, and less positive (Crnic, Pedersen y Arbona, Baker, & Blacher, 2009). Clearly, supporting parenting skills can reduce the risk of later problem behavior for children with ID and may support family well-being and parent mental health (Baker, Fenning, Crnic, Baker, & Blacher, 2007; Floyd et al., 2004; McIntyre, 2008a, 2008b).

Parent training and education programs are interventions that target parenting skills to enhance behavior and adjustment in children. A robust literature has demonstrated the efficacy of parent training for reducing disruptive behavior in young children (see Kaminski, Valle, Filene, & Boyle, 2008; Lundahl, Risser, & Lovejoy, 2006; Serketich & Dumas, 1996, for reviews). Relevant to families of children with ID, a growing literature supports the efficacy of behavioral parent training programs (McIntyre, 2013) and other strategies for reducing disruptive behavior, such as Mindfulness-Based Stress Reduction (MBSR) approaches (Bazzano et al., 2015; Dykens, Fisher, Taylor, Lambert, & Miodrag, 2014; Minor, Carlson, Mackenzie, Zernicke, & Jones, 2006; Neece, 2014).

In this chapter we describe and review parent training interventions, such as behavioral parent training and mindfulness-based programs, that are designed to reduce challenging behavior in children and adolescents with ID, and we discuss the research that is illustrative of these approaches. The chapter concludes with a discussion of future research directions and recommendations for practice.

Description of Parent Training Approaches

Behavioral Parent Training

Given the role that parents play in shaping children's development, behavioral parent training programs have adopted procedures from the disruptive behavior disorder treatment literature and applied them to the prevention and treatment of challenging behavior in children with ID (Brookman-Frazee, Stahmer, Baker-Ericzen, & Tsai, 2006). Parent training as an intervention for families with children with behavior disorders stems from social learning theory (Bandura, 1977), principles of operant theory and behavior modification (Holland & Skinner, 1961), and an understanding of developmental psychopathology (Hinshaw, 2002). The rationale behind parent training is that building parents' positive parenting skills and targeting parent–child interactions will have collateral effects on children's behavior problems (Forehand & McMahon, 1981; Patterson, 1982). Parent training with typically developing children with conduct problems has been useful for reducing children's observed aggressive and antisocial behaviors and increasing parental competence and positive parent–child relationships (Eyberg, 1992; Webster-Stratton, 2000; Webster-Stratton & Hammond, 1997). There is a growing evidence base that similar behavior-based parent training programs generate reductions in behavior problems in children with ID (e.g., Hudson et al., 2003; McIntyre, 2008b; RUPP Autism Network, 2007).

Behavioral parent training programs focus on teaching parents to use reinforcement and other consequences to increase positive, prosocial, and adaptive behaviors and decrease problematic behaviors. In these programs, parents are taught to systematically praise and reward certain behaviors and neutralize other behaviors through the use of time out, ignore strategies, or removal of privileges. Some behavioral parent training programs also incorporate functional analysis or functional behavioral assessment (e.g., McIntyre, 2008a; RUPP Autism Network, 2007).

Mindfulness-Based Approaches

Although behavioral parent training emphasizes the acquisition of parenting skills that are linked to child behavioral outcomes, mindfulness-based strategies directly target stress that may be associated with the presence of child problem behavior (Bazzano et al., 2015; Dykens et al., 2014; Minor et al., 2006; Neece, 2014; Singh, Lancioni, et al., 2006). Given the bidirectional relation between parental stress and child problem behavior (Neece et al., 2012), it is logical to consider interventions that target the reduction of parental stress in terms of their impact on child behavioral outcomes. Surprisingly, although parenting stress has been shown to be an important predictor of several child outcomes, it is rarely directly addressed in interventions that target child behavior problems. This is concerning not only because parental stress has been shown to affect the development of children's emotional and behavior problems over time, but also because parenting stress has been associated with poor outcomes for interventions focused on children with ID and other developmental disabilities. More specifically, high parental stress predicts less beneficial outcomes for children in early intervention programs (Brinker, Seifer, & Sameroff, 1994; Osborne, McHugh, Saunders, & Reed, 2008; Robbins, Dunlap, & Plienis, 1991; Strauss et al., 2012) and fewer gains in parenting skills in behavioral parenting training interventions (e.g., Baker, Landen, & Kashima, 1991).

Two types of mindfulness-based interventions have been used primarily with parents of children with ID. First is MBSR, which is an evidence-based stress-reduction intervention program supported by more than two decades of extensive research that has revealed its effectiveness for reducing stress, anxiety, and depression and for promoting overall well-being (Chiesa & Serretti, 2009); however, only recently has MBSR been used to address parenting stress specifically (Bazzano et al., 2015; Dykens et al., 2014; Minor et al., 2006; Neece, 2014). This approach involves training individuals to use strategies to disengage attention from internal thoughts and feelings that elicit distress and to focus on their present experience directly without appraisals or interpretations (Singh et al., 2014). By focusing on the immediate experience, individuals are able to become more aware of which aspects of the experience are worth responding to, ignoring, or simply observing. It is thought that mindfulness training improves participants' emotion regulation skills through enhancing their attention monitoring abilities and facilitating nonjudgmental awareness of emotions, allowing people to genuinely experience and express their emotions without underengagement (e.g., avoidance) or overengagement (e.g., rumination; Chambers, Gullone, & Allen, 2009). In the MBSR program, parents learn to cope more effectively with both short- and long-term stressful situations. These coping skills are critical for parents of children with ID. MBSR may also help improve one's parenting experience in that mindfulness may help parents slow down, notice impulses before they act, truly listen to their children, and come to a more relaxed and peaceful state of mind, which in turn may have a positive effect on their children with ID.

The second kind of mindfulness-based parenting intervention, mindful parenting, has also been used with parents of children with ID and other developmental disabilities, and initial findings are promising (Singh et al., 2007, 2014; Singh, Lancioni, et al., 2006). These interventions incorporate mindfulness, self-awareness, and intentionality into the parent–child relationship. As a result, parent–child interactions are less reactive and are characterized by more relaxed communication and problem solving, which are ultimately thought to result in the reduction of children's challenging behavior (Singh et al., 2014). Findings indicate that mindful parenting interventions are effective for reducing children's externalizing behavior and attention problems and for improving children's self-control, compliance, and attunement to others (Bögels, Hoogstad, van Dun, de Schutter, & Restifo, 2008; Singh et al., 2009, 2010). Mindful parenting differs from MBSR in that that the focus of mindful parenting is on using mindfulness specifically in the context of parent–child interactions and identifying interactions that result in relational disconnectedness (Altmaier & Maloney, 2007), rather than on applying mindfulness techniques to parental stress more broadly, regardless of the source of stress.

The standard MBSR program includes eight weekly 2.5-h group sessions, a daylong meditation retreat during the sixth week of the program, and daily home practice based on audio CDs, including a minimum of 45 min per day of formal mindfulness practice and 5–15 min of informal practice (J. Kabat-Zinn, 2009; Santorelli, 2014). Formal mindfulness exercises are aimed toward increasing the capacity for mindfulness (i.e., present-moment awareness with a compassionate, nonjudgmental stance) and include a body scan, mindful yoga, and sitting meditation. Participants receive audio recordings of 45-min guided mindfulness exercises (i.e., body scan, yoga, and sitting meditation) that they are instructed to practice daily at home. To facilitate the integration of mindfulness into daily life, parents are also taught to practice mindfulness informally in everyday activities. During classes the formal mindfulness exercises are practiced, and didactic instruction is provided on stress physiology and using mindfulness for coping with stress in daily life.

Mindful parenting interventions may be varied in terms of duration, format, and content. Regardless of specific format, they all focus on integrating mindfulness into one's parenting experience (M. Kabat-Zinn & Kabat-Zinn, 1997). Similar to MBSR, parents are taught formal meditation practices and are assigned homework to promote continued mindfulness practice in between sessions. However, in contrast to MBSR, the specific formal meditation practices vary across mindful parenting programs and focus on parent–child interactions (e.g., *Being Your Child* meditation in Singh et al., 2007), and homework exercises ask parents to practice mindfulness during interactions with their children.

Parent Training Formats

A multitude of parent training formats, including those that are self-administered, group based, and individually administered, have been investigated in behavioral parent training programs and in mindfulness-based parenting programs. The format of the parent training intervention may be a key clinical consideration in terms of feasibility of delivery, cost, and goodness-of-fit with certain participant subgroups (e.g., those from economically disadvantaged backgrounds); however, parent training format has not received a great deal of empirical attention. Following is a description of advantages and disadvantages associated with three parent training formats: self-administered, group-based, individually administered.

Self-Administered Programs

Self-administered parent training may offer an accessible intervention format for many families, especially for those who have difficulty participating through traditional means. By providing parents with literature, audio/visual material, or computer-delivered information, this mode of delivery requires little to no contact between the professional and parent. Self-administered intervention has been shown by some to be as effective as therapist-directed programs (Markie-Dadds & Sanders, 2006; Nicholson & Sanders, 1999). Webster-Stratton, Kolpacoff, and Hollingsworth (1988), on the other hand, found this mode of intervention delivery to be less effective in comparison with a group discussion videotape modeling program. In a follow-up study, Webster-Stratton (1999) recognized the importance of giving families access to more cost-effective programs and sought to determine which participant variables were associated with positive outcomes in self-administered programs. Results of Webster-Stratton's (1999) study suggested that single mother status, maternal depression, and mother's low mental age were significantly correlated with at least two of the four outcome variables at posttreatment. Therefore, although self-administered intervention may be helpful for some families, others may not respond to this form of intervention and may need additional support. Preliminary evidence has also provided initial support for the efficacy of self-directed mindfulness-based interventions. A study by Warnecke and colleagues (2011) found that medical students reported a significant reduction in stress and anxiety following a self-directed mindfulness intervention using an audio CD of guided mindfulness practice. In addition, studies have indicated that mindfulness interventions delivered via a mobile application (Carissoli, Villani, & Riva, 2015) and virtual training (Hudlicka, 2013) may also be effective.

Group-Based Programs

Being involved in a group format enables families to receive more therapist attention than they would receive in a self-administered format. Although group-based programs require more resources to implement, they are still more cost efficient than individually delivered interventions. Several group parent training programs have been designed to promote parent competencies and to address and/or prevent conduct problems (see reviews: Brestan & Eyberg, 1998; Webster-Stratton & Taylor, 2001). Similarly, mindfulness interventions are most commonly delivered in a group-based format, and group-based interventions, such as Mindfulness-Based Stress Reduction (MBSR) and Mindfulness-Based Cognitive Therapy (MBCT), have the most empirical support (Chiesa & Serretti, 2009, 2011; Grossman, Niemann, Schmidt, & Walach, 2004; Piet & Hougaard, 2011). A collateral benefit of group programs is the support and kinship available from other participants, which may increase parental engagement with the intervention and with their child's early education program. Greater parental engagement is an important benefit of group formats, especially for those who may be socially isolated (e.g., low-income single mothers) with little support and few friendships (Dumas & Wahler, 1983). Although group-based parent training programs have many advantages, not every family benefits from this approach (Webster-Stratton & Hammond, 1997). Individually administered parent training allows participants to receive the most intensive, flexible, and individualized support.

Individually Administered Programs

There are many advantages to providing parents with individually administered programs rather than self-administered or group-based programs. These interventions have been used with both behavioral parent training and mindfulness-based approaches (Singh et al., 2007, 2014; Singh, Lancioni, et al., 2006). Individually administered programs offer increased flexibility in scheduling sessions and tailoring the content. Therapists who provide individualized sessions can give parents feedback specific to their situation and address parents' questions and concerns in a more individualized, tailored fashion. The primary disadvantage of individually administered programs is the cost. Webster-Stratton (1984) argued that group-based programs were more efficient and effective for many families. As previously discussed, individually administered programs also lack the provision of social support provided by group members. On the other hand, parents are more likely to accept and participate in individually based intervention than in group intervention (Chadwick, Momcilovic, Rossiter, Stumbles, & Taylor, 2001). In a meta-analysis examining the variability of treatment effects in terms of participant and treatment characteristics, Lundahl et al. (2006) found individually delivered intervention to be superior to group-delivered intervention for financially disadvantaged groups. That is, families with low socioeconomic status who participated in individually delivered parent programs had larger treatment effects than did those who participated in group-delivered programs, which suggests a greater need for more individualized support for these individuals.

Review of Approach and Research Illustrative of This Approach

Following is a review of key behavioral parent training studies and mindfulness-based intervention studies published in the past decade. Because it is beyond the scope of this chapter to provide an in-depth review of each study, research illustrative of the approach is summarized in Table 17.1, which offers a more detailed description of critical study components. All studies listed in Table 17.1 focused on parent training interventions to reduce challenging behavior in children or adolescents with ID, including autism spectrum disorder (ASD); were published in English between 2005 and 2014; were quantitative, with methods and results related to parent training; and included child challenging behavior as a dependent variable.

The majority of recently published parent training intervention studies targeting challenging behavior in children with ID use behavioral parent training approaches. Twelve of the 16 studies listed in Table 17.1 used behavioral parent training strategies. There is a growing evidence base for using mindfulness-based approaches to reduce both parenting stress and challenging behavior in children and adolescents with ID and other developmental disabilities, such as ASD. Four of the 16 studies are mindfulness-based intervention (see Table 17.1). The following study characteristics are described in Table 17.1: (a) participants; (b) dependent measures; (c) study design; (d) generalization, maintenance, consumer satisfaction, treatment integrity; (e) parent training interventions; and (f) treatment outcomes.

Behavioral Parent Training Programs

A range of behavioral parent training curricula has been evaluated and reported in terms of reducing challenging behavior in children and adolescents with ID. The Incredible Years Parent Training program, Stepping Stones Triple P, Signposts for Better Behavior, RUPP Parent Training, and Parent Child Interaction Therapy are some of the most extensively evaluated programs for this population.

Table 17.1 Behavioral parent training and mindfulness-based studies for child challenging behavior in children with ID 2005–2014

Study	Target group	Sample size	Intervention	Design/approach	Dependent variables	Key outcomes
Aman et al. (2009)	Caregivers and their 4-to 13-year-old children with PDD and elevated behavior problems	$N=124$	• Behavioral Parent Training	• Randomized controlled trial	• Parent-reported child compliance	• Relative to MED group, COMB group had:
		$n=75$ COMB	• RUPP Parent Training	• ITT analysis	• Observed improvement on the	• More parent-reported child compliance
		$n=49$ MED	• Combined treatment (COMB) of individual parent training plus resperidone	• Blinded evaluation	• Parent-reported maladaptive behavior	• Less parent-reported maladaptive behavior
		Attrition: 24 %	• Medication alone (MED)	• Treatment integrity reported		• No difference on clinical impressions of symptoms
Bagner and Eyberg (2007)	Caregivers and their 3- to 6-year-old children with ID and comorbid oppositional defiant disorder	$N=30$	• Behavioral Parent Training	• Randomized wait-list control trial	• Parent-reported behavior problems	Relative to WL group, the IT had:
		$n=15$ Immediate treatment	• Parent–child Interaction Therapy (PCIT)	• Intent to treat (ITT) analysis	• Observed parent and child behavior	• Less reported problem behavior
		$n=15$ wait-list	• Immediate treatment (IT)	• Reliable change index (RCI) analysis	• Parent-reported parenting stress	• More observed child compliance
		Attrition: 47 %	• Wait-list control (WL)	• Treatment integrity reported	• Consumer satisfaction	• More observed positive parenting
				• 4-month follow-up		• Less reported parenting stress
						• High consumer satisfaction with PCIT treatment

(continued)

Table 17.1 (continued)

Bagner, Pettit, Lewinsohn, and Seeley (2010)	Caregivers and their 18-to 60-month-old children born premature (<37 weeks gestation) with elevated behavior problems	$N=28$	• Behavioral Parent Training	• Randomized wait-list control trial	• Parent-reported behavior problems	Relative to WL group, the IT had:
		$n=14$ Immediate treatment	• Parent–child Interaction Therapy (PCIT)	• Intent to treat (ITT) analysis	• Observed parent and child behavior	• Less reported problem behavior
		$n=14$ wait-list	• Immediate treatment (IT)	• Reliable change index (RCI) analysis	• Parent-reported parenting styles	• More observed child compliance
		Attrition: 21 %	• Wait-list control (WL)	• Treatment integrity reported	• Parent-reported parenting stress	• Less reported parenting stress
				• 4-month follow-up		• Less reported laxness, overreactivity, and verbosity in parenting styles
Hudson, Cameron, and Matthews (2008)	Parents of 2-to 18-year-old children with ID and challenging behavior	$N=2119$	• Behavioral Parent Training	• Group design	• Parent-reported behavior problems	Posttreatment parents reported:
		$n=22$ self-directed	• Signposts for Building Better Behaviour program	• No control group	• Parent-reported competence	• Less child problem behavior
		$n=119$ telephone	4 levels:	• Wide-scale implementation trial	• Parent-reported mental health	• Less stress, depression, and anxiety
		$n=1675$ group	• Self-directed	• 3-month follow-up	• Parent-reported parenting hassles	• More competence and satisfaction in parenting
		$n=303$ individual	• Telephone	• No treatment integrity reported	• Consumer satisfaction	• Less parenting hassle
		Attrition:	• Group			
		58 % pre–post	• Individual			
		87 % pre-follow-up				

Kleve et al. (2011)	Parents of 2-to 11-year-old children with a range of neurodevel-opmental disorders and challenging behavior involved in social services	$N=128$	• Behavioral Parent Training	• Group design	• Parent-reported behavior problems	Postintervention, parents reported:
		Attrition: 31 %	• Incredible Years Parent Training	• No control group	• Visual analogue scales	• Decreased problem behavior
			• Group-based intervention	• No treatment integrity reported		
McIntyre (2008a)	Parents of 2- to 5-year-old children with ID, including ASD	$N=25$	• Behavioral Parent Training	• Group design	• Parent-reported behavior problems	Postintervention:
		Attrition: 11 %	• Incredible Years Parent Training–DD Modifications	• No control group	• Observed parent–child interactions	• Decreases in observed child problem behavior and negative parenting
			• Group-based intervention	• Parent–child interaction observations scored by coders naïve to study goals	• Parent-reported impact of the child on family	• Increase in parent-reported positive impact of the child
				• Treatment integrity reported	• Parent-reported depression	• No significant changes in parent-reported behavior problems, child negative impact, or maternal depression
				• RCI analysis	• Consumer satisfaction	
				• Analysis of correlates of change		

(continued)

Table 17.1 (continued)

McIntyre (2008b)	Parents of 2-to 5-year-old children with ID, including ASD	$N=49$	• Behavioral Parent Training	• Randomized, controlled trial	• Parent-reported behavior problems	Postintervention, children in IYPT-DD group showed
		$n=24$ IYPT-DD	• Incredible Years Parent Training–DD Modifications (IYPT-DD)	• Blinded evaluation	• Observed parent–child interactions	• Reductions in observed problem behavior and parent-reported problem behavior
		$n=25$ usual care control	• Group-based intervention	• Treatment integrity reported	• Parent-reported impact of the child on family	• Reductions in observed negative parenting
		Attrition: 10 %				• No treatment effect on parent-reported impact of the child on family
Neece (2014)	Parents of 2-to 5-year-old children with ID, including ASD	$N=46$	• Mindfulness-based	• Random assignment	• Parent-reported stress	Postintervention, children in MBSR group showed
		$n=21$ MBSR	• Mindfulness-Based Stress Reduction (MBSR)	• No treatment integrity data reported	• Parent-reported impact of the child on family	• Reduction in parent-reported ADHD symptomatology
		$n=25$ wait-list control	• Group-based intervention		• Parent-reported depression	• Reductions in parent-reported stress and depression
		Attrition: 9 %			• Parent-reported satisfaction with life	• Increase in life satisfaction
					• Parent-reported child problem behavior	• No treatment effect on internalizing or externalizing problem behaviors
					• Parent-reported subjective units of distress	

Okuno et al. (2011)	Mothers and their 4- to 9-year-old children with ASD and challenging behavior	*N* = 14	• Behavioral Parent Training	• Group design	• Parent-reported child problem behavior	• Decrease in parent-reported behavior
		Attrition: 0 %	• Parent Training with Smaller Groups and Shorter Schedules (PTSS)	• No control group	• Parental confidence	• Increase in parent confidence for handling child's challenging behavior
			• Group-based intervention	• Treatment integrity monitored but no data reported		
Phaneuf and McIntyre (2011)	Parents of 2- to 4-year-old children with IDD, including ASD	*N* = 8	• Behavioral Parent Training	• Single-case design	• Parent-reported child behavior problems	• Decreased parent-reported child problem behavior
		Attrition: 25 % pre-follow-up	• Three-tier model of interventions based on the Incredible Years	• Used parents' response to intervention to inform treatment	• Observed child problem behavior	• Decreased observed child problem behavior
			• Self-administered	• 3-month follow-up	• Observed parenting behavior	• Decreased observed negative parenting behavior
			• Group-based program (IYPT-DD)	• Treatment integrity reported	• Consumer satisfaction	
			• Individual sessions with video feedback and modeling			

(continued)

Table 17.1 (continued)

Plant and Sanders (2007)	Parents and their preschool-age children (<6 years) with ID, including ASD, and challenging behavior	$N = 74$	• Behavioral Parent Training	• Randomized, controlled trial	• Parent-reported child behavior	Both SSTP-S and SSTP-E interventions were associated with:
		$n = 24$ SSTP-E	• Stepping Stones Triple P Standard version (SSTP-S) and SSTP Enhanced (SSTP-E)	• Coders blind to intervention condition	• Parent–child interactions	• Reduced levels of observed negative child behavior
		$n = 26$ SSTP-S	• Individualized sessions	• RCI analysis	• Caregiving problems	• Reductions in the number of caregiving settings with child problem behavior
		$n = 24$ wait-list		• Treatment integrity data reported	• Parenting skills and ability	• Improvements in parental competence
		Attrition: 10 %		• 1-year follow-up	• Parenting competence	• Improvements in satisfaction parenting role
					• Parental depression and anxiety	
					• Marital quality	
					• Consumer satisfaction	
RUPP Autism Network (2007)	Parents and children age 14–13 years with ASD and challenging behavior	$N = 17$	• Behavioral Parent Training	• Group design	• Parent-reported child noncompliance	Postintervention there were:
		Attrition: 17.6 %	• RUPP Parent Training	• No control group	• Parent-reported maladaptive behavior	• Reductions in parent-reported rates of noncompliance
			• All children were receiving medication for irritability, tantrums, aggression, and self-injury	• Treatment integrity reported	• Observed improvement on the scale	• Reductions in parent-reported rates of irritability
					• Adaptive behavior	• Increases in daily living skills
					• Basic language and learning	• Reeducations in parenting stress
					• Parenting stress	
					• Parent satisfaction questionnaire	

Singh, Lancioni, et al. (2006)	Mothers and their 4- to 6-year-old children with autism and challenging behavior	*N* = 3 mother–child dyads	• Mindfulness training	• Single-subject experimental design	• Parent-observed aggression, noncompliance, and self-injury	• Reduction in parent-observed child noncompliance, aggression, and self-injury
			• Individual sessions	• Multiple baseline across mother–child dyads	• Subjective units of parenting satisfaction	• Increase in parenting satisfaction
				• 12-month follow-up • No treatment integrity data	• Subjective units of use of mindfulness	• Increase in interaction satisfaction
Singh et al. (2007)	Mothers and their 4- to 6-year-old children with ID and challenging behavior	*N* = 4 mother-child dyads	• Mindfulness training	• Single-subject experimental design	• Parent-observed aggression	• Reduction in parent-observed child aggression
			• Individual sessions	• Multiple baseline across mother–child dyads	• Parent-observed child social interactions with siblings	• Increase in parent-observed child social interactions with siblings
				• 12-month follow-up	• Subjective units of parenting satisfaction	• Increase in parenting satisfaction
				• No treatment integrity data	• Subjective units of use of mindfulness	• Increase in interaction satisfaction
					• Parent-reported parenting stress	• Increase in use of mindfulness
						• Decrease in parenting stress

(continued)

Table 17.1 (continued)

Singh et al. (2014)	Mothers of adolescents with ASD and challenging behavior	$N=3$ mother–adolescent dyads	• Mindfulness training with positive behavior support	• Single-subject experimental design	• Parent-observed aggression, disruptive behavior, and compliance	• Reduction in parent-observed adolescent problem behavior
			• Individual sessions	• Multiple baseline across mother–adolescent dyads	• Parent-perceived stress scale	• Increase in parent-observed adolescent compliance
				• 12 month follow-up		• Decrease in parent-reported perceived stress
				• Treatment integrity reported		
Whittingham, Sofronoff, Sheffield, and Sanders (2009)	Parents of 2-to 9-year-old children with ASD and challenging behavior	$N=59$	• Behavioral Parent Training	• Randomized wait-list control trial	• Parent-reported child behavior problems	Relative to WL control participants, children in SSTP group had:
		$n=29$ SSTP	• Stepping Stones Triple P (SSTP)	• RCI analysis	• Parent-reported parenting styles	• Decreased parent-reported behaviors
		$n=30$ wait-list	• Partial-group format (group and individual sessions)	• 6-month follow-up	• Parenting satisfaction and efficacy	• Decreased dysfunctional parenting
		Attrition: 11 %		• No treatment integrity data		• Increased parenting self-efficacy at follow-up

Incredible Years

Webster-Stratton and colleagues have developed a parent training program, the Incredible Years Parent Training series, that has been demonstrated to be more effective than control treatments in six randomized trials and in five independent replication studies (Webster-Stratton, 1984, 1994, 2000) for reducing children's maladaptive behavior and increasing parents' adaptive parenting skills in families of children with or at risk for behavior problems (without ID). Webster-Stratton's parent training series uses videotape modeling, role-playing, rehearsal, and weekly homework activities in small groups of 8–14 parents (see Webster-Stratton, 2000, for a review). In addition to targeting clinical samples of children with conduct problems, Webster-Stratton and colleagues have used Incredible Years Parent Training with families who have children at risk for adverse academic/socio/behavioral outcomes attributable in part to their poverty status (Gross et al., 2003; Webster-Stratton, Reid, & Hammond, 2001). Webster-Stratton has also added teacher and child skill-building components to her training series, which makes the model not only an efficacious treatment for children with conduct problems, but also a useful prevention technique for high-risk children and families. The Division 12 (clinical psychology) task force of the American Psychological Association deemed Webster-Stratton's Incredible Years series to be one of two well-established psychosocial treatments for childhood conduct problems (Brestan & Eyberg, 1998) on the basis of effect sizes, sampling, methodology, treatment integrity, and a host of other criteria (Lonigan, Elbert, & Johnson, 1998).

Four studies (Kleve et al., 2011; McIntyre, 2008a, 2008b; Phaneuf & McIntyre, 2011) investigated the effects of Webster-Stratton's Incredible Years Parent Training program (IYPT; Webster-Stratton, 2001) on challenging behavior in children with ID. McIntyre (2008a, 2008b; Phaneuf & McIntyre, 2011) used an adapted version of the Incredible Years for use with parents of children with developmental disabilities (IYPT-DD; McIntyre, 2008a). IYPT is an evidence-based parent training program based on principles of operant and social learning theories (Webster-Stratton, 2000). IYPT is designed to be delivered in approximately 12 weekly sessions. Group leaders use discussion, video modeling, role-playing, and didactics to cover topics in five main areas: play, praise, rewards, limit setting, and handling challenging behavior. Challenging behavior is reduced through altering negative and coercive parent–child interactions (Webster-Stratton, 2001). DD modifications implemented by McIntyre (IYPT-DD) included discussing the unique challenges and blessings associated with raising a child with developmental delays, understanding children's developmental levels and support needs, conducting descriptive functional behavioral assessments, and developing behavior support plans based on the hypothesized function of the child's challenging behavior (McIntyre, 2008a). Kleve et al. (2011) and McIntyre (2008a, 2008b) used the Incredible Years group program. Phaneuf and McIntyre (2011) incorporated a three-tiered model of intervention that increased the intensity of support, depending on parents' responsiveness to intervention. The three tiers of intervention evaluated by Phaneuf and McIntyre included self-administered reading materials (based on the Incredible Years: A Trouble-Shooting Guide for Parents of Children Aged 2–8 Years; Webster-Stratton, 2005), group-based parenting training based on the Incredible Years with DD modifications (IYPT-DD), and individualized video feedback based on the behavioral skills training literature (e.g., Himle, Miltenberger, Gatheridge, & Flessner, 2004) with content covering the IYPT-DD (see also Phaneuf & McIntyre, 2007).

Kleve et al. (2011) and McIntyre (2008a) used a single group pretest-posttest design to evaluate the effects of the Incredible Years program on the parent-reported behavior problems of their children. In addition, McIntyre (2008a) included direct observations of parent–child interactions to gauge intervention effects on parenting behavior/skills and child problem behavior. Kleve et al. reported significant reductions in parent-reported behavior problems and McIntyre (2008a) reported significant reductions in observed child behavior problems and negative parenting behaviors following the Incredible Years intervention. McIntyre (2008b) used a randomized controlled trial to investigate the effects of the modified Incredible Years (IYPT-DD) on parent-reported behavior problems of their preschool children and direct observations of parent–child interactions. Relative to a control group, the intervention condition demonstrated statistically significant reductions in parent-reported problem behavior, observed child problem behavior, and observed negative parenting behaviors. Although this is the most rigorous evaluation of the Incredible Years published to date with children with ID, the sample size was small ($N=49$) and therefore offers limited evidence on the efficacy of the Incredible Years approach with families of children with ID. Phaneuf and McIntyre (2011) used a single case design to evaluate a three-tier model of interventions based on the Incredible Years. Findings suggest that all families benefited from the intervention package; however, some required more intensive support (i.e., tier 3 individualized services) to show decreases in observed child problem behavior and negative parenting behavior.

Stepping Stones Triple P

Two studies (Plant & Sanders, 2007; Whittingham et al., 2009) reported on the effects of Stepping Stones Triple P (SSTP) in families of children with ID or ASD. Stepping Stones is a variant of the evidence-based Triple P Positive Parenting Program (Sanders, 1999) and was developed especially for use with caregivers of children with disabilities. Triple P is grounded in operant and social learning theories and draws on principles guided by applied behavior analysis and coercion theory for reducing child problem behavior through altering parent–child interactions (Sanders, 1999). SSTP includes many components of the original Triple P program (e.g., reinforcement-based approaches for increasing positive behavior, differential reinforcement for)decreasing challenging behavior, consideration of the function of the problem behavior) but also includes teaching strategies from the special education literature (e.g., skill acquisition, functional communication training). Plant and Sanders compared SSTP with an enhanced version of SSTP. The enhanced intervention consisted of SSTP with additional content focused on stress and coping, strengthening social support, and partnering with professionals. In Whittingham et al. (2009) the SSTP focused on parents of children with ASD and included generic SSTP plus strategies on using Comic Strip Conversations and Social Stories (Gray, 1998) developed to promote social awareness, understanding, and problem solving.

Findings from Plant and Sanders (2007) suggest that, relative to a wait-list control group, both the)standard and enhanced versions of SSTP were associated with reductions of observed child problem behavior in children with ID. Whittingham et al. (2009) reported similarly strong effects of SSTP with children with autism spectrum disorder (ASD), although relied on parent-reported problem behavior rather than direct observations of parent–child interactions. Taken together, findings from these two studies suggest growing evidence supporting the efficacy of SSTP for the treatment of challenging behavior in children with ID and ASD.

Signposts for Building Better Behavior

Hudson et al. (2008) reported on the effects of the Signposts for Building Better Behaviour program (see also Hudson, Cameron, & Matthews, 2003). Signposts is a multilevel program designed to be a preventive intervention of challenging behavior in 3- to 16-year-old children with ID. Signposts is designed to teach parents strategies for reducing challenging behavior before the behaviors escalate and warrant costly and time-consuming specialized interventions. Signposts is based on operant and social learning theories and uses behavioral parent training approaches to reduce challenging behavior and promote positive child and family adjustment (Hudson et al., 2003). In Hudson et al. (2003), three modes of intervention delivery were evaluated, including self-directed intervention using guidebooks and DVDs, telephone-delivered support, and group-delivery intervention. Hudson et al. (2008) expanded on this initial efficacy trial and reported on a wide-scale implementation trial of the Signposts program. In this large implementation trial ($N = 2119$), a fourth level of intervention (i.e., individual parent training sessions) was added and evaluated for effectiveness.

Findings from Hudson et al. (2008) suggest that the intervention can be scaled up and delivered via multiple formats. As would be expected in an implementation trial, a control group was not included in the design. Data from postreatment and follow-up assessments suggest reductions in parent-reported child problem behavior; however, caution should be used when interpreting the findings given the extremely high levels of attrition (58 % attrition from pre–post and 87 % attrition from pre-follow-up).

RUPP Parent Training

Two studies (Aman et al., 2009; RUPP Autism Network, 2007) reported outcomes for the Research Units in Pediatric Psychopharmacology (RUPP) Autism Network medication trial that involved comparing the effects of psychotropic medication with a combined treatment of medication and parent training in children with pervasive developmental disorders (PDD). The RUPP Parent Training (RUPP PT) program is a manualized, individually delivered treatment based on principles of applied behavior analysis, operant theory, and behavioral skill training (Johnson et al., 2007). The goal of RUPP PT is to increase compliance and decrease problem behavior in children with PDD. RUPP PT consists of 11 core treatment sessions, three optional sessions, and as many as three booster sessions. Core sessions include topics such as basic behavioral techniques used to decrease problem behavior and increase adaptive behavior, functional communication training, skill building, and promoting generalization and maintenance (Johnson et al., 2007). As many as 17 sessions are individually delivered to parents during a 24-week period (Aman et al., 2009; RUPP Autism Network, 2007).

A single group pre–post design was used to demonstrate feasibility and preliminary evidence of efficacy of the RUPP PT intervention on parent-reported rates of noncompliance and child irritability in children with ASD (RUPP Autism Network, 2007). Findings from the small feasibility study suggest positive effects associated with RUPP PT intervention (RUPP Autism Network, 2007). Aman et al. (2009) used a randomized controlled trial to evaluate the effects of RUPP PT plus medication in comparison to a medication only control group. Findings from Aman et al. (2009) suggest that relative to the medication only control group, children in the combined medication and RUPP PT intervention group demonstrated increased parent-reported child compliance and decreased parent-reported maladaptive behavior. Given the size and rigor of this study, findings suggest compelling evidence in support of the additive effects of a behavioral parent training intervention to medication management for children with ASD and elevated behavior problems.

Parent–Child Interaction Therapy

Two studies reported on the use of Parent–child Interaction Therapy (PCIT) for children with developmental delays. Bagner et al. (2010) focused on a sample of children born prematurely who developed externalizing behavior problems and Bagner and Eyberg (2007) focused on children with ID and comborbid oppositional defiant disorder. PCIT is an evidence-based parent-training intervention grounded in attachment and social learning theories (Eyberg, Boggs, & Algina, 1995) and is designed to reduce children's disruptive behavior through strengthening positive parent–child interactions. This individually delivered intervention is paced according to the parent's responsiveness to intervention and consists of two treatment phases: a child-directed intervention (CDI) phase and a parent-directed intervention (PDI) phase. The parent must master aspects of CDI before moving on to the PDI portion of treatment. CDI focuses on increasing positive interactions between the parent and child through play and praise. PDI focuses on increasing the child's compliance and decreasing their aggression through limit setting and the use of effective commands (Eyberg et al., 1995).

Both Bagner and Eyberg (2007) and Bagner et al. (2010) found that relative to a waitlist control group, caregivers in the PCIT immediate treatment group reported fewer problem behaviors for their children. Further, children in the immediate PCIT treatment group had significantly higher rates of observed compliance with maternal commands than children in the waitlist control group. Parents in the PCIT immediate treatment group were observed to interact with their children significantly more positively than parents in the waitlist control group. Taken together, findings from these studies are promising and provide support for the use of PCIT with parents of young children with developmental disabilities and behavior problems.

Mindfulness Training

Four studies reported about the effects of mindfulness training to decrease challenging behavior in children with autism and developmental disabilities (Neece, 2014; Singh et al., 2007, 2014; Singh, Lancioni, et al., 2006). Singh and colleagues' mindfulness training focused on teaching parents to "have a clear, calm mind that is focused on the present moment in a nonjudgmental way" (Singh et al., 2007, p. 752). Mindfulness training was individually provided to parents in 12 two-hour sessions. The book *Everyday Blessings*: *The Inner Work of Mindful Parenting* (M. Kabat-Zinn & Kabat-Zinn, 1997) supplemented weekly topics covered in sessions. The 12 weekly topics included a general introduction to mindful parenting, knowing your mind, focused attention, focused attention on arousal states, being present in the moment, beginner's mind, being with your child, nonjudgmental acceptance, letting go, loving kindness, problem solving, and using mindfulness in daily interactions (Singh et al., 2007). Neece (2014) evaluated the efficacy of MBSR for reducing parental stress and subsequent behavior problems. Results found MBSR to be efficacious for reducing overall parenting stress in parents of children with developmental delays in that parents who participated in this study reported significantly less stress and depression and greater life satisfaction than did waitlist-control parents. Children whose parents participated in MBSR were reported to have fewer behavior problems following the intervention, specifically in the areas of attention problems and ADHD symptomatology. These findings demonstrate that treatments focused on parent stress alone may have an indirect "spillover effect" on the child.

Singh, Lancioni, and colleagues (2006) used a multiple baseline across mother–child dyads to examine the effects of a 12-week mindful parenting intervention on the challenging behavior of three preschool children with ASD. Mothers were trained in the mindful parenting intervention as well as the data collection procedure. Mothers used a mobile, hand-held device to collect data on their children's aggression, noncompliance, and self-injury during their child's waking hours. Following intervention, mothers observed fewer aggressive and self-injurious behaviors and less noncompliance in their preschool children with ASD. Mothers reported an increase in their parenting satisfaction and satisfaction with interactions with their children. Singh et al. (2007) replicated these findings with four parent–child dyads. Participants in Singh et al. (2007) included four mothers and their preschool children with developmental disabilities. Findings suggest that mothers trained in mindful parenting observed fewer aggressive behaviors. Further, children were observed to engage in more social behavior with their typically developing siblings following mindful parenting intervention delivery.

Singh and colleagues (2014) examined the benefits of a mindfulness-based positive behavior support (MBPBS) intervention for three parents of adolescents with ASD. In this intervention parents learned mindfulness-based practices, which were then paired with positive behavior support. When a single-subject multiple baseline approach was used, results indicated that MBPBS led to reductions in mothers' reports of stress and decreases in adolescents' challenging behaviors and increases in compliance behaviors. These findings suggest that mindfulness strategies may help parents effectively manage their child's behavior through positive behavior support without the increased parental stress that may accompany these interventions (Hastings, 2002; Singh, Lancioni, Winton, & Singh, 2011).

Future Research Directions

Although still in its infancy, research examining mindfulness-based interventions for parents of children with intellectual and developmental disabilities is growing rapidly. During the past decade the feasibility and preliminary efficacy of mindfulness-based interventions have been tested in pilot studies (Bazzano et al., 2015; Minor et al., 2006; Roberts & Neece, 2015) and in larger, well-controlled studies that consisted of methodologically rigorous, single-case designs (Singh et al., 2007, 2014; Singh, Lancioni, et al., 2006); waitlist-control randomized trials (Neece, 2014); and large-scale randomized, controlled trials with an active comparison group (Dykens et al., 2014). Currently, the majority of the literature about mindfulness interventions for parents in general consists of studies of parents with children who have developmental disabilities, which underscores the compelling need for stress-reduction and parenting interventions among this population.

It behooves future researchers investigating mindfulness interventions for parents and children with ID to use common intervention protocols and measures in order to compare and perhaps collapse findings across studies. Broadly speaking, one of the most significant problems in mindfulness intervention research is that nearly every study uses a different mindfulness intervention and a different set of outcome measures, making it difficult for the reader to synthesize this literature and identify what intervention works best and for whom. When researchers choose to apply mindfulness interventions to a new population, it would be advantageous to first determine if standard manualized intervention protocols (e.g., MBSR, MBCT) are effective before making adaptations for the group; if adaptations are made before the standard protocol is tested, one cannot determine if the observed effects are a result of the mindfulness intervention or the adaptations made. In addition, the literature base for mindfulness interventions with parents of children with ID would greatly benefit from systematic dismantling of studies to identify which aspects of the intervention are related to the observed benefits. Standard mindfulness interventions are quite intensive, requiring several hours of intervention each week and daily homework for several weeks. Preliminary data indicate that adaptations to these interventions that are less time intensive may be worthwhile for people seeking to reduce psychological distress (Carmody & Baer, 2009). Studies to systematically examine each of these individual concerns identified above are needed.

Examination of the possible benefits of integrating behavioral parent training and mindfulness-based interventions is a key area for future research on interventions for parents of children with ID. For example, there is small but growing literature supporting the use of adding a mindfulness component to interventions or approaches (e.g., Kazdin & Whitley, 2003; Singh et al., 2014; Singh, Singh, Sabaawi, Myers, & Wahler, 2006). Future investigation is needed to determine whether adding a parental stress reduction module that uses mindfulness-based techniques to existing evidence-based treatments for child behavioral issues (Bagner & Eyberg, 2007; McIntyre, 2008b) maximizes the efficacy of parent training and behavior interventions that target challenging behavior among children with ID. Given that elevated parental stress has been associated with decreased efficacy of behavioral interventions for children (Baker et al., 1991; Brinker et al., 1994; Osborne et al., 2008; Robbins et al., 1991; Strauss et al., 2012), one would expect that addressing parental stress would improve the impact of interventions commonly used with children with ID. The challenge lies in identifying what aspects of mindfulness-based interventions for parents are most effective for reducing stress and the intensity of the intervention so the desired outcome is achieved, which further underscores the critical need for identifying the “active ingredients” of the interventions. Kazdin and Whitley (2003) examined the effect of adding a parent stress-reduction component to augment the effects of evidence-based parent management training for children with aggressive and antisocial behavior problems. The component consisted of five additional individual sessions during which parents developed problem-solving skills and used these skills to address stressors in their everyday life. Findings indicated that the additional stress-reduction treatment component resulted in enhanced therapeutic change for both the children and their parents and reduced the barriers parents perceived during the treatment (Kazdin & Whitley, 2003). These results emphasize the potential benefit of directly addressing parental stress in interventions designed to reduce child problem behavior.

Practice Recommendations

We offer several recommendations for practice. These recommendations are organized under the general categories of: (a) evidence-based approaches; (b) prevention and early intervention; (c) comorbidities; (d) family participation and engagement; and (e) logistics.

Evidence-Based Approaches

There is a robust literature supporting the use of behavioral parent training approaches and a growing literature supporting the use of mindfulness-based parent training interventions to reduce challenging behavior of children with ID. Thus, we suggest that clinicians select interventions that are based on the extant literature rather than developing idiosyncratic, "home grown" approaches. Although there are still gaps in our understanding of basic mechanisms of these interventions and intervention moderators (e.g., under what circumstances and for whom do the interventions work most effectively?), we have important foundational knowledge to inform the selection of interventions. Thus, we suggest that clinicians should select parent training interventions that are either behavioral in nature or based on mindfulness principles when targeting the reduction of challenging behavior in children with ID or ASD. We suggest that valuable resources be used to implement interventions with a track record of effectiveness.

Prevention and Early Intervention

Policymakers and service providers in health, education, social services, and juvenile justice now recognize the importance of intervening early in children's lives and supporting families before their children's behavior becomes so well established that intensive, more costly intervention is needed (Olchowski, Foster, & Webster-Stratton, 2007; US Public Health Service, 2000; VanDerHeyden & Snyder, 2006; Webster-Stratton, 2001). Given that age is a moderator of behavioral parent training outcomes in studies of typically developing children with behavior problems (e.g., Serketich & Dumas, 1996), we suggest that behavioral parent training interventions may be especially relevant and useful with children 8 years old and younger. Interventions based on mindful parenting, on the other hand, have been demonstrated to be effective with a range of child ages (e.g., Neece, 2014; Singh et al., 2014) and thus may be appropriate for parents of young children through adolescence and young adulthood. Regardless of child age and particular format of parent training intervention adopted, we recommend a focus on prevention of problems and promotion of well-being in both children and parents.

Comorbidities

Children with intellectual and developmental disabilities are more likely than typically developing children to have behavioral or psychiatric problems (e.g., Emerson, 2003). Further, children with ID are more likely to have medical, sensory, or physical limitations. Thus, careful attention should be paid to the unique support needs of participants. What may seem like a routine behavioral problem may be a manifestation of an undiagnosed medical or health problem. In addition to the increased likelihood of child comorbid condition, parents of children with ID may be at risk for heighted stress (e.g., Woodman, Mawdsley, & Hauser-Cram, 2015), depression (e.g., Olsson & Hwang, 2001); poor health (e.g., Murphy, Christian, Caplin, & Young, 2007), and financial burden (e.g., Anderson, Dumont, Jacobs, & Azzaria, 2007). Clinicians should attend to both risk and resilience in families they serve.

Family Participation and Engagement

Most would agree that it is important to involve fathers in parenting interventions; however, few studies have focused directly on involving fathers. In our review, we only found one study that focused on the effects of fathers in parent training interventions for children with ID (Bagner, 2013). Bagner (2013) summarized results from two PCIT treatment studies (Bagner et al., 2010; Bagner & Eyberg, 2007) and concluded that in families where a father participated in treatment for their child with ID, parents reported lower levels of child problem behavior than when fathers did not participate in parent training intervention. Further, Bagner (2013) reported that children from father involved families had significantly higher rates of compliance during clean-up tasks posttreatment than children from single-mother households. Although much more research is needed in this area, we recommend that clinicians consider ways to make parenting interventions relevant and accessible to both mothers and fathers. For example, clinicians can specifically reach out to fathers and invite their involvement, target father identified goals and priorities during sessions, and provide supports (e.g., childcare) to families so that both parents can attend sessions.

Logistics

Our final recommendations focus on important logistical considerations for carrying out successful parent training interventions. These recommendations are based on our collective experience conducting parent training interventions for parents of children with developmental delays and disabilities. Clinicians may wish to consider a variety of locations for parent training interventions including family homes, schools, clinics, and community venues (e.g., churches, community centers). University-based clinics are not always easy for families to access given issues with parking and other barriers. Furthermore, some families may be intimidated by coming to a university campus with their child with a disability. Thus, we suggest that having a strong community presence may allow families to more readily attend sessions. Providing childcare, food, and assistance with transportation may also enhance family participation in parent training interventions. If group sessions are being held, clinicians may wish to consider whether families can "make up" sessions if they are unable to attend a session. Such make-up sessions can potentially enhance rapport and provide families with missed content and overall support. Such allowances may allow families to stay engaged with the intervention and minimize the risk of attrition. Ultimately, no matter the theoretical orientation of the intervention, parent training involves interventionists working directly with families in an effort to support their use of strategies to improve their lives and the lives of their children. Building and maintaining strong relationships with parents is a critical piece of the intervention foundation.

In summary, parent training interventions based on behavioral principles or mindfulness-based strategies may be effective approaches for the reduction of problem behavior in children or adolescents with ID or ASD. Additional studies are needed in order to more fully understand mechanisms, moderators, and additive effects of combining aspects of mindfulness training with behavioral approaches. Further, little research has targeted fathers. Thus, the inclusion of fathers in research studies and the focus of fathers in clinical practice is sorely needed. Finally, we outline suggestions for integrating mindfulness and behavioral approaches in the treatment of problem behavior in children with ID.

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Social Skills

18

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Introduction

Appropriate social skills allow us the ability to interact with those around us and provide opportunities to engage in new environments, learn from others, and function independently. Although these skills are seemingly a natural component of everyday life, social skills are complex. A person is perceived to be socially competent if he or she is able to interact socially with others in an effective manner, generalize interaction styles across multiple social situations, and maintain such interactions over time (Kennedy, 2004). Social interactions that contribute to a person's overall social competence and success often require an intricate, nuanced, and dynamic set of skills.

Social skills can be defined as all those behaviors, both verbal and nonverbal, that are necessary for successful social exchange and interpersonal communication. Social skills can sometimes mean very specific behaviors such as greetings, initiating interaction, or responding to initiations made by others. Social skills can also involve more complicated cognitive and behavioral phenomena such as accurately interpreting a social context, behaving according to contextually and culturally appropriate mores, and ongoing evaluation and adjustment of one's own behavior in light of the responses.

These critical social skills may be especially challenging for individuals with intellectual and developmental disability as a result of the social deficits and difficulties with social interaction that are central to the diagnostic definition of the disorder. Adaptive functioning deficits in the social domain exhibited by individuals with intellectual disability, as described in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5-TR), include deficits in social judgment, interpersonal communication skills, social problem solving, making and maintaining friendships, and interpreting and demonstrating emotional and social empathy. These social deficits in children have been linked to a variety of unfavorable outcomes including loneliness, social anxiety, peer rejection, and poor academic performance. Social difficulties continue to persist as an individual reaches adolescence and adulthood and can lead to withdrawal, isolation, and social rejection,

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making integration into the community difficult. Many adults with intellectual developmental disabilities are unemployed, have little social support, and suffer from mental health issues. Comprehensive social skills interventions for this population spanning across all stages of development are therefore vital.

Many social skills training intervention strategies for individuals with disabilities can be found in the educational and behavioral literature (Matson & Ollendick, 1988). These skills have been taught within a multitude of social contexts such as the home environment (e.g., responding appropriately to parent initiations), school activities or play situations (e.g., initiating interaction with peers in the classroom or on the playground), and work settings (e.g., expanding interactions with coworkers). As an individual's social context changes and grows across the lifespan, it is important to identify strategies that target the social skills appropriate for each phase of development.

For the purposes of this chapter, we organize social skills interventions by different developmental stages including early childhood, elementary school age, adolescence, and adulthood. In each section, we present a brief description of the social skills significant at these various developmental stages and provide commentaries on studies using intervention techniques that target those skills. In the first section, we describe joint attention interventions that establish social engagement between young children and their parents and caregivers. Second, we focus on socially appropriate classroom behaviors and social play interventions for school age children. Third, we focus on peer social interaction interventions for adolescents both in and out of school. Last, we describe social problem solving and choice-making interventions for adults in work and community settings.

Social Skills in Early Childhood

The ages of birth to three are a rapid time of growth and development. Most infants and toddlers make tremendous gains in their motor, communication, and interaction skills throughout this stage in life. Oftentimes, much of this development is socially mediated. An infant crying simply to be picked up, a parent holding out his arms and encouraging a child to take her first steps toward him, a toddler telling his mother, "look" and pointing to the sky as an airplane flies above are all examples of common early social experiences. For some children however, these natural social interactions may be more challenging to navigate, and direct interventions need to be in place in order to teach these skills.

When considering these direct interventions it is important to note that unlike later years in life, the natural environment for children under the age of three is generally the home. Parents oftentimes have to be both the caregiver, and also the instructor, interventionist, and problem solver for their child. This means that the child's social world often revolves around the parent. For this reason, it is imperative that professionals help parents to recognize deficits in social interaction and to train them in strategies to elicit appropriate social responses from their child.

Joint Attention and Social Engagement Interventions for Early Childhood

Disruptions in the development of joint attention are one of the earliest markers for concern in regard to social development in a variety of disabilities, including autism spectrum disorder (ASD). Although joint attention (i.e., the visual coordination of attention with a partner to an external focus, showing social engagement and an awareness of the partner's mutual interest) is one of the first discernable social skills that appears in both the form of responding and initiating, there are developmental precursors to this milestone that are often missed in children with ASD or some forms of intellectual disability.

Schertz and Odom (2007) suggested four steps in promoting interaction among toddlers with ASD and their parents. In this study, the parents of three children age 24, 33, and 22 months were taught mediated learning principles as they related to the development of joint attention as well as suggestions for activities across each of the four phases. Phases included focusing on faces, turn taking, responding to joint attention, and initiating joint attention. Each phase first relied on parent initiations and then moved to child seeking initiations. Activities for focusing on faces included, (a) using interactive face oriented vocal games with strong rhythms, (b) pairing looks to the face with expressions of affection, (c) positioning the parent's face in the child's line of sight, (d) imitating facial expressions, and (e) playing in front of a mirror. For turn taking, activities included (a) imitation of child-initiated gestures, (b) response to child's actions as if they were intended as initiations, (c) embedding of parents' actions into the child's isolated repetitive play, (d) following the child's lead, and (e) expectant pausing for child's response. Activities for responding to joint attention included (a) introducing a toy only after establishing eye contact, (b) holding a toy near one's eyes when offering it to the child, and (c) use of excitement or suspense to promote the child looking between the toy and the parent's face. Finally, activities for initiating joint attention included (a) encouraging the child to engage the parent's attention in relation to an object by expressing excitement about the child's play with a toy or (b) introducing "surprise" objects.

During baseline participants showed varying levels of focusing on faces and turn taking; however, no participants showed the ability to respond to or initiate joint attention. Post intervention results indicated that all three participants increased engagement in focusing on faces and turn taking, with two of the three participants also consistently increasing their responses to and initiations of joint attention. These results suggest that a parent mediated, developmentally oriented, and interaction based model can assist in increasing the social engagement and joint attention skills of toddlers with ASD by breaking down the components necessary to teach more advanced social engagement. It is important to consider the initial components necessary for engagement of joint attention as well as the specific effective mechanisms for teaching each step in order to assist children in reaching more sophisticated social interaction skills.

Some children may already have the prerequisite skills needed to begin working on more advanced social engagement including initiating and responding to joint attention, as we all as the general ability to engage with others during an activity. One study focusing on these outcomes was conducted by Kasari, Gulsrud, Wong, Kwon, and Locke (2010), and used a randomized controlled trial in order to find variations in joint engagement between toddlers whose parents are trained in intervention procedures compared to those on a waitlist. In this study, random numbers were used to assign families to a wait list or intervention group with no significant differences between these groups found prior to intervention.

The intervention group, which consisted of 19 toddlers ranging in age from 21 to 36 months with validated ASD diagnoses, and their caregivers, received 24 sessions of targeted intervention training. During these sessions, parents were trained through use of direct instruction, modeling, and guided practice to follow the child's lead and interest in activities, imitate their child's actions, talk about what their child is doing, expand on what their child says, give corrective feedback, sit in close proximity to their child and make eye contact, and make environmental adjustments to engage their child. Sessions were video recorded prior to the study, at the start of the training intervention, at the completion of the training intervention, and at a 12-month follow up visit. Reviewers' blind to both the group status and point in time coded primary outcomes, including engagement states and joint attention, in time of video. Joint engagement was defined as child and partner actively involved with the same object or event with the child showing awareness of the parent or coordinating their attention between the parent and event.

Results indicated that the intervention group engaged in significantly more joint engagement and responsiveness to joint attention at the end of the intervention than the wait list group. These results maintained at the 1 year follow up. Initiations of joint attention however were not found to be significantly higher for the intervention group than for the wait list group. So while the results indicate that training parents in key intervention strategies can assist with increasing joint engagement and responses, it suggests that more needs to be done to specifically increase initiations for joint attention among toddlers with ASD. This finding again highlights the necessity of interventionists to look at the specific components of early engagement that an individual child needs assistance in developing. It also supports previous research suggesting positive implications for instructing parents in effective strategies for the targeted goal (e.g., Lang, Machalicek, Rispoli, & Regester, 2009).

One such strategy for increasing initiations of joint attention that has been suggested in the research is the use of preservative interests within learning. In an effort to find a specific strategy for teaching and generalizing joint attention Vismara and Lyons (2007) began by measuring the instances of joint attention between three toddlers diagnosed with ASD and their parents, using both toys of perseverative interests and toys unrelated to perseverative interests. The parents of the toddlers were then taught an overview of pivotal response training (PRT) and were trained on implementation of specific strategies including following the child's lead and interests, interspersing maintenance of previously learned tasks and acquisition of new tasks, consistently varying tasks to maintain child interest, reinforcing correct responses and reasonable attempts at a correct responses, administering reinforcement immediately and contingently following the child's demonstration of a target behavior, and providing direct natural reinforcement.

After parents met mastery criteria for implementation of the selected PRT techniques, conditions began where the same teaching occurred, but perseverative interests (PI) materials or non-perseverative interests (NP) materials were used throughout all teaching opportunities. Two participants began with the PI condition, and one began with the NP condition. For all participants, rates of joint attention initiations were at zero during baseline, but increased during PI conditions. During NP conditions all children again showed initiations of joint attention at or near baseline levels. The study then used an alternating treatments design to randomly alternate between sessions of PI and NP materials. During this final phase, all participants increased their use of joint attention during both PI and NP sessions. The findings of this study suggest that use of perseverative interests as reinforcers during naturalistic behavioral interventions like PRT can increase levels of joint attention in toddlers with ASD without direct teaching. In addition, the findings suggest that generalization of these skills to objects unrelated to their perseverative interests occurs when sessions are varied to include both PI and NP materials. This finding is important to note when considering the teaching of early social skills in that the use of perseverative interests is something to highlight as a way to elicit social interaction.

Although many interventions during the early childhood years focus on implementation within the home with parents as the primary delivery agent, there are many toddlers who spend time in some form of classroom-based setting. For this reason, it is critical to also be aware of key strategies for teaching social engagement to toddlers in these settings (Koegel, Matos-Fredeen, Lang, & Koegel, 2012). Landa, Holman, O'Neill, and Stuart (2011) used a randomized control trial to study the effects of only the Assessment, Evaluation, and Programming System for Infants and Children (APES) as compared to the use of the APES with supplementary social curriculum in a classroom setting for toddlers diagnosed with ASD and ranging in age from 21 to 33 months. There were no significant differences between the groups at the start of intervention, and all children received instruction through use of the APES, with the Interpersonal Synchrony (IS) group also receiving additional focused social curriculum.

Because joint attention and imitation are a component of the APES curriculum, there were goals for these skills across both groups. However, the group in the IS condition received many more orchestrated opportunities to respond to and initiate joint attention, as well as imitate others during social engagement. Interventionists leading this group were trained to model and prompt social targets, as well as to create a physical learning environment that presented opportunities for initiating and responding. This environment included use of enticing or preferred objects and images in the classroom, the use of "surprise" events, and provision of engaging activities based in imitation goals and preferred activities.

Children were assessed prior to intervention, at the completion of intervention, and at a 6-month follow up by a clinician blind to the group membership and unfamiliar to the child, for initiation of joint attention and socially engaged imitation. For this study, social engaged imitation was defined as proportion of imitations paired with eye contact to the examiner. A statistically significant effect was found for socially engaged imitation in the SI group who had received additional imitation goals, modeling, prompting, and environmental arrangements to create and assist with social opportunities. Additionally, while the difference between groups for measures of initiated joint attention were not statistically significant, a trend was found toward significance for initiated joint attention between post-test and follow up. This study suggests that, although comprehensive developmental curriculums (e.g., APES) can be effective for increases in global development, using targeted interactions that involve a joint focus of attention within motivating activities as well as using prompting and modeling strategies to reach child initiation program goals may be necessary in order to develop increased levels of social engagement.

Practice Recommendations

The focus of intervention in the early years is primarily on parent training, but it is important to know key overarching components of teaching social interaction skills to children under the age of three, regardless of the intervention agent. The above examples have some commonalities that are to be noted as main mechanisms in the teaching of these skills.

Following the child's lead is an important strategy in order to begin with the child's interest in an already engaging moment (Kasari et al., 2010; Schertz & Odom, 2007; Vismara & Lyons, 2007). This strategy was used across almost all successful interventions. Vismara and Lyons (2007) highlighted the importance of following the child's lead by finding joint attention was emitted at a higher rate when the child was engaging with perseverative over non-perseverate interests. This use of perseverative interests specifically displays the ability to gain social interaction by starting with items the child is already engaged in. A common misconception is that a child engaging with an item only in a perseverative manner will not direct their attention away from the item to make it a social event, making the use of this item ineffective for therapeutic purposes. Vismara and Lyons (2007) however, showed the opposite may be true.

In addition to following the child's preference, the strategies of prompting and reinforcement were consistently beneficial components of teaching social interaction (Kasari et al., 2010; Landa et al., 2011; Schertz & Odom, 2007). Prompting was often seen in the form of expectant waiting, or material placement and environmental arrangement. Reinforcement was used both through receiving desired materials and social reactions. Reinforcement was effective across studies, when delivered immediately after a social behavior, to help produce more social interactions in the future.

Overall, knowing the appropriate steps towards social interactions in early childhood, having goals that specifically focus on these interactions, defining and measuring the goals, and using appropriate strategies to accomplish growth, are all necessary components of teaching social skills to young children. Additionally, teaching parents or other caregivers to facilitate and reinforce appropriate social interactions, not only during scheduled intervention time but embedded within the context of typical activities throughout the day with their child, can have a lasting impact on the child's social world.

Social Skills in School Age Children

As children enter school, their social context naturally expands. Rather than engaging primarily with parents and other family members as in the earliest years of development, the child interacts with a variety of new adults and peers. In school, a child is expected to follow rules and comply with teacher requests, demonstrate appropriate classroom conduct, and engage in prosocial behaviors. Friendships with peers outside of the family become important, and the child learns to socially engage with peers through play, sharing, and cooperating in joint activities. The development of appropriate social skills at this age has a positive impact upon a child's success in school, emotional wellbeing, and quality of life (Carter, Sisco, Chung, & Stanton-Chapman, 2010; Rubin, Bukowski, & Laursen, 2009). Conversely, social skill deficits can detrimentally affect academic performance and damage peer and teacher relationships.

As children with developmental disabilities are more likely than their typical peers to exhibit social deficits, social skills training is particularly important in order to ensure the success of these students during the elementary school years. The ability to demonstrate self-control, follow directions and attend to teacher instructions, cooperate with and respond appropriately to peers and adults, and use free time in an appropriate manner are social skills identified by general and special education teachers as crucial for success in elementary school classrooms (Gresham, Dolstra, Lambros, McLaughlin, & Lane, 2000; Lane, Givner, & Pierson, 2004). Interventions that focus on these social behaviors are essential at this developmental stage so that students with disabilities can better meet the demands and expectations of an elementary school setting.

Social Behavior and Social Interaction Interventions for School Age Children

For children both with and without disabilities, observational learning can be an important tool in developing social skills. Observing a socially competent model perform desired social behaviors has been shown to produce increases in the child's own use of such behaviors. Video modeling, in which individuals view a recording of a socially competent model performing targeted social behaviors, is a form of observational learning that has been found to be particularly effective in improving the social skills of children with developmental disabilities. Targeted behavioral outcomes successfully improved with video modeling have included social initiations, responses, perspective taking, answering questions, reciprocal play, imitative play, and compliance with instructions (e.g., Kagohara et al., 2013; Lang, Shogren, et al., 2009).

Simpson, Langone, and Ayres (2004) utilized video modeling to improve social behaviors of four 5 and 6-year olds with ASD and speech and language delays during small group activities with a teacher. The four children spent a majority of their day in a special education classroom and participated in inclusion periods in the general education kindergarten class. All children had limited verbal skills, exhibited deficits in social functioning, and rarely demonstrated the social skills required for appropriate participation during small group activities with the teacher. Targeted social behaviors included social greetings, sharing with peers, and compliance with teacher directions.

During the intervention, the participants used a computer to view video models of appropriate social behaviors. The video presented a statement about the function of the targeted social behavior and provided a definition of the behavior using simple language appropriate to the child's understanding. Then, the participant viewed a 4–6 s video clip of typical peers modeling the behavior during structured school activities. After the peer-modeling clip, a summary of each behavior was presented using still photos. Finally, participants viewed the video clip one additional time.

Observation of social behaviors occurred during structured small group reading, math, and art activities. Each participant was given four opportunities during each activity to demonstrate compliance with teacher directions, initiate greetings to the teacher and other students in the group, and share materials with a peer during the activity. During baseline, children demonstrated low levels of the targeted behaviors. Following the video modeling intervention, all participants showed increases in unprompted use of the targeted social skills, and these gains continued to rise steadily over the course of the intervention. By the end of the intervention one participant demonstrated the targeted social behaviors during small group activities 94 % of the opportunities, two participants demonstrated the targeted social behaviors 97 % of opportunities, and one participant demonstrated the targeted social behaviors 100 % of opportunities.

Although students had demonstrated some use of the social behaviors prior to intervention, these skills were used inconsistently and at low levels. Video modeling increased the consistency and frequency of occurrence of three social behaviors necessary for participation in small group activities.

Chan and O'Reilly (2008) similarly focused on improving the socially appropriate behaviors of two 5 and 6-year old participants with ASD during instructional times using an intervention package that included Social Stories and role-play. Social Stories are used frequently in schools and consist of written or visual guides that simply and concretely describe a situation, skill, or concept, as well as relevant social cues and appropriate behaviors (Gray & Garand, 1993). In this study, Social Stories and role-playing were used to reduce inappropriate social interactions and vocalizations and increase appropriate hand raising and social initiations during circle time and center activities.

During baseline, both participants showed high frequencies of inappropriate vocalizations and interactions, with low frequencies of appropriate behaviors. Intervention sessions occurred on an individual basis before school began and only one story describing one target behavior was read per session. First, either the participant read the story silently, or the instructor read the story aloud to the participant. Next, the instructor asked three comprehension questions to check the participant's understanding of the story. If a response was incorrect or not given, the instructor prompted the participant to reread the pertinent part of the story pertaining to the question. The instructor then introduced a role-playing activity and verbally described the situation and target behavior. Next, the instructor, participant, and another adult acted out the situation and target behavior. The participant received verbal prompts if he had difficulty performing a step, and verbal praise was given for correct responses. Observation then occurred during circle time and center activities as in baseline.

After the intervention was implemented, one participant demonstrated an immediate decrease in inappropriate social interaction, a reduction in inappropriate vocalizations, and a progressive increase in appropriate hand-raising. The other participant showed an increase in hand-raising and an increase in social initiations. Follow up data taken 10 months later when both participants were in a new grade with a new classroom teacher indicated that the positive results were maintained over time. In addition, anecdotal evidence suggested that the participants performed appropriate social behaviors comparably to peers once the intervention was introduced.

Children with developmental disabilities may also need social skills support during play and leisure activities as well as during more structured classroom activities. Recess presents an opportune time for children to interact with peers, and a number of studies have focused on social skills interventions in this setting (e.g., Lang et al., 2011). For example, Mason et al. (2014) examined the effects of social skills instruction and peer networks on the communicative acts of three 6 and 8-year olds with ASD during recess.

The three participants in this study utilized multiword phrases and were able to understand and respond to directions. All struggled with social interactions during recess and failed to engage or initiate with peers. Four to six peers from each participant's class also participated in the study. All children had received introductory training on how to engage with friends during play, yet social interaction did not occur during recess periods. During the intervention, a teacher introduced a play skill and explained its use to the participants and their peer network. The teacher asked the children for examples of how they could talk, share, and play with friends during recess and then wrote relevant answers on cue cards. Next, the teacher introduced a token economy system in which demonstrations of target skills would earn smiley face stickers that could be exchanged for prizes at the end of recess. As the children played, the teacher provided behavior specific praise when participants demonstrated target skills. If the participant did not exhibit any targeted social skills after 30 s, the teacher prompted a peer to use strategies on the cue cards to interact with the participant. If after two peer prompts the participant did not exhibit the targeted social skills, the teacher directly prompted the participant to use the skill. After 10 min of play, the teacher offered the children verbal praise for using the skill. Reinforcement cards were reviewed and prizes were given if the children met pre-established criterion.

During the intervention, the communicative acts between participants and peers increased significantly. The participants averaged 5.8 communicative acts per session during baseline. This number rose to an average of 28.2 communicative acts per session during treatment. Raters strongly agreed that social interaction improved for the participants and peers during treatment and indicated that all children enjoyed and benefitted from the intervention. Furthermore, two of the three participants continued to interact with peers following the intervention, suggesting the durability of the positive gains made during treatment.

After children with disabilities learn desired social behaviors, environmental arrangements that promote the use of the desired social skills may be necessary. Koegel, Vernon, Koegel, Koegel, and Paullin (2012) used a motivating antecedent variable by incorporating the age-appropriate interests of three children with ASD and developmental disabilities into leisure activities with peers in order to improve social engagement and initiations. The participants included three third, fifth, and sixth graders with social difficulties who, although able to initiate communication, exhibited no interaction with peers during social activities. When offered opportunities to participate in social clubs and after school activities, the participants failed to engage with their peers.

Baseline data were taken during lunch periods in which various social clubs were available to all students. The dependent variables included social engagement with peers and unprompted verbal initiations. Engagement was defined as being within proximity of a peer and talking, playing a game, creating a project, discussing the activity, or listening to the peer while making sustained eye contact. Initiations were defined as unprompted verbal utterances directed towards a peer about the club activity or general social conversation. During baseline the participants exhibited no social engagement and made zero initiations to peers.

Following baseline, the preferred interests of the participants were incorporated into the club activities. Clinicians met with the participants and their parents in order to conduct an activity preference assessment. Following identification of preferred interests, the clinicians and parents determined which of the interests would be mutually appealing to the participant's peers. Activities of mutual interest that were chosen and incorporated into club included board games with cartoon characters, cooking and crafts, and video game trivia. During the intervention, these clubs based on the participants' interests were introduced to the participants and peers. Adult facilitators introduced the club activity, explained the rules, and answered questions but did not provide any direct social skills instruction or feedback to any participants or peers during the course of the activity.

During intervention, social engagement and initiations rose dramatically. Two participants' engagement level rose to 100 %, and the other participant's level of engagement rose to 98.5 %. For two participants, initiations increased to an average of 12 per club session, which was within range of the number of initiations made by typically developing peers. The other participant's initiations also increased, but still fell below the range of the typical peers. Despite the fact that no systematic data were taken on the generalization of skills outside the intervention sessions, anecdotal observations indicated that the participants continued to interact with their peers once the club activities were finished.

Practice Recommendations

There is a wide body of literature pertaining to social skills interventions for children with disabilities at this developmental stage from which practitioners can draw upon to inform their work. The primary objectives of social skills treatments are to promote skill acquisition, enhance skill performance, remove competing problem behaviors, and facilitate the generalization and maintenance of skills (Gresham, Sugai, & Horner, 2001). The studies presented in this section successfully address these objectives and can provide valuable guidance for practitioners providing social skills interventions to school age students with disabilities.

Regard for the particular social needs of a student and a careful consideration of intervention strategies based upon individual need would seem important to the overall success of an intervention. Video modeling (Simpson et al., 2004) and Social Stories with role-playing (Chan & O'Reilly, 2008) were effective strategies to increase the socially appropriate behaviors needed for successful participation in instructional activities such as circle time, centers, and small groups. Peer networks combined with teacher instruction of social skills using behavioral techniques were successful both in teaching the desired skills and encouraging the use of those skills during recess with peers (Mason et al., 2014). Creating a socially supportive environment by incorporating the preferred activities of students with disabilities into social clubs with peers significantly improved social engagement and initiations for students failing to demonstrate these skills consistently (Koegel, Vernon, et al., 2012). All of these studies utilized behavior analytic strategies such as modeling, prompting, role-playing, and reinforcement, and these strategies are recommended for clinical use when developing individualized social skills interventions.

Social Skills in Adolescence

During adolescence, children tend to spend less time with family members and more time with peers, and peer relationships become increasingly important to the social development of the child. These relationships can provide companionship as well as offer adolescents opportunities to improve existing social skills and develop an understanding of peer norms (Hartup & Stevens, 1999). However, the social deficits exhibited by adolescents with developmental disabilities can make it difficult to benefit from these social relationships, and the treatment of social deficits remains a priority as many individuals continue to experience social difficulties that may not improve with age (Bauminger, 2002; Pituch et al., 2011). Social deficits in adolescents may contribute to a variety of unfavorable outcomes including loneliness, isolation, social anxiety, depression, peer rejection, bullying, and poor academic performance. Successfully treating these social impairments may lead to better short and long-term outcomes as well as contribute to an overall improved quality of life.

Though many evidence-based social skills interventions exist for younger children with developmental disabilities, there is considerably less research focused solely on the social needs of adolescents. Clearly, research involving younger populations can provide valuable guidance in developing social skill interventions for adolescents, but older individuals may require treatments with different intervention procedures and outcomes as a result of changes experienced during this developmental phase. Greater self-awareness and autonomy, changes in cognition, and more complex peer relationships and interactions are all changes associated with adolescence, and interventions that take these developmental changes into consideration are necessary (McDonald & Machalicek, 2013).

Social Interaction and Social Communication Interventions for Adolescents

Social skills group interventions, in which two or more similar aged participants receive group lessons on specific social skills or general social competence using behavioral or social learning strategies, have been shown to improve the social functioning of adolescents with developmental disabilities. Strategies used in social skills groups often include direct instruction of social skills, modeling of desired social behaviors, role-playing of skills, and performance feedback. Goals of social skills groups include increased social motivation, increased social initiations, improved social responding, a reduction of inappropriate social behaviors, and the promotion of skill generalization (White, Keonig, & Scahill, 2007).

In a randomized controlled trial, Laugeson, Frankel, Gantman, Dillon, and Mogil (2012) examined the efficacy and durability of the Program for the Education and Enrichment of

Relational Skills (PEERS), a parent assisted social skills group intervention designed to improve social competence and friendship skills of adolescents with ASD. Twenty-eight adolescents ranging in age from 12 to 17 years old participated in the study. Fourteen participants received the intervention, while 14 were assigned to a delayed treatment group. The intervention took place in a clinical setting and consisted of fourteen 90-min group sessions delivered once a week over a 14-week period. Parents and adolescents attended separate concurrent sessions led by clinical psychologists on social skills and friendship development. Sessions consisted of didactic instruction of the targeted social skill, modeling, behavioral rehearsal, performance feedback, and a related homework assignment, and each session introduced a new-targeted social skill. These skills included trading information to find common interests, conversational skills, electronic communication, choosing appropriate friends, appropriate use of humor, peer entry strategies, peer exit strategies, get-togethers, good sportsmanship, handling teasing, handling bullying and bad reputations, handling arguments and disagreements, and handling rumors and gossip.

Following the intervention, significant improvement in the treatment group versus the control group was found. Parents of adolescents in the treatment group reported significant improvements in social awareness, social cognition, communication, and social motivation. Significant knowledge of social skills was also found in the treatment group versus the control group, and adolescents in the control group reported more frequent peer interactions and get-togethers following the intervention. A 14-week follow up with the treatment group indicated that gains were maintained across almost all domains. Parents additionally indicated improvements in cooperation, assertiveness, responsibility, and self-control as well as decreases in problem behaviors and externalizing behaviors. The adolescents' increases in social communication, social awareness, and knowledge of social skills were also maintained at the 14-week follow up.

For adolescents who have already acquired social skills but fail to demonstrate them consistently, a less intensive intervention approach may be warranted. Peer-mediated interventions, in which socially competent peers are trained in strategies to model, prompt, and/or reinforce targeted social skills, have been used effectively to increase social interaction in adolescents with disabilities. These interventions are supported by a large evidence base and have been successfully used to improve skills such as initiating interaction, responding to initiations made by others, maintaining conversational reciprocity, and maintaining social engagement (e.g., Chan et al., 2009).

Hughes et al. (2013) utilized a peer-mediated intervention to increase social interaction between three 16 and 17-year old students with ASD and intellectual disabilities and their peers in a general education high school setting. All three participants had some verbal abilities and conversation skills but infrequently interacted with peers unless prompted by an adult. Three typically developing classmates were chosen as interaction partners for the adolescents with disabilities. Selection criteria for the peers included sharing a class with the participant, teacher recommendation, an expressed willingness to interact with the participant, and agreement to monitor social interactions with the participant.

The outcome measures of the intervention included the frequency of social initiations and duration of social interaction. Zero initiations or interaction between the participants and peers were observed during baseline. Following baseline, the peer partners received training in how to interact with a classmate with a disability. Peers were given a description of the participant's communication style and then given suggestions for topics of conversation with participants based upon shared interests such as music or sports. Peer partners were instructed to set a daily goal for the number of times they intended to interact with the participant in class that reflected the number of times they typically interacted with classmates. Finally, the peer was taught to self-monitor the goal by recording the number of interactions with the participant. Only peers were given any direct training prior to the intervention and no additional training was offered to peers during the intervention.

After training, the peer partner goal setting and self-monitoring intervention was implemented. Initiations from both peers and participants increased during the intervention. Peer to participant initiations increased from zero during baseline to an average of 9.3 social initiations per intervention session. Participant to peer initiations increased from zero during baseline to 2.2 social initiations per intervention session. Total time spent interacting increased from 0 % of the time per session to 37 % of the time per session, with an average time of 23.7 min interacting. Examination of the peer partners' daily goals and self-monitoring data revealed that the peers were able to meet or exceed their interaction goals a majority of the time and were able to accurately record whether the goals had been met. Furthermore, normative data collected in the participants' classes showed that the percentage of time the participants and peer partners spent interacting was similar to that of the general education classmates in the same settings, indicating socially valid results.

For some adolescents with disabilities, it may be necessary to use interventions that teach the use of desired social skills as well as promote socially responsive environments by teaching others to support the use of these skills. In such instances, using a variety of social skills intervention strategies may be necessary. Ganz et al. (2012) implemented a multicomponent intervention package in order to improve the social communication skills of a 15-year old with intellectual disability, ASD, and speech-language impairment who exhibited impairments in social interaction and displayed repetitive and stereotyped behavior. The intervention involved strategies including peer training, implementing visually supported social scripts, and direct instruction of social skills through modeling, prompting, and reinforcement.

Baseline and intervention sessions took place between the participant and peer during craft activities. The peer had received introductory lessons on how to interact with an individual with a disability. The participant's targeted behaviors included asking questions, offering praise, and requesting help. During baseline, the peer was instructed to interact with the participant as usual but no further instruction was provided. Following baseline, researchers taught the peer to implement prompting strategies with the participant. The prompts were used to promote the participant's use of various social scripts that related to the target behaviors. The scripts provided a picture supported by relevant two to three word phrases appropriate to the participant's assessed ability level. After the peer was trained, she in turn trained the participant to use the social scripts by using verbal and gestural prompts. The peer prompted the participant to use the scripted phrases at pertinent times by pointing to the phrase and, if the participant did not respond, verbally modeling the scripted phrase and then saying "your turn." The peer reinforced correct responses with verbal praise. During the intervention sessions, verbal models were faded and only gestural prompts were provided. Scripts were also faded throughout the intervention by first removing one-fourth of the image and words from the end of the script, then removing half of the image and words, and finally leaving the script cards blank.

During baseline, the participant used few questions, no praise statements, and no requests for help. Following intervention, use of all three types of social phrases increased significantly. During intervention, the percentage of communicative acts per session increased 33 % for questions, 21 % for praise, and 18 % for requests for help. When the scripts were withdrawn, the participant's use of social phrases dropped, but once scripts were reintroduced and gradually faded, the use of social phrases were maintained. In addition, normative data indicated that the levels of the participant's social behaviors were similar to the levels of social behaviors demonstrated by her peers. Generalization to an untrained peer was not successful, though the authors note that making the scripts available to the participant when interacting with the untrained peer instead of withdrawing them completely may potentially lead to better generalization results.

Practice Recommendations

During adolescence, peer interaction plays a prominent role in social development, and social skills interventions for adolescents with developmental disabilities that focus on these interactions in the context in which they occur are recommended. The three studies outlined in this section demonstrate the effectiveness of a variety of different intervention strategies from the broader literature that have a strong or promising evidence base. Social skills groups, behavioral strategies, visual supports, and peer-mediated interventions are all recommended treatment approaches for clinical use to address the social needs of adolescents during this developmental phase.

A consideration of an adolescent's particular social needs is necessary when choosing which treatment approach to employ. Some adolescents may benefit from direct instruction of social skills in a group setting using didactic instruction and behavioral techniques such as modeling, role-play, and performance feedback (Laugeson et al., 2012). Other adolescents failing to demonstrate previously acquired skills may benefit from interventions that promote the use of desired social skills by creating a socially supportive environment in which peers increase the levels of social interactions directed to classmates with developmental disabilities (Hughes et al., 2013). Finally, some adolescents may benefit most from social skills training using behavioral strategies and visual supports as well environmental arrangements through peer training to encourage the use of these skills (Ganz et al., 2012).

Social Skills in Adulthood

The transition from adolescence to adulthood is marked by yet more changes in an individual's social context. Large proportions of time are often spent in the workplace where an individual is expected to interact with coworkers, supervisors, clients, or customers. In addition, leisure time for adults often changes from organizationally based programs (e.g., art club, sports team) to independently driven activities. Furthermore, family environments may also change during this period as an individual moves away from home, develops romantic partnerships, or starts a family. Social competence during this stage of development is necessary if an individual is to successfully navigate these major life changes.

Individuals with intellectual disability may experience challenges understanding and independently accessing social environments, and these challenges may cause complications in successful employment, forming personal relationships, participating in social and leisure activities, and independent living. While independence should be a goal of treatment at all stages of development, teaching adults the skills that allow them to function as independently as possible in their environment is particularly vital. Appropriate social and communication skills are essential for independent functioning and should therefore be an important focus of treatment during this phase of life (Njardvik, Matson, & Cherry, 1999).

While programming throughout the lifespan may help to improve a variety of social skills, the changing contexts in adulthood are cause for interventions that directly focus on social needs of the individual at this developmental stage. Adulthood is the longest stage in the lifespan for most people, yet individuals with disabilities are oftentimes provided with the least amount of organized support during this phase. With this knowledge, many of the interventions in this section of the chapter are appropriately focused not only on a single skill, but instead on teaching strategies that will assist adults with disabilities in self-monitoring their social behavior across the varying situations and environments that they may encounter throughout the later years. It is important to note that, relative to the corpus of research involving children and adolescents, there is a paucity of research involving social and communication skills in adults with disability (Lang et al., 2014).

Social Problem-Solving and Choice-Making Interventions for Adults

One social skills intervention strategy that has been successfully used to enhance appropriate social behavior for adults with intellectual disability is social problem solving or process social skills training (Gumpel, 1994). This type of intervention has typically been reported with individuals with mild to moderate intellectual disability, as it requires that the participant be capable of understanding and then using relatively complex verbal instructions. This strategy has been successfully used to teach such social skills as initiating, maintaining, and terminating interactions; negotiating conflict; and responding to corrective feedback.

Training in this problem-solving technique involves teaching the person to ask and answer a series of questions in relation to the social context, to perform appropriate social behaviors, and finally, to examine the outcomes of the social interaction. The person is first taught to discriminate the salient social stimuli by asking himself or herself, "What's happening here?" the person should then accurately describe the social situation. Next, the person should make a decision with regard to how he or she should behave, "What should I do?" The person is prompted to generate a series of alternative action plans and then to choose the most appropriate social interaction for the current context. At this point, the person performs the overt social skills. Finally, the person evaluates the social interaction by asking himself or herself, "What happened when I [description of how he or she behaved]?" the person is prompted to generate a description of the responses of other people in the social interaction and to evaluate whether these responses were positive of negative. Participants are taught this process using verbal instruction, modeling, and role-playing strategies.

Park and Gaylord-Ross (1989) published an early example of a social problem-solving intervention. In this study, the authors taught three individuals with intellectual disability appropriate social skills within a supported employment setting. Some of the behaviors reported with these individuals included failure to initiate conversations with coworkers, unclear or off-topic conversations when they did initiate, and stereotyped hand weaving. Participants were taught to initiate, expand, and terminate conversations using the problem-solving procedure in a setting removed from the employment site. The appropriate social skills rapidly generalized to the employment site once the participants were taught to use this problem-solving strategy. Subsequent research has replicated the use of social problem-solving interventions in supported employment settings (O'Reilly, Lancioni, & O'Kane, 2000).

The problem-solving strategy has also been used to teach leisure social skills. O'Reilly, Lancioni, and Kierans (2000) taught four individuals with moderate levels of intellectual disability to order and pay for their own drinks in a local bar. Prior to the intervention participants did not interact with bar staff or fellow patrons. Instead, staff who accompanied the participants to the bar ordered and paid for the drinks. Participants were taught to use the problem-solving strategies to greet bar staff, order a drink, accept the drink, and pay for it appropriately. Training occurred individually for participants in their group homes. All participants quickly generalized the skills to the local bars. They also were able to use the skills in different bars without further training. In addition, participants maintained the skills for up to 3 years following training.

For individuals with more severe disabilities, it may be necessary to teach choice-making social communication skills in social situations if choice-making opportunities have not been provided in the past. Several studies have found that individuals with severe and profound developmental disabilities can be taught to make choices using such techniques as errorless learning (e.g., Browder, Cooper, & Lim, 1998) and least to most prompting strategies (e.g., Cooper & Browder, 1998). For example, Browder et al. (1998) taught three adults with severe intellectual disability to choose between segregated settings (i.e., adult day center for people with disabilities) and inclusive (i.e., community) settings for various leisure activities. They first identified individual activity preferences (e.g., practicing golf, viewing magazines, attending meetings), then used an errorless teaching method with time delay to teach the participants object cues to represent each activity in the segregated and integrated settings. For example, the object cue for viewing magazines in the segregated setting was the magazine subscription card, and in the integrated setting, it was the library card. The researchers were successful in teaching the adults with disabilities to make choices using the object cues and found that, when given a choice, they more often chose to participate in leisure activities in the integrated setting over the segregated setting, highlighting the need for providing social skills training, in order to allow individuals to appropriately access integrated environments.

Practice Recommendations

Social problem-solving interventions have proven to be powerful preemptive or antecedent strategies for addressing important social deficits with adults with intellectual disability. This strategy has typically been used with individuals with mild or moderate disabilities who are experiencing difficulties interacting socially with peers without disabilities in inclusive social contexts (work, leisure, or school environments). Findings seem to indicate that social problem solving is a powerful antecedent intervention strategy. It can be described as an antecedent intervention strategy in that intervention does not occur at the point in time when the person is expected to perform. Instead, training occurs prior to when the person is expected to perform and typically in a setting that is removed from the criterion environment. For example, social skills for interacting in the community are taught to participants in the privacy of their group homes (i.e., O'Reilly, Lancioni, & Kierans, 2000). This form of intervention appears to be quite powerful in that it produces generalization of skills across setting and maintenance of skills over time.

As demonstrated by Browder et al. (1998), the provision of choice as an antecedent intervention appears to be an effective method of increasing engagement in social situations and empowering individuals with disabilities. These interventions allow individuals to communicate their wants and needs and can, therefore, enhance their quality of life by providing greater opportunities for expressing self-determination. In order for interventions relying on the provision of choice to be effective, two issues need to be taken into consideration: (1) ensuring that the individual is able to make choices, and if he or she is not, teaching choice-making skills, and (2) training teachers, staff, parents, and caregivers to provide choices appropriately and consistently. Once these issues have been addressed for an individual, the benefits of providing choice become apparent.

Summary

Social skills are not fixed but are instead a dynamic combination of continually developing abilities that change and grow as an individual enters new environments and develops a variety of relationships with varying expectations. From interacting with family members in the home, to peers and teachers at school, to coworkers, friends, and acquaintances at work and in the community, social expectations and opportunities continuously change. Changes throughout the lifespan bring about new contexts and expectancies for an individual to understand and navigate. For many individuals with developmental and intellectual disabilities, these complex social experiences can be both challenging and confusing and may limit their ability to independently access home, school, work, and community environments. Continual treatment of social skills is critical for many individuals across all phases of the lifespan.

In this chapter, we described four stages of the lifespan and presented some of the appropriate social skills and targeted intervention strategies for each corresponding stage of development. In early childhood social development is often focused on the parent and child, and the development of joint attention is the primary objective. These early interactions set the foundation for engagement with others outside of oneself and can be improved with appropriate training and intervention. For school age children, the focus of social skills treatments are to promote skill acquisition, enhance skill performance, remove competing problem behaviors, and facilitate the generalization and maintenance of skills with teachers and peers within the school environment. These skills assist school age children in appropriately interacting within their natural environment and generalizing their social abilities to new settings. During adolescence, interactions between peers become increasingly important, and social skills interventions that focus on improving peer relationships for adolescents with disabilities are necessary. While individualization of treatment is always best practice and recommended across all stages of life, an individual's skills and needs are greatly taken into consideration during this time period, as previous learning histories may strongly impact current skill levels and the need for independence across a variety of contexts continues to grow. In adulthood the focus is often on social problem solving and choice making, in order to teach self-monitoring skills that are generalizable across a variety of contexts. This focus is highlighted by the continually changing domain of adulthood and need for independence.

We have provided a variety of strategies for treating social deficits in individuals with disabilities across all stages of development. As social contexts can change at various points in the lifespan and require continuous development of social skills, it is important to both help the individual develop an understanding of his or her present context as well as how to respond appropriately within that context. While many of the specific skills expected at each stage in life vary, many of the strategies used are effective across all points in time. The majority of successful treatments are individualized based upon the individual's skill level and specific needs and utilize individual interests to promote engagement. Specifically, the use of preferred activities or choice is seen across all stages as an important component of social skills programming. Additionally, the use of behavioral strategies, environmental arrangement, and visual feedback in order to assist with the direct teaching of the skill are components of many effective treatments. Finally, and most importantly, many of the interventions described directly program for maintenance of skills across time and generalization of skills across people and settings. When treating individuals across the lifespan, many of these skills and strategies are also preemptive, in that when used collectively they build on each other in order to teach the person the foundational skills needed prior to entering a developmental stage filled with new expectations. Again, the continual change of social expectations throughout one's life highlights the importance of social goals and treatments across all ages.

We encourage teachers and practitioners who work with this population to routinely incorporate the strategies described in this chapter into their regular instructional arsenal. These educational strategies are recommended practices that are designed to teach communication and social skills and to ultimately enhance active participation of individuals with disabilities in their environment. An education environment that focuses on actively enhancing social communication, social engagement, and social interaction will maximize an individual's social inclusion in regular life settings.

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Early Intensive Behavioral Intervention

19

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Introduction

Early Intensive Behavioral Intervention (EIBI) is, arguably, the most successful and well known example of an evidence-based approach for young children with autism or Autism Spectrum Disorder (ASD), many of whom have comorbid Intellectual Disability (ID). In the past 20 years, enormous amounts of human and financial resources have been devoted to this approach in North America and elsewhere. In many jurisdictions, EIBI has generated debate, excitement, controversy, and litigation. This has resulted in the launching of new service systems (public and private), new training programs for staff, new degree programs, professional certification initiatives, and new research programs.

Historically, behavioral interventions have been used with individuals with ID and/or autism since at least the 1950s, including specific treatments and teaching strategies designed to increase skills (such as speech, play, toileting) and decrease problem behavior (e.g., self-injury, aggression). DeMyer, Hingtgen, and Jackson (1981) reviewed 300 studies up to 1980 and Matson and colleagues reviewed 250 studies published between 1980 and 1995 (Matson, Benavidez, Stabinsky Compton, Paclawskyj, & Baglio, 1996). Most of these studies used single-case research design methodology (e.g., Kazdin, 2011) involving a small number of individuals being treated for very specific behavioral goals.

In the 1960s and 1970s, early intervention for young children with ID was identified as a possible way to improve children's prognosis and such programs have been considered to be well established for some time (Guralnick, 1998). Beginning in the 1980s, EIBI was shown to be especially effective for young children with autism. Although there were several studies published in the early 1980s, the seminal Lovaas (1987) study brought EIBI into the forefront. The dramatic results (47 % of children showing "recovery" from autism, large IQ changes, and functioning without support in regular school settings) were in sharp contrast with previous assumptions about the bleak prognosis for children with autism.

The past 30 years or so has seen the development of more comprehensive behavioral treatment programs that use a combination of behavioral techniques to teach skills across a variety of developmental domains (i.e., communication, social skills, academics, self-help, etc.). Such programs are provided in a very intensive

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manner for many hours per week, sometimes across environments, for 1 or 2 years. These intensive, comprehensive programs target broad treatment outcomes, such as large IQ gains or diagnostic change (i.e., losing the diagnosis of autism), as opposed to more specific behavioral goals such as the frequency of aggressive outbursts or number of pictures correctly identified. Concomitantly, a growing body of research on EIBI has been accumulating that, essentially, replicates and extends the early work. Meta-analyses are now being published summarizing this work and effect sizes are generally reported to be large for IQ change and medium for adaptive skills, although outcomes show great heterogeneity across children. EIBI is now considered to be well established or evidence-based according to various expert panels and evidence-based practice guidelines, described further below.

In this chapter, we first describe the characteristics of the EIBI approach and then review the research evidence regarding efficacy and effectiveness, as well as factors associated with heterogeneity in children's outcomes. Following that, we provide recommendations for practitioners, grounded in the research evidence, as well as recommendations for future research.

Description of EIBI

Behavioral Intervention for Autism

A wide variety of treatment and educational approaches have been suggested and tried in order to help children with autism. For example, Perry and Condillac (2003) reviewed over 50 types of treatment. Results of this review, as well as other comprehensive reviews of the research evidence (NAC, 2009; NRC, 2001; NYSDH, 1999; Wong et al., 2013), demonstrated that interventions that have the best evidence of effectiveness are behavioral in nature (versus medical or psychological). The term "behavioral" is quite a broad term and includes many specific treatment approaches, or focused intervention strategies (Odom, Collet-Klingenberg, Rogers, & Hatton, 2010), that are based on the principles of Applied Behavior Analysis. It is important to understand the distinction between the terms *Applied Behavior Analysis* (ABA) and *Early Intensive Behavioral Intervention* (EIBI), which are not interchangeable.

Applied Behavior Analysis or ABA is a very broad field. It is defined as, "*…the science in which tactics derived from the principles of behavior are applied systematically to improve socially significant behavior and experimentation is used to identify the variables responsible for behavior change*" (Cooper, Heron, & Heward, 2007, p. 20). ABA includes a large variety of specific evidence-based methods of assessment and intervention based on behavioral theory. These methods can be applied to a wide range of human problems and are not limited to a specific age group or diagnosis. There is no particular setting, therapist–client ratio, or intensity that makes the treatment an ABA-based treatment. Rather, it is the theoretical framework that makes it ABA. To be ABA, a treatment should have the following characteristics (Baer, Wolf, & Risley, 1968): Applied (treat socially significant behavior, either increase skills or decrease problem behaviors or both); Behavioral (focus on observable, measurable behavior); Analytic (define, measure, and use data in every case to show treatment's effectiveness); Technological (use written, replicable programs); Conceptually Systematic (based on behavioral principles such as reinforcement, prompting, shaping); Effective (results in measurable improvement); and Generality (behavior change generalizes over time, people, environments). These attributes may be found in a wide variety of applications (e.g., mainstream education, organizational behavior management, behavioral medicine/health), in different populations (e.g., individuals with ID, brain injuries, learning difficulties, mental health issues), and across the life span (i.e., children, adolescents, adults).

In contrast, ***Early Intensive Behavioral Intervention*** (***EIBI***), sometimes called simply Intensive Behavioral Intervention or IBI (NYSDH, 1999; Perry, 2002), is a specific example of an ABA-based approach. EIBI is a very intensive treatment package designed specifically for young children with autism, based on the principles and techniques of ABA. The term EIBI emphasizes the early start to intervention (in the preschool years) and the intensive manner in which it is delivered (typically 20–40 h/week). The goal of EIBI is to change children's rate of learning so as to fundamentally alter their developmental trajectory, rather than just to teach specific skills or decrease problem behavior, which is generally the goal of focused ABA interventions.

Several other comprehensive, early intervention approaches have been proposed including Pivotal Response Treatment (Schreibman & Koegel, 2005), Early Start Denver Model (Dawson et al., 2010), and the Learning Experiences and Alternative Program for Preschoolers and Their Parents (Strain & Bovey, 2011) and there is emerging evidence of their utility. Although there are certain differences among approaches, all share certain commonalities (see Handleman & Harris, 2008 for a description of various model programs). However, the early intervention programs with the strongest support and the largest body of research to date are EIBI, based originally on the UCLA model (Lovaas, 1987). As such, this model will be the focus of the current chapter.

There are a number of treatment characteristics believed to be integral to effective EIBI. Specifically, it is recommended by many (Eikeseth, 2009; NRC, 2001; Perry, 2002; Rogers & Vismara, 2008) that successful programs: begin in the preschool years; are intensive in nature (i.e., provide many hours per week of direct service with frequent supervision); use structured behavioral teaching principles; use curricula which are comprehensive in scope, developmental in sequence, and individualized to the child; collect and analyze data frequently and make data-based treatment decisions; involve parents as part of the treatment team; involve programming across a variety of settings; involve opportunities for systematic inclusion with typical peers; plan for a systematic transition into the next environment; and include plans for generalization and maintenance of skills. Each of these ten characteristics of EIBI is now described further and available research pertaining to some of these factors is reviewed in more detail in the Research section below.

Characteristics of EIBI

1. Begins in the Preschool Years

By definition, EIBI is a form of Early Intervention and typically takes place during the preschool years. It can be argued from several theoretical viewpoints why an early start might be important. From a neurological perspective, there may be critical or sensitive periods when there is still sufficient experience-dependent synaptic plasticity (Chugani, 2005) for EIBI to alter brain functioning. From a developmental perspective, intervening early, before a child has fallen too far behind their peers, would be advantageous. A behavioral perspective would stress the importance of developing adaptive repertoires of skills early to prevent, and not have to unlearn, nonfunctional and less desirable behavioral repertoires. Empirical findings regarding starting age are discussed below in the Research section of this chapter.

2. Is Intensive in Nature

EIBI is intended to be an intensive treatment, meaning it takes place over many hours per day across many of the child's daily environments (Eikeseth, Klintwall, Jahr, & Karlsson, 2012; Lovaas, 1987). Often, children receive between 20 and 40 h per week of therapy for 1–2 years, or even longer. The NRC (2001) Report recommended a minimum of 25 h per week for 12 months per year. Research findings on the importance of intensity, as well as duration of treatment, are also discussed below in the Research section of this chapter. The intensity of EIBI also extends to an intensive model of supervision, whereby the treatment and progress of each child is examined frequently with the child's treatment team by a highly qualified supervisor.

3. Uses Structured Behavioral Teaching Principles

It is not simply the amount of time the child is in intervention but the behavioral nature of the treatment that is crucial (Eikeseth, Smith, Jahr, & Eldevik, 2007; Howard, Sparkman, Cohen, Green, & Stanislaw, 2005). Recently, a comprehensive review of the literature identified a total of 27 evidence-based practices for use with children and adolescents with ASD, referred to as "focused intervention practices" (Wong et al., 2013). The majority of the identified evidence-based practices were typical behavioral teaching strategies (e.g., discrete trial teaching, reinforcement, task analysis), or combinations of these strategies used to develop skills or reduce interfering behavior (e.g., functional communication training). Many of these practices form the foundation of EIBI. For example, children's programming might involve the use of time delay prompting to encourage spontaneous communication (Matson, Sevin, Fridley, & Love, 1990), prompting to teach sight-word reading (Birkan, McClannahan, & Krantz, 2007), task analysis to teach more complex vocal imitation skills (Tarbox, Madrid, Aguilar, Jacobo, & Schiff, 2009), discrete trial teaching to teach household safety skills (Summers et al., 2011), and reinforcement to increase early vocalizations (Esch, Carr, & Grow, 2009). In addition, ABA strategies may be used to reduce interfering behavior. For example, functional communication training (Carr & Durand, 1985) may be used to teach an appropriate replacement skill, such as asking for a break, while also using extinction to reduce the occurrence of interfering behavior, such as aggression, in order to avoid a difficult task. Another example of the layering of focused behavioral practices within EIBI is in the use of the Picture Exchange Communication System or PECS (Frost & Bondy, 2002). PECS incorporates evidence-based practices including prompting, modeling, task-analysis, time delay, and reinforcement and may be used within EIBI as a form of Augmentative and Alternative Communication.

4. Uses Curricula That Are Comprehensive in Scope, Developmental in Sequence, and Individualized for the Child

EIBI is intended to achieve broad learning or developmental impact and to maximize children's intellectual, adaptive, and socio-emotional functioning (Smith, Buch, & Gamby, 2000; Wong et al., 2013). Comprehensive curricula are designed to teach skills across all areas of development, including language, play, social skills, pre-academics, self-help skills, and motor skills. Further, EIBI programs specifically target the core deficits associated with ASD (such as imitation, eye contact, joint attention) and intervention goals are guided by typical developmental sequences. For example, programs focus on developing language, social behavior, independent toy play, and cooperative play with peers (McEachin, Smith, & Lovaas, 1993). The skills targeted build systematically over time, beginning with early verbal targets (i.e., labeling and requesting), and simple toy play, progressing to the use of more abstract language in sentence format and interactive peer play, and eventually extending to the use of speech to express emotions and make friends (Eikeseth, Smith, Jahr, & Eldevik, 2002; Lovaas, 1987; Sallows & Graupner, 2005). In order to address specific social-communicative deficits, a wide variety of strategies are used to promote joint attention, social interaction, and intentional communication, using a variety of expressive communication modalities (e.g., gestures, words, PECS) (Perry, 2002).

Areas of behavioral concern, such as self-injury, aggressive or disruptive behavior, as well as stereotypical or repetitive behaviors commonly associated with ASD, are also addressed within comprehensive programs. Approaches have changed over time, based on research evidence. Best practice currently includes the use of Functional Behavior Assessment (e.g., Iwata, Dorsey, Slifer, Bauman, & Richman, 1994) in order to determine the function of the behavior and to identify appropriate intervention strategies based on function. Positive approaches (e.g., Koegel, Koegel, & Dunlap, 1996) to promote engagement, prevent challenging behavior, and teach more appropriate skills to replace the problem behavior, are increasingly common (NRC, 2001).

Given the tremendous variability among children with ASD, the curriculum needs to be individually tailored for each child. The specific teaching goals, as well as the methods of instruction, are individualized based on a thorough (and ongoing) assessment of the child's strengths, weaknesses, and preferences. A variety of program variables are commonly individualized, including environmental arrangements (i.e., level of distraction, amount of integration into natural environments), child to adult ratios, balance and timing of peer integration, approach to communication (i.e., speech, AAC), type and schedule of reinforcement, and selection of focused intervention practices (NRC, 2001; Odom, Hume, Boyd, & Stabel, 2012).

5. Data are Collected and Analyzed Frequently in Order to Make Data-Based Treatment Decisions

Ongoing measurement of progress is considered a hallmark of behavioral treatment. In 2001, ten model programs were reviewed (NRC, 2001), all of which had data-based mechanisms for monitoring progress. The results of standardized, norm-referenced assessments (e.g., measures of intellectual and adaptive functioning) are commonly used to establish initial program priorities, evaluate child and program outcomes, and for research purposes. However, this form of data is insufficient to guide the individualization of teaching targets and strategies, and to ensure that timely adjustments are made to programming. For this reason, behavioral programs rely on regular, direct observational data (i.e., trial-by-trial data, frequency, percent correct, rate of responding, duration, latency, etc.) in order to monitor children's ongoing performance. These data are reviewed for every child regularly (e.g., weekly) by highly trained supervisors, and used to make frequent adjustments to teaching procedures, such as instructions, prompts, reinforcement strategies, and pace of learning. In addition, EIBI programs often incorporate the use of curriculum-referenced assessment tools, such as the Assessment of Basic Language and Learning Skills—Revised (ABLLS-R) (Partington, 2010) and the Verbal Behaviour Milestones and Assessment Placement Program (VB-MAPP) (Sundberg, 2008) in order to guide specific goal selection and to monitor progress across developmental domains.

6. Involves Parents in Programming

In most EIBI programs, parents are identified as integral members of the child's treatment team. However, the manner in which parents are involved varies significantly across programs. At a minimum, parents are reported to receive education and training in ASD, EIBI, and their child's specific program characteristics. In some situations, parents are expected to teach their child at home informally or to generalize skills to natural settings (e.g., Howard et al., 2005). Other programs provide parents with extensive training in treatment and data collection procedures and require parental commitment to deliver a minimum number of intervention hours per week in home and community settings (e.g., Lovaas, 1987).

There are also some parent-directed EIBI programs, in which parents hire and train staff as well as conducting some therapy hours themselves. In a study comparing parent and clinic-directed EIBI, Sallows and Graupner (2005) did not find any significant differences between groups on measures of outcome. Thus, it seems that at least some parents are capable of organizing and delivering their children's EIBI home programs. However, other parents may need significant support to be actively involved in ways that will benefit their children.

7. Involves Programming Across a Variety of Settings

As alluded to in the prior section, EIBI takes place in a variety of settings, including homes, clinics, schools, and community settings. As with other characteristics of EIBI, there is significant variation in the setting, or combination of settings, in which treatment is offered. Some programs offer programming solely in one environment, such as the home (Bibby, Eikeseth, Martin, Mudford, & Reeves, 2002; Magiati, Charman, & Howlin, 2007) or an autism-specific classroom (Zachor & Ben-Itzchak, 2010). Others provide therapy in multiple settings (e.g., Fava et al., 2011). Programming in school settings may involve one-to-one work in a separate room, as well as time spent in the regular classroom (e.g., Eikeseth et al., 2007). The setting of training may also vary over the course of treatment as children's educational requirements change and they develop new skills (especially peer interaction skills, discussed next). Other practical considerations may impact on the choice of setting (e.g., supervision may be easier in clinic settings) but there is no clear evidence related to treatment outcomes that mandates one particular setting.

8. Involves Some Systematic, Supported Inclusion with Typically Developing Peers

Deficits in social communication and social interaction with peers are among the core deficits of ASD (APA, 2013). As such, EIBI programs regularly incorporate inclusion with typically developing peers as a program component; although there is considerable variation in the timing and manner in which this is done (Handleman & Harris, 2008; NRC, 2001). Many programs recommend a period of individualized one-to-one instruction in order to develop basic social and play skills, followed by opportunities to generalize these skills to typically developing peers, gradually transitioning from one-to-one treatment to small- and large-group formats or from home-based programming to settings such as preschool, kindergarten, or elementary school (Eldevik, Hastings, Jahr, & Hughes, 2012; Smith, Groen, & Wynn, 2000). Social interaction and cooperative play may begin with staff, then expand to play with siblings and peers (Sallows & Graupner, 2005), or supervised play dates with typical peers may be systematically incorporated into programming (Howard et al., 2005).

Although there is uncertainty as to the optimal timing of and approach to peer involvement, it is worth noting that none of the aforementioned programs relies on simple exposure to peers in natural environments. Rather, systematic plans are developed, many of which use behavioral strategies (i.e., prompting, reinforcement) and follow a developmental hierarchy. Learning objectives are developed to meet the needs of individual children, program data are collected to monitor progress toward these objectives, and skills training is provided to peers, staff, and families. Further, evidence-based approaches, including peer-mediated interventions, errorless learning, time delay prompting, incidental teaching, pivotal response training, social skills training, and structured play groups are used (Strain & Bovey, 2011; Wong et al., 2013).

9. Involves Systematic Planning for Transition to the Next Setting

As stated earlier, EIBI is not a long-term treatment; rather, the goal is to maximize children's functioning in order to reduce their need for special education services and enhance their success in less restrictive environments, such as mainstream classrooms (Lovaas, 1987; Smith, Buch, et al., 2000). As transitions may be particularly difficult for some children with ASD, careful planning is required to prepare the child for the next setting, typically school. To achieve this outcome, EIBI programs plan from the outset to systematically reduce one-to-one instruction, while concurrently increasing time within mainstream settings. For example, several authors (Cohen, Amerine-Dickens, & Smith, 2006; Sallows & Graupner, 2005; Smith, Groen, et al., 2000) have reported that, as children developed a number of prerequisite skills (e.g., spoke in short phrases, cooperated with verbal requests, demonstrated peer play and self-care skills), they were introduced to the mainstream classroom with the support of EIBI therapists. Therapists were responsible for helping teachers establish instructional control and for helping children adjust to classroom routines and develop skills such as attending to the teacher's instructions and joining others on the playground. Support remained in place until the data revealed that children achieved independent responding during prespecified activities (such as circle time, center time). With success in the academic environment, the hours of one-to-one treatment were gradually reduced.

Although there are variations in the approach to transition, certain similarities are worth noting. First, there is a period of gradual transition, reducing time in one-to-one therapy, while systematically increasing time in the regular classroom setting. Second, this transition is not arbitrarily initiated; rather, it is started when children demonstrate a number of prerequisite skills. Third, children are transitioned with the support of an aide who is extensively trained in EIBI and who also has experience with the specific child's individual programming. Finally, this support is gradually reduced and discontinued contingent upon the child's success, as determined by data.

10. Includes Plans for Generalization and Maintenance

Generality is one of the core characteristics of ABA programming (Baer et al., 1968). The goal of generality is that behavior change continues over time, appears in settings and activities other than the initial training situation, and impacts behaviors not directly targeted in programming (Stokes & Baer, 1977). Early research in intensive behavioral programming showed that treatment gains were often not observed outside of the training environment, nor were these gains maintained at follow-up in many cases (Lovaas, Koegel, Simmons, & Long, 1973). These findings were the impetus for important changes in programming for children with autism, including: beginning very young, providing treatment for the majority of child's waking hours, and involving caregivers as integral members of the treatment team (Lovaas, 1987). Further, incidental teaching strategies, which tend to promote generalization, were increasingly employed, as well as a gradual transition into more natural contexts, in order to improve transfer of skills to everyday use. These changes had significant implications for outcomes and continue to be essential components of EIBI.

ABA includes a sophisticated technology of generalization. Stimulus generalization has been found to be enhanced when functional skills are taught loosely using multiple exemplars, varied instructions and materials, common stimuli, natural reinforcers, within natural settings and daily routines, across a variety of activities, with a variety of other people (Stokes & Baer, 1977). Response generalization, in which children are taught a variety of response topographies, is also essential. To enhance generalization, EIBI is generally conducted in a variety of settings (home, school, community), with a variety of adults (treatment teams include several different direct therapists, as well as parents), and across various activities (classroom-based, play-based, etc.), as described above.

Research on EIBI Approach and Research Illustrative of This Approach

EIBI is clearly considered to be an evidence-based approach by evidence-based practice guideline processes conducted by various bodies over the past 15 years, including the New York State Department of Health (NYSDH, 1999), the National Research Council (NRC, 2001), the National Standards project of the National Autism Center (NAC, 2009), and the National Professional Development Center on ASD (NPDC) (Odom et al., 2010; Wong et al., 2013). These documents are based on rigorous reviews of the research literature taking into account the strengths and weaknesses of the research designs; sample size and participant specification (age, IQ, diagnosis); method of determining comparison groups (random assignment, parent choice, etc.); measures used, and so on. Some of them include experimental single-case design research studies as well (e.g., NAC, 2009; Wong et al., 2013).

Since the seminal study of Lovaas (1987), group design research studies using standardized measures (e.g., IQ) have been accumulating that document the substantial impact of EIBI. This body of research evidence is now of sufficient magnitude to warrant meta-analytic synthesis and there have been several meta-analyses published (e.g., Eldevik et al., 2009; Makrygianni & Reed, 2010; Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011; Reichow & Wolery, 2009). Authors of the meta-analyses use slightly different samples of studies and slightly different statistical methodology (Reichow, 2012). However, they generally report an effect size (ES) of approximately 1.00 (a large effect by Cohen's convention) for IQ change and approximately 0.60 for adaptive behavior (a medium ES). Effect sizes are, essentially, a statistic in standard deviation units, so an ES of 1.00 means there was a 1 SD difference (i.e., about 15 IQ points) between treatment and control groups at follow-up (or, in some uncontrolled studies, in the treatment group from pre- to post-EIBI). Since IQ is correlated with virtually all other outcomes, these are powerful effects that are highly clinically significant for many children. However, in spite of group-based statistically and clinically significant improvements, it should be noted that individual outcomes are variable across children in all studies (Reichow, 2012).

Most of the studies included in the meta-analyses could be considered to be *efficacy* studies. Efficacy studies show that a treatment can work under particular, usually quite ideal, conditions (selected children, well-trained and supervised staff, and so on). Thus, EIBI can be considered to be efficacious. The next step in establishing that a treatment is transferable to real-world conditions are studies of *effectiveness*. That is, does the intervention work under less than ideal conditions in which children may be more challenging, parents may have complex needs, staffing ratios and skill level may not be as favorable, treatment intensity may be lower, and so on. Very few studies have been published examining effectiveness of EIBI in community settings but this work is being done in Ontario (Perry, Cummings, et al., 2008) and elsewhere and will be crucial to consider.

The variability in children's outcomes, even in the best designed efficacy studies, has been noted by virtually every researcher, and understanding this heterogeneity is the focus of much of the current literature. In the following sections, we summarize the research on the impact of child factors, family factors, and treatment factors on children's outcomes in EIBI. Relevant meta-analytic findings are presented, followed by selected primary efficacy studies and effectiveness studies when possible, including data from the large Ontario community-based effectiveness program that we have studied.

Child Factors Affecting Treatment Outcomes

Several child factors (measured at the beginning of treatment) have been examined in order to determine their effect on EIBI outcomes: age at intake, initial cognitive level, initial adaptive skill level, autism severity, presence of medical/genetic conditions, and diagnoses of ID without ASD. Research findings on each of these will now be reviewed.

Age at Intake to EIBI

As noted earlier, an early start is one of the defining features of EIBI for a number of reasons. Perhaps surprisingly, meta-analyses typically conclude that age does not have a significant effect on EIBI outcomes (e.g., Reichow, 2012) within the range included in the studies. For example, Howlin, Magiati, and Charman (2009) reviewed 11 studies of children under the age of 7 years at the start of intervention, with most being much younger (e.g., under 4), and concluded that initial age was unrelated to outcomes. However, Makrygianni and Reed (2010) conducted a meta-analysis of 14 studies and suggested that studies of children who began treatment very early (around 3 years of age) were more likely to report large effect sizes, whereas studies that included some children beginning later had more variable effect sizes.

Looking at individual studies, the evidence for the effect of age on children's outcomes in EIBI is somewhat conflicting. Many studies have, in fact, shown that a younger starting age is associated with improved outcomes (Eldevik et al., 2012; Fenske, Zalenski, Krantz, & McClannahan, 1985; Goin-Kochel, Myers, Hendricks, Carr, & Wiley, 2007; Harris & Handleman, 2000). For example, considering educational placements as a measure of outcome, Harris and Handleman (2000) demonstrated that children beginning EIBI under 4 years of age were more likely to achieve subsequent placements within a regular classroom compared to children over 4 at intake. Similarly, Fenske et al. (1985) indicated that children admitted under 5 years of age were more likely to achieve placements in schools as opposed to requiring continued clinic-directed treatment. More recently, in a sample of 31 children aged 2–6 in a preschool setting, Eldevik and colleagues (2012) found that children who were younger at intake scored higher on a measure of adaptive functioning after EIBI. Similarly, in a sample of 29 children aged 30–61 months at the start of treatment, Goin-Kochel and colleagues (2007) found that younger children showed better adaptive functioning after intervention.

On the other hand, a number of studies have found that the age a child began treatment was not a significant predictor of outcomes following

EIBI, at least within the age range studied (Eikeseth et al., 2002, 2007; Eldevik, Eikeseth, Jahr, & Smith, 2006; Hayward, Eikeseth, Gale, & Morgan, 2009; Lovaas, 1987; Magiati et al., 2007; Sallows & Graupner, 2005). Eikeseth and colleagues (2002), in particular, found that age was not reliably associated with amount of change or absolute outcomes in a small sample of 4- to 7-year-olds. However, Perry and colleagues (2011) noted that these findings may be attributed to small sample sizes (often only 10–15 children) with the inherent statistical power limitations, as well as more limited age ranges (e.g., 24–42 months in Hayward et al., 2009; 16–46 months in Lovaas, 1987) than the studies that do find an effect for age.

The research done on this topic in Ontario's large government-funded program (see Freeman & Perry, 2010; Perry, Cummings, et al., 2008 for a description) shows a strong relationship between starting age and children's EIBI outcomes. In the original large retrospective study of children aged 2–7 ($n=332$), age was a significant predictor of outcome in several different analyses (Perry et al., 2011). For example, comparing children 4 years and younger to those over 4 at intake revealed significant differences post-EIBI on virtually all outcome variables, including a 20-point difference in IQ. In our subsequent waitlist-controlled study, younger starting age was a significant predictor of better cognitive outcomes in the EIBI group ($n=61$; M age of 3½) but not in the comparison group (Flanagan, Perry, & Freeman, 2012). Looking specifically at older children, Blacklock, Perry, and Dunn Geier (2014) examined outcomes of a group of 68 children in the Ontario program who began treatment at age 6–13 years. We found that there were no significant gains on standard scores for cognitive or adaptive functioning for these older children after about 20 months of EIBI. Although there was some variability in outcomes of the relatively younger children within this sample (i.e., 6- and 7-year-olds), children who started at approximately 8 years or older had uniformly poor outcomes. Combining samples of younger and older children together ($n=207$; aged 2–14) younger age was predictive of better cognitive outcomes (Perry, Blacklock, & Dunn Geier, 2013). Additionally, in a carefully matched sample, cognitive outcomes were substantially better in the younger group (2–5 years old at intake) than the older group (6–13 years old at intake), who were equal at the start of EIBI in terms of IQ, adaptive skills, autism severity, and treatment duration. Although IQ was an important predictor (see next section), results showed that starting age was more important than starting IQ for the outcome variable of IQ-point gain. That is, only very young children (mean age about 3½ years at start of EIBI) made very large IQ gains of 30 points or greater (Perry, Blacklock, et al., 2013).

This body of literature is quite varied in terms of the age ranges included, the ways that outcome is defined, and the results obtained. Within the usual age range of children in most studies (2 years to 4 or 5 years), starting age may not be a strong determinant. However, studies that include wider age ranges seem to be pointing to the theoretically logical conclusion that starting intervention at a younger age is more conducive to better outcomes following EIBI.

Cognitive Level Prior to EIBI

Meta-analyses exploring the relationship between children's IQ at the start of EIBI and their outcomes have provided somewhat inconsistent results as well. One meta-analysis of 11 studies concluded that initial IQ was an important predictor of IQ at follow-up (Howlin et al., 2009). However, another meta-analysis of 13 studies found that pre-treatment IQ did not significantly affect children's post-treatment IQ (Reichow & Wolery, 2009). Yet another meta-analysis of 14 studies found that intellectual ability at intake was not correlated with effect sizes, even though intake IQ was very highly correlated with outcome IQ (Makrygianni & Reed, 2010).

Likewise, individual studies provide variable results. A number of studies have found that a child's IQ at the start of EIBI is moderately or highly correlated with the child's outcome after treatment (Eikeseth et al., 2002, 2007; Harris & Handleman, 2000; Hayward et al., 2009; Sallows & Graupner, 2005). Initial IQ has predicted which children were the most responsive to treatment

(Remington et al., 2007) and had the most improved outcomes (Leaf, Taubman, McEachin, Leaf, & Tsuji, 2011; Szatmari, Bryson, Boyle, Streiner, & Duku, 2003). It has also been correlated with higher communication scores on a measure of adaptive behavior (Eldevik et al., 2012; Grindle et al., 2012). It is important to note that IQ at one time tends to be highly correlated with IQ at another time, regardless of treatment. In fact, initial IQ has also been shown to predict outcomes for children in control groups (e.g., Eikeseth et al., 2002, 2007). Furthermore, in some studies IQ has not been shown to demonstrate a significant relationship with outcome at all (Birnbrauer & Leach, 1993; Cohen et al., 2006; Smith, Groen, et al., 2000).

In a sample of children taking part in Ontario's EIBI program, initial IQ was very strongly correlated with outcomes and accounted for significant unique variance in different outcome variables (5–12 %; Perry et al., 2011). In the study described in the previous section of 207 children spanning both a wide age range and a wide IQ range at intake, initial IQ was the strongest predictor for most outcome variables and was strongly related to both cognitive and adaptive outcomes (Perry, Blacklock, et al., 2013). In addition, we found that children with very low initial IQs (under 30), regardless of age, showed uniformly poor cognitive outcomes (Perry, Blacklock, et al., 2013).

Taking all of these studies together, large IQ ranges have been examined, including children with very low ratio IQs, as well as IQs in the average range. Overall, with a few exceptions, children's starting IQ seems to be an important contributor to outcomes in EIBI, particularly when outcome IQ is used as a measure of the child's success after EIBI, but also when other outcomes (e.g., adaptive skills) are considered.

Although adaptive behavior is frequently used as a measure of outcome in studies, less attention has been given to initial adaptive levels as predictors of outcome. One meta-analysis, though, did report that initial adaptive levels correlated with effect sizes for language outcomes and adaptive behavior outcomes (Makrygianni & Reed, 2010).

A few studies have also provided some evidence that children with better adaptive skills tend to have better outcomes. For example, Remington and colleagues (2007) reported that children with higher baseline adaptive behavior skills had more positive responses to EIBI. Similarly, Sallows and Graupner (2005) reported that the strongest pretreatment predictors of outcome in their sample were imitation, language, daily living skills and socialization, behaviors which make up what is often thought of as adaptive skills.

In an Ontario sample, adaptive behavior levels were correlated with outcomes, and regressions indicated that adaptive level accounted for significant incremental variance in most outcome variables (Perry et al., 2011).

Looking at this limited literature together, pretreatment adaptive skills seem to have an important relationship with treatment outcomes following EIBI.

Diagnostic Severity Prior to EIBI

Although one might expect that degree of autism severity at intake would be widely studied as a predictor of outcomes of EIBI, this factor has received surprisingly little attention in the literature. No meta-analyses to date have examined the relationship between autism severity and children's variable outcomes in EIBI, though some individual studies have.

For example, Eldevik et al. (2012) reported that children with a diagnosis of PDD-NOS (Pervasive Developmental Disorder—Not Otherwise Specified; a less severe diagnosis than Autistic Disorder in the DSM-IV) were more likely to have increased daily living skills and communication on an adaptive behavior measure following treatment. Also, Sallows and Graupner (2005) reported that fewer autism symptoms were predictive of post-treatment IQ. However, Harris and Handleman (2000) reported no relationship between autism severity and outcome, and Remington and colleagues (2007) found, conversely, that children who were the most responsive to treatment initially had more severe autism symptoms.

In Ontario, Perry et al. (2011) found some degree of relationship of diagnostic severity to outcome using an observational measure of autism severity. Furthermore, children with a diagnosis of PDD-NOS, versus those with a diagnosis of Autistic Disorder, were more likely to achieve average functioning following EIBI.

Overall, this small body of literature shows that children at the less severe end of the Autism Spectrum tend to do better following EIBI, than children who are more severely affected.

Presence of Medical/Genetic Conditions

Children with ASD often have additional medical diagnoses or genetic conditions (Eriksson et al., 2013), although there has been very little research on this because such characteristics are often exclusion criteria for treatment studies. Therefore, no meta-analysis has yet been performed to determine how children with additional diagnoses fare in EIBI.

Only one study, by Eriksson and colleagues (2013), examined the impact of these conditions on EIBI outcome, as measured by changes in adaptive behavior over the duration of treatment, in a community sample. A medical or genetic condition was present in 18 % of the children in their sample. Children with such medical conditions were referred to treatment at a younger age. However, children who are diagnosed with autism at a younger age have an increased risk of having comorbid ID (in addition to medical/genetic disorders), whereas children diagnosed at older ages may be more likely to have milder forms of ASD. The children with medical/genetic conditions, though they started treatment earlier, demonstrated poorer outcomes than children without a medical or genetic condition. The results of this study emphasize the importance of taking medical conditions and needs into account, as these may diminish the effectiveness of EIBI.

Children with Intellectual Disabilities Without ASD

In principle, EIBI should be applicable to children with ID without ASD, as well. In fact, the main outcomes of EIBI treatment in studies of children with autism are improvements in cognitive functioning (IQ) and adaptive skills, the two areas that define ID. However, there have been very few published studies exploring applications of EIBI to disorders other than ASD, even though there is an extensive literature using broader ABA methods in ID. Attempts to use EIBI in three girls with Rett syndrome were found to be ineffective (Smith, Klevstrand, & Lovaas, 2005) but this may be a consequence of the extremely low cognitive level and the deteriorating course of the disorder in girls with Rett syndrome (Perry, Sarlo-McGarvey, & Haddad, 1991), and, as previously mentioned, EIBI seems to be less effective in children with autism with very low pre-treatment IQs (Perry, Blacklock, et al., 2013).

Two small, controlled studies of children with ID have shown effectiveness, however. Smith, Eikeseth, Klevstrand, and Lovaas (1997) provided EIBI treatment to 11 children with severe ID and autistic features, who did not meet the inclusion criteria for the Lovaas EIBI study (1987) because of their low developmental level. These children gained a mean of 8 IQ points, which was less than the children in the Lovaas (1987) study, but was significantly better than the comparison group (who received a less intensive treatment) and whose IQ actually declined 3 points, on average. More recently, Eldevik and colleagues (2010) published a retrospective study of a small group ($n = 11$) of children (aged 34–67 months) in Norway with various forms of ID without autism who received 1 year of a non-intensive form (10 h/week) of intervention in their regular preschools or schools (Eldevik et al., 2010). The children showed changes in cognitive and adaptive functioning comparable to those reported in autism and significantly greater than those of a control group of 14 children who received the standard educational provision. More specifically, the ABA treatment group showed, on average, a 17-point IQ gain (a large effect size), versus the eclectic treatment/education group who showed only a 4-point gain. Eldevik et al. (2010) speculate that children who have ID without autism may actually benefit *more* from behavioral intervention because it may be easier to find reinforcers to motivate them (especially social reinforcers), they may have fewer attentional difficulties, and they may have less difficulty with generalization.

In summary, this small body of literature shows some mixed results, and also some promise, of the application of EIBI to children with ID without ASD.

Treatment Factors Affecting Treatment Outcomes

Several characteristics of the intervention itself have been explored or proposed to be important correlates or predictors of children's outcomes in EIBI. These can be divided into *quantity* of treatment (intensity and duration) and what might be considered *quality* aspects of treatment.

Treatment Quantity

The effect of different intervention factors on children's variable outcomes in EIBI has been explored, in particular the quantity of the intervention. In a comprehensive synthesis of EIBI research, Reichow and Wolery (2009), found that standardized regression coefficients for duration of therapy and total hours of therapy were large. Results suggested that the number of months of intervention and/or the number of hours of therapy were related to a higher probability of achieving a large change in IQ scores. Meta-analyses have found treatment quantity to be an important factor in children's progress in EIBI. For example, one meta-analysis of 14 studies found that the intensity and duration of the programs were correlated with children's outcomes (Makrygianni & Reed, 2010).

Intensity

Studies have shown that higher intensity of intervention, about 20–40 h per week, has been linked to improved outcomes (Eikeseth et al., 2002; Granpeesheh, Kenzer, & Tarbox, 2011; Lovaas, 1987; Smith, Groen, et al., 2000). For example, Lovaas (1987) showed that children who received about 40 h of intervention per week had significantly higher IQ scores after treatment, as compared to children who received 10 h or less. Smith, Groen, et al. (2000) replicated and extended this study by including children with a wider range of functioning levels, as well as randomized assignment to group. They found that children who received 25 h per week of intervention for 2 years had significantly better outcomes on measures of IQ, visual-spatial ability, language and academic achievement and were in less restrictive school placements than those who received 5 h of intervention per week.

This question was also addressed in a large effectiveness study of 245 children receiving treatment ranging from 20 to 168 h per month (Granpeesheh, Dixon, Tarbox, Kaplan, & Wilke, 2009). Results indicated that increased treatment hours were associated with greater skill acquisition (although they used no standardized measures) in children under 7 years (but not over 7). Similarly, Reed, Osborne, and Corness (2007) reported that children receiving EIBI at a high intensity (30.4 h per week on average) demonstrated greater gains in intellectual, educational, and adaptive functioning than children receiving a lower intensity (12.6 h per week on average), with the greatest gains in intellectual, educational, and adaptive functioning achieved following 20 h of EIBI per week. Interestingly, they also found an inverse relationship between treatment intensity and outcome for children in the high intensity group (i.e., as intensity increased beyond 20 h per week, gains began to diminish).

As providing children with 20–40 h of treatment is not always possible, researchers have also examined the effects of lower-intensity intervention. In a study of very low intensity (6.5 h per week) behavioral treatment supplementing preschool services for young children (3–6 years old) with ASD and severe to mild ID, Peters-Scheffer, Didden, Mulders, and Korzilius (2010) reported that children receiving the low-intensity behavioral treatment made more gains in adaptive skills than children in the control group. Similarly, Eldevik and colleagues (2006) found that children receiving about 12 h per week did make gains. However, these gains were more modest than those reported in studies examining higher intensity treatment. Large cognitive gains have not typically been shown in lower intensity interventions.

Duration

The other aspect of treatment quantity is the duration of the intervention. Research on this question does suggest that duration of EIBI can be an important predictor of outcome, within the range studied. For example, according to Luiselli and colleagues (2000), duration of EIBI significantly predicted outcomes on a measure of early learning such that children who had completed 11 months of EIBI demonstrated greater progress than children who had completed 7 months of EIBI (Luiselli et al., 2000). Recently, Virues-Ortega, Rodriguez, and Yu (2013) followed 24 children, aged about 4 years on entry, over approximately 2 years of EIBI and found that total intervention amount, which is a combination of both treatment intensity (hours per week) and treatment duration (total weeks of treatment) was predictive of gains on an age-equivalent curriculum-based outcome measure.

It is also important to note, however, that research seems to show that children make the most gains at the beginning of treatment, e.g., Eikeseth and colleagues (2007) found that the greatest gains were achieved within the first 12 months of EIBI. Similarly, in a study that followed children for up to 3 years, Cohen and colleagues (2006) reported that the greatest gains in IQ occurred during the first year of treatment, without any significant changes in the remaining 2 years. Sallows and Graupner (2005) examined children's outcomes after 4 years of EIBI and reported that the children who were deemed "rapid learners" showed significant gains in all areas such as IQ, language, and adaptive skills during the first year of treatment, while changes during the second year were comparatively modest, though some children did improve with ongoing treatment up to 4 years in length.

Both aspects of treatment quantity seem to be important to children's outcomes. More intensive programs (about 25–40 h per week) tend to lead to better results. As for duration, it seems that some children can continue to improve somewhat in treatment, although the largest gains are typically achieved within the first year of EIBI.

Treatment Quality

Though the quantity of intervention is important, what happens during all those hours is also undoubtedly important to children's outcomes (Bibby et al., 2002; Green, 1996; Perry, 2002). Treatment quality has rarely been examined in the literature and there is no current consensus on the measurement of quality in EIBI. Following a meta-analysis of 25 outcome studies, Eldevik et al. (2009) hypothesized that some outcome variability may have been due to too little supervision or to the lack of quality control measures in treatment. In a meta-analysis by Reichow and Wolery (2009), which examined 11 studies including 251 children participating in UCLA-model EIBI, seven hypothesized treatment-related outcome moderators were examined. Of these, only one, the supervisor training model, was significantly related to change in IQ. Specifically, those studies in which supervisory personnel were trained in the UCLA model were more likely to report larger changes in IQ. The UCLA model includes weekly supervision with each child, their parents, and treatment team (i.e., direct staff or therapists, senior therapists, clinical supervisors). Tasks during supervision include data review and analysis, program demonstration, procedural clarifications, performance feedback, and general education for parents around EIBI and ASD (Davis, Smith, & Donahoe, 2002). Children's curricula, including the selection or revision of instructional programs, are modified based on a review of the data and information gathered during the weekly supervision.

Studies that have attempted to examine treatment quality have examined treatment fidelity in therapists providing home-based behavioral intervention (Symes, Remington, Brown, & Hastings, 2006), and adherence in a parent-mediated behavioral program (Allen & Warzak, 2000). One study (Klintwall, Gillberg, Bölte, & Fernell, 2011) found that therapist allegiance to behavioral techniques accounted for 19 % of the variance in children's adaptive outcomes. Conversely, there is some evidence to suggest that programs that are of uncertain quality (e.g., low number of hours, poor training, and poor supervision) are associated with less optimal outcomes (e.g., Bibby et al., 2002; Magiati et al., 2007).

Although the need for well-trained supervisors is generally accepted, not much is known about the frequency or type of supervision required for best EIBI outcomes. Only two studies thus far have included frequency of supervision as a predictor of outcomes following EIBI and the results of these studies are inconsistent, with one not finding any significant relationship between these two variables (Sallows & Graupner, 2005), and the other indicating that a higher intensity of supervision (i.e., more frequent supervision and more supervision hours) was significantly correlated with higher IQ scores after EIBI (Eikeseth, Hayward, Gale, Gitlesen, & Eldevik, 2009, based on data from Hayward et al., 2009).

The York Measures of Quality

While the attempts at examining quality from the perspective of those providing the interventions and the amount of program supervision are important, it is also imperative to examine the quality of the intervention itself. This has been a focus of our research at York University. We made an initial attempt to delineate the important ingredients of EIBI quality by asking parents and professionals to choose important characteristics of high quality EIBI (Perry, Prichard, & Penn, 2006). The answers revealed that parents stressed the importance of varying the discriminative stimuli and therapist characteristics (e.g., enthusiasm), whereas clinical directors/supervisors stressed the more technical aspects of EIBI such as reinforcement type, program design, and supervision/training. Combining both groups, the overall 'top 3' characteristics of quality EIBI teaching were: creating opportunities for generalization (endorsed by 49 % of participants); administering reinforcers of the appropriate type (44 %); and using effective/appropriate behavior management strategies (38 %).

Based on these results, together with a review of the literature and clinical experience, we created the ***York System of Quality Assurance*** (YSQA; Perry, Koudys, & Sheese, 2008), with the purpose of assisting programs providing EIBI to assess the quality of their services relative to evidence-based and best practice standards. The overarching goal of the YSQA is to promote continuous improvement in quality of service to maximize outcomes for children. The YSQA is designed to assess the quality of an EIBI program in a comprehensive way at different levels: quality of EIBI teaching, quality of programming, and quality of the larger organization, with data gleaned from live and videotaped observations of EIBI sessions, reviews of children's binders, central clinical files, organizational files, and surveys of parents and staff (described in more detail in Table 19.1)

One central component of the broader YSQA is the ***York Measure of Quality of IBI*** (YMQI; Perry, Flanagan, & Prichard, 2008), which takes a very detailed look at the quality of the EIBI teaching. In order to use the YMQI, a video of an EIBI session at least 20 min in length is obtained and two 5-min segments are chosen at random. Trained coders then code each 5-min segment according to the detailed instructions outlined in the YMQI Administration Manual (Perry, Flanagan, et al., 2008). Each segment is scored according to 31 individual items in nine categories (See Table 19.2). Each item is operationally defined and specific criteria for a particular rating are listed in the Administration Manual to help guide the coder in scoring the video. Each item is rated on a 5-point Likert scale (1–3 with half-points). Because the YMQI is a measure with high reliability and strong validity, training is required to implement it accurately, which includes completing a quiz on behavioral principles, viewing a self-guided training DVD and completing the included exercises, and achieving at least 80 % inter-rater agreement with the YMQI developers on sample videos. The YMQI is currently being used in a study examining its factor structure and the relation of those factor scores to children's progress and outcomes in EIBI. Preliminary analyses show a modest correlation between YMQI total score and children's developmental gains (Perry, Freeman, Dunn Geier, & Blacklock, 2013). Others are using the YMQI internationally as a measure of quality of intervention in various situations (Perry, 2014). For more information about the YMQI or YSQA, please contact perrylab@yorku.ca

Table 19.1 Conceptual layers and sources of data of the York System of Quality Assurance (YSQA; Perry, Koudys, et al., 2008)

Quality area	Description	Sources of data
Quality of teaching	Effectiveness with which behavioral teaching strategies, such as prompting and reinforcement, are implemented	• Live Observation Checklist (e.g., data recording, procedural fidelity)
		• Video Checklist (e.g., procedural fidelity, inter-staff consistency)
		• Coding of videos according to the YMQI (described in detail below)
Quality of programming	Program selection, staff training and supervision, and parent-professional collaboration	• Local Child Clinical Files Checklist (e.g., curriculum, data collection, behavior protocols)
		• Organizational Files Checklist (e.g., program intensity, amount of supervision)
		• Staff and Parent Surveys (staff and parent perception of their involvement in programming)
Quality of organization and administration	Policies and procedures detailing expectations for staff orientation and performance, human resources, and continuum of services	Central Child Clinical Files Checklist (e.g., supervision processes, continuum of services)
		Organizational Files Checklist (e.g., staff qualifications, training)
		Staff Surveys (e.g., staff perception of their workload, job satisfaction)
		Parent Surveys (e.g., parents' perceptions of communications with program, training opportunities)
Quality of mandate	Mandate under which the program operates and allocation of human and financial resources and policy decisions	

Practice Recommendations

Based on the research described above and our clinical experience, we now provide a series of key recommendations for practitioners. These are grouped into recommendations related to child factors to take into account, quantity aspects of EIBI, and, perhaps most important, factors related to the quality of the EIBI.

Child Factors Recommended for EIBI

Age

It is important for children to be diagnosed early and to begin EIBI as early as possible. Certainly children should begin before age 5 and preferably when they are 2 or 3 years old. Older children may, of course, benefit from an ABA-based approach to teaching skills and reducing problematic behavior, as well as special education approaches. But the comprehensive, intensive form of intervention defined as EIBI is intended, and proven to be effective, for preschool children with ASD.

Level of Functioning

While research does not permit us to specify precisely a minimum IQ or a pre-treatment IQ range that is optimal, it appears that children with mild to moderate levels of intellectual disability are the best candidates with the most research evidence. Within this range, pre-treatment IQ levels seem to

Table 19.2 Categories and items of the York Measure of Quality of IBI (YMQI; Perry, Flanagan, et al., 2008)

YMQI category	YMQI category description	YMQI items
Discriminative stimuli (S^Ds)	Verbal and nonverbal instructions given to the child to follow.	1. Attending during S^Ds 2. Varying S^Ds
Reinforcement	A stimulus that strengthens a response it follows, such that the response is more likely to occur again in the future, and includes verbal praise or feedback, tangible items, social/physical activities, games, or tokens, as well as negative reinforcement such as a break.	3. Rapid reinforcer delivery 4. Motivating reinforcers 5. Varying reinforcers 6. Relation of reinforcers to the task 7. Sincere/motivating verbal reinforcers 8. Differential reinforcement
Prompting and error correction	A stimulus that increases the probability of a correct response and can follow or precede the S^D, and may be full or partial, physical, modeled, gestural.	9. Effectiveness of prompts 10. Fading and augmenting of prompts 11. Lack of prompting errors 12. Follow through 13. Implementation of error correction
Organization	The preparation of the therapist in terms of knowing what she is supposed to be teaching and having all the necessary materials accessible and arranged properly to facilitate the session running smoothly.	14. Clear plan and teaching goals 15. Accessible materials
Pacing	The speed at which trials are presented and the rate at which the child is exposed to learning opportunities.	16. Length of inter-trial intervals 17. Suitable pace for the child 18. Intensive teaching
Teaching level	Whether the level of task difficulty appears to be appropriate for the child, such that there is evidence of the child learning new skills and making progress.	19. Suitable task difficulty 20. Evidence of skill acquisition
Instructional control	The therapist's ability to engage the child for a significant period of time without the child engaging in problem behavior.	21. On-task following requests 22. Maintenance of the child's focus
Generalization	The ability to generalize the skills learned in therapy to new situations, includes stimulus generalization, response generalization, child-directed learning, teaching away from the table, and capitalizing on teachable moments.	23. Varying teaching materials 24. Mixing tasks 25. Teaching away from the table 26. Teaching embedded in naturalistic activities 27. Response generalization 28. Flexible teaching
Problem behavior	Serious behavior such as self-injury, aggression, destruction of toys or materials, and having a tantrum, as well as less serious behaviors, such as throwing teaching materials, actively refusing to participate in the session, refusing to return to the task, and repetitive behavior that is not under the control of the therapist.	29. Result of problem behavior 30. Reinforcement of appropriate behavior 31. Use of prevention strategies

have an important relationship with outcome. That is, children with relatively better cognitive and adaptive skills before EIBI seem to have more positive responses to EIBI (although they may have better outcomes regardless of treatment). Considering the very low and the very high ends of the IQ range associated with ASD, the data are sparse. Research suggests that children who have very low IQs (e.g., in the profound range of intellectual disability) have shown minimal progress. It is also important to consider the complications that accompany certain genetic and medical conditions, as children with these conditions may not respond well to EIBI. At the other end of the IQ range, there is virtually no research specifically on high functioning children (although a few children in some studies have had average IQs prior to EIBI). Children with ASD who have average or higher IQs probably require a different form of intervention focusing on social communication skills in typical settings.

Quantity Factors Recommended in EIBI

Intensity

As the name (and research) suggests, EIBI should be delivered in an intensive format, in other words, for about 25–40 h per week, 12 months per year, bearing in mind that there is no precise number and that quality of treatment is also crucial (see below). When planning for treatment intensity, it is recommended that the amount of treatment or learning opportunities that exist outside of formal treatment hours also be considered. Children require many opportunities to respond actively to functionally and developmentally appropriate learning targets, with high levels of motivation (Strain & Hoyson, 2000). As such, treatment should include year round weekly structured sessions, *plus* informal instruction and practice throughout most of the child's waking hours (Eldevik et al., 2009; Lovaas, 1987).

Intensity is more than just the amount of time the child is in therapy, however. The construct of treatment intensity should include consideration of the number of meaningful learning opportunities, the functionality of objectives, the use of instructional methods that minimize errors and maximize engagement, the competence of staff to deliver the intervention with adequate fidelity, and data-based decision making in order to minimize children's exposure to poor interventions (Strain & Bovey, 2011). Consideration of these factors is recommended to ensure the most effective use of therapy hours. In situations where the amount of treatment is lower than recommended, these considerations are even more important. See below regarding the specific aspects of quality treatment we recommend.

Duration

EIBI is not intended to be a long-term treatment. Rather, it is intended to boost children's developmental trajectory, often within a 1- to 2-year period of time, so they are better equipped to learn in a less restrictive environment. Although the minimum amount of treatment required is unclear, it is unlikely that best outcomes will be achieved in less than 1 year of treatment. Given the aforementioned variability in child factors, including autism symptom severity and level of comorbid intellectual disability, it is probable that different children may benefit from varying lengths of time in treatment. Some children may demonstrate early gains with limited additional improvement in subsequent months or years of treatment, as described previously. Other children may continue to make gains over a longer period of time. As such, it is recommended that children's progress in EIBI be monitored on an ongoing basis to determine whether intervention continues to be warranted. For example, Autism Connection (Cohen et al., 2006) recommends reviewing progress at 6, 12, 24 and 36 months to determine whether children have achieved predetermined skill markers to support continuation. See also Blacklock and Perry (2010) for a preliminary test of such an approach.

Quality Factors Recommended in EIBI

Behavioral Technology

It is recommended that young children with autism receive intensive behavioral intervention based on the principles of ABA. Eclectic models of treatment and "treatment as usual" are not recommended as research clearly indicates poorer outcomes for children receiving these. Further, within the comprehensive behavioral program, it is recommended that specific evidence-based focused intervention strategies (Odom et al., 2010) be used to teach skills across developmental domains.

Curriculum

Programming should be comprehensive in scope and developmental in sequence, with particular focus on the core deficits and behavioral excesses associated with ASD. Given the pervasive nature of ASD symptoms, EIBI curricula should include targets across all areas of development (i.e., communication, self-help, play and social skills, and so on). Targets should be selected to meet the current needs of the child, and, with success, new targets established in a developmental manner. Particular emphasis should be on the development of social-communicative and social interaction skills, often best addressed using incidental and naturalistic teaching strategies. Given the variation in children's expressive communication abilities, consideration should be given to the use systems such as PECS, which have been associated with increases in spontaneous communicative behavior, reductions in interfering behavior, and for some children, speech development. For those children exhibiting behavioral excesses, including stereotypical, self-injurious, aggressive or disruptive behaviors, a positive approach to behavior reduction is recommended. The use of evidence based strategies, such as functional behavior assessment, functional communication training, differential reinforcement, and extinction, is recommended to help children develop more appropriate skills, while reducing interfering behavior.

Individualization

Programming should be individualized for each specific child. Given the diversity of profiles of children with ASD, clinicians and researchers should not dogmatically subscribe to one approach to skill development, behavior reduction, modality of communication, or "brand" of intervention. Rather, programming should draw from the available research to support the development of an individualized treatment plan which takes into consideration each child's profile of strengths and weaknesses. Programming needs to be individualized to take into account child factors (e.g., pretreatment cognitive and language abilities, early social behaviors), family characteristics (e.g., ethnicity, culture, marital status, parental attitudes and stress level, socioeconomic status), and the service setting and system (e.g., in-home versus inclusive settings, amount and timing of social inclusion, service system constraints) (Stahmer, Schreibman, & Cunningham, 2011). It is probable that different treatments might be appropriate for different children at different points in the treatment process, depending on ASD symptom severity, age, and developmental level.

Data-Based

Direct observational data need to be collected and analyzed regularly, along with standardized assessment data. Standardized assessments (i.e., measures of intellectual and adaptive functioning) should be used in order to establish program priorities, to assess change in developmental rate, and to evaluate child and program outcomes. In addition, direct observational data (i.e., trial-by-trial data, frequency, rate, duration, percent correct) should be collected and analyzed in order to monitor children's ongoing performance in programming. These data should be graphed and reviewed regularly in order to ensure timely adjustments are made, including adjustments to teaching procedures, discontinuation of ineffective teaching strategies, and the selection of new targets. Data should also be used to monitor rate of skill acquisition, to determine whether skills are generalizing beyond the teaching environment, and to determine whether the child is ready to transition to less structured and less intensive teaching formats (i.e., naturalistic teaching methodologies, group settings, school and peer integration). Finally, data should be collected in order to determine the function of interfering behavior, as well as to monitor the change in interfering behavior over time.

Expert Supervision

EIBI should be frequently supervised by individuals with appropriate levels of academic training and credentials. It is recommended that program supervisors possess graduate level training in ABA, autism, and developmental psychology, as well as demonstrated expertise in ABA, through activities such as BACB Certification (www.bacb.com). In addition, supervisors should have minimum 1 year of supervised experience in a high quality EIBI program, and demonstrated proficiency in supervision of multidisciplinary teams and/or unregulated health professionals, comprehensive curriculum planning, working with families, data collection and analysis, and assessment of treatment integrity and program outcomes (Eikeseth, 2010). See also the ABAI Autism Special Interest Group Consumer Guidelines regarding suggested supervisor qualifications (www.autismpppsig.org). A model of direct supervision is recommended; a consultation model is *not* recommended. Supervision should involve direct observation of every child's program on a frequent basis (typically weekly), with the involvement of the treatment team and the family. During these meetings, program demonstration and procedural clarifications should occur, and children's curricula should be modified based on a review of data and information gathered during the supervision.

The direct EIBI staff or Instructor Therapists should receive appropriate didactic training, including theoretical training on the principles of ABA and their application in children with ASD. As well, staff should receive hands-on supervised practice in one-to-one treatment, during which they are expected to demonstrate proficiency in teaching complex behavioral repertoires and implementing functionally based behavioral interventions with good fidelity. Objective requirements for the demonstration of adequate knowledge and proficiency may include passing written tests and meeting prespecified criteria on observational measures of fidelity. Further, best outcomes may not be achievable without an appropriate level of treatment fidelity. Thus, measures of treatment fidelity, including direct observation and monitoring of teaching practices, the use of fidelity checklists, and frequent supervision are strongly recommended.

Parent Involvement

It is important to involve parents as part of the treatment team, although such involvement can take different forms depending on the situation and the parents' interest, capacity, and availability. Minimally, parents should receive education about ASD and the principles of EIBI. Their attendance and participation in meetings to review progress and set treatment goals should be strongly encouraged. Whenever possible, parents should also receive behavioral parent training and be encouraged to promote skill generalization, if not actually deliver some of the intervention at home. Within increasingly diverse and multicultural societies, in which therapists are often not the same ethnicity as the child they are treating, parent involvement is increasingly important to ensure treatment gains are generalized to the child's everyday life. It is recommended that interventions be tailored to each family's culture and ecology and individual family differences be integrated into parent-delivered interventions (Moes & Frea, 2002). Regardless of culture or ethnicity, parent involvement is needed to ensure that the treatment is appropriately tailored to the child and the family's needs.

Variety of Settings

It is recommended that EIBI take place in selected setting(s) based on individual child and family requirements. Consideration should be given to child variables, such age, developmental level, social skills, language, and the presence of interfering behaviors. Family variables, such as parent preference and the selection of a setting which allows for parental involvement in treatment, should also be considered. Finally, consideration should be given to current program priorities that may impact on setting suitability, such as the need for more intensive basic skill development versus a focus on the development of social, self-help and language skills. As with other facets of IBI, the appropriateness of the treatment setting should be regularly monitored as children develop new skills and their educational requirements change. For example, it may be appropriate to begin in one-to-one home-based programming and then shift to natural settings, such as classrooms, once additional language and social skills have been developed. As always, treatment decisions should be guided by ongoing data collection and analysis.

Typical Peers

Given the identified social-communicative deficits associated with ASD, programs should incorporate opportunities for inclusion with typically developing peers. Inclusion opportunities should be supported and systematic, involving developmentally appropriate play and interaction goals, with predetermined teaching strategies, and objective measures to monitor progress. Simple exposure to peers, or inclusion "for the sake of inclusion," is *not* recommended. Rather, inclusion opportunities should be developmentally sequenced and use evidence-based teaching strategies, such as errorless learning, time delay prompting, incidental teaching, pivotal response training, and peer-mediated social skill interventions.

Transition Planning

Good EIBI programs include careful planning for a systematic transition into school or the next environment. The school integration and transition process should be approached systematically, with prespecified goals and teaching targets, as well as appropriate levels of support in order to achieve these goals. A period of gradual transition, reducing time in one-to-one therapy, while systematically increasing time in the classroom setting, is recommended. Children's development and use of appropriate social, language and school readiness skills should be monitored and used to guide the transition process. Consideration should be given to the provision of support from IBI therapists in the classroom setting in order to help children generalize previously learned skills, learn new skills in the classroom setting, and adjust to classroom routines. Similar to other areas of EIBI practice, school transition should be guided by evidence of children's success; as children demonstrate success in the classroom, support should be reduced, as should ongoing one-to-one treatment.

Generalization

Systematic plans need to be created from the start of EIBI to promote generalization and maintenance of skills. Practitioners are encouraged to train loosely, whereby multiple exemplars, varied instructions and materials, including common stimuli and natural reinforcers, are integrated into EIBI. Further, a variety of response topographies should be taught, so children may develop a diverse and flexible repertoire of abilities. A "train and hope" approach to generalization (Stokes & Baer, 1977) is *not* recommended. Rather, plans for generalization and maintenance should be developed a priori and evaluated over time (i.e., data collected and analyzed). To enhance generalization, it is recommended that IBI be conducted in a variety of settings (home, school, community), with a variety of adults (different therapists, parents), and across various activities (classroom-based, play-based, etc.). Additionally, programming should gradually transition from one-to-one sessions to small- and large-group formats including peers; from highly structured discrete trial teaching formats to the increasing use of incidental teaching and naturalistic strategies.

Unproven Approaches Avoided

The use of non-evidence-based practices is strongly discouraged. In recent years there have been several Expert Panels and literature reviews resulting in lists of comprehensive and focused treatment approaches that are considered evidence-based and those that are not (e.g., NAC, 2009; Perry & Condillac, 2003; Wong et al., 2013). There are two situations in which treatments are not considered evidence-based. First, the existing research demonstrates that the approach is ineffective. Approaches that have been shown *not* to be effective, or to be harmful, should not be used or recommended. Examples of these approaches include: facilitated communication, patterning, gentle teaching, auditory training, secretin injections, vitamin B6/magnesium, chelation, and the gluten- and casein-free diet. The second way an approach may not be evidence-based is when limited research has been conducted, or the quality of the existing research is weak. In certain situations, such treatments may be worth considering. However, caution must be used when implementing practices with insufficient research support. Response to treatment must be monitored closely using direct observational data which is compared to prespecified indicators of success, including single-subject experimental designs whenever feasible.

Other Disciplines

Interdisciplinary consultation may be appropriate and helpful. Children with ASD often present with a complex array of medical, communication, sensory, and physical requirements. Psychologists, speech language pathologists and occupational therapists may provide helpful information related to the developmental sequencing of targets in the areas of communication, play and social skills, fine and gross motor development, and self-help skills. Developmental pediatricians and family doctors may help ensure good physical health, rule in or out biological contributions to presenting behavioral difficulties, and prescribe medical treatments when appropriate. Educational professionals may aid in the selection of appropriate academic and school readiness targets. The expertise gleaned from these broader disciplines should be integrated and monitored in an evidence-based manner, as deemed appropriate by an appropriately qualified IBI supervisor (as described above). While consultation from a diversity of professionals may be beneficial to IBI, the use of an eclectic model of treatment is *not* recommended; the expertise of varying professionals should be integrated into the behavioral program, while maintaining the use of evidence-based practices to teach new skills and reduce interfering behaviors.

Research Recommendations

Although EIBI is, at this time, a solidly evidence-based treatment approach for young children with autism, there remain a number of questions requiring further research.

The caliber of the research needs to be improved in several respects. The participants need to be described fully both diagnostically and developmentally and should be assessed with standardized instruments. Sampling procedures need to be specified clearly, especially in the case of non-random assignment to groups (which is most often the case). Given the likely importance of parent factors influencing outcomes, having parent choice be the method of group allocation is problematic.

Specification of the nature and quality of the intervention needs to be done more precisely. Odom et al. (2010) found, in an evaluation of 30 comprehensive treatment programs, only about a third of them operationalized procedures or curricula well enough to be replicated. Fidelity of implementation is also essential to be documented, which very few studies provide.

More research is needed on predictors/correlates of outcome, to help account for the tremendous heterogeneity among children's outcomes. Existing research has focused on child characteristics such as age and IQ but there is a need for studies examining treatment quality-related factors as well as family-related factors and perhaps, the interactions of these factors with each other and with child characteristics.

Research is needed on what ABA procedures, at what level of intensity, are suitable for children who are not good responders to EIBI, in particular children who are older and/or have very low IQ.

A small body of research is beginning to focus on specific models of EIBI. Studies are needed that operationalize the commonalities and differences among these approaches. It would be beneficial to compare different specific models in relatively large, diverse samples, with a view to perhaps determining whether certain approaches are more effective for certain types of children and families.

More effectiveness studies and community implementation applications are needed, since these are the conditions under which most children are receiving EIBI, rather than in a small university-based, model program (Love, Carr, Almason, & Petursdottir, 2009). Some researchers are pushing the boundaries in various nonideal circumstances (lower intensity, different delivery methods, and so on) which will help us understand more about the essential ingredients of EIBI.

Finally, it would be important to extend EIBI methods to other populations such as children with Intellectual Disability. Although the research is limited (as described above), some evidence suggests EIBI may be beneficial for children with ID and this might be a fruitful area for further research and practice.

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Active Support

20

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Introduction

Deinstitutionalization offered the prospect of an improved quality of life for many people with intellectual disabilities. It was widely expected that most individuals would prosper from simply occupying small ordinary homes in community locations with supervision from a paid staff. Experience quickly revealed that, while small community homes provided many more opportunities than institutions for people to live ordinary valued lives, those opportunities needed to be worked upon to realize their potential. The quest to take full advantage of these opportunities, especially for people with a severe degree of disability, led to the development and subsequent refinement of Active Support.

Active Support describes a philosophy of care, a set of working practices, and a method of providing staff training and support. The philosophy of care defines participation in the ordinary activities of everyday life both as a determinant of quality of life and as an outcome of good quality service support. The working practices in Active Support are rooted in systems of personalized support that aim to manage the social context of home and community life and the process of transacting momentary support and assistance from staff for resident engagement in everyday activity. The training procedures in Active Support are grounded in behavior theory and combine workshop-based learning formats with on-site coaching and ongoing practice leadership.

Active Support creates well-managed person-centered environments that deliver support and assistance in place of demand and control, social attention contingent mainly on engaging in activities, and ensure activity materials are readily and predictably available to the residents of the home (McGill & Toogood, 1994). A key outcome of Active Support training is that staff continually adjust the level and type of support they provide from moment to moment, so that residents are almost always successful when engaging in activities and yet, at the same time, avoid becoming unnecessarily dependent on staff help.

Research has consistently shown greater levels of participation by residents in everyday activities after Active Support is implemented, and in comparison with non-Active Support environments (Felce, 1989; Stancliffe, Jones,

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Mansell, & Lowe, 2008; Totsika, Toogood, & Hastings, 2008; Totsika, Toogood, Hastings, & Nash, 2008). These findings are associated with improved organization of the home environment, increased levels of more effective assistance from staff, and improved deployment of staff in relation to resident ability. Challenging behavior has not so far been a barrier to Active Support implementation and careful adoption of Active Support procedures may even lower its rate of occurrence.

In this chapter, we describe the development and evolution of working methods into a system of Active Support. We delineate the defining features of Active Support and highlight similarities and differences between two main ways in which the model has been operationalized. We then update and review research on Active Support and Active Support training and identify future directions for researchers working in the field. Finally, we consider practice issues that commonly arise when services begin to think about implementing Active Support, and identify possible strategies for overcoming or avoiding some of the challenges they may face.

Active Support

Active Support is a systematic model of working that helps people with intellectual disabilities participate in everyday activities that are meaningful to them. It defends against the risk of imposed passivity and disengagement from the social environment by training staff to supply individually tailored momentary support and assistance instead of persisting in passive minding and simple caretaking roles. Active Support is not a single procedure, however. Rather, it is a collection of working methods that originated from research-based initiatives, which began in the UK over 30 years ago.

The Origins of Active Support

Influenced by research from the US, a small group of UK-based researchers designated engagement as a quality indicator for services and a marker for quality of life (Mansell, Felce, Jenkins, de Kock, & Toogood, 1987). The construct spanned social and nonsocial forms and was concerned from the outset with outcomes associated with both activity participation and social interaction. A set of working methods was developed to support implementation and subsequently evaluated using observational measures. The working model, which has been described in detail elsewhere (Jenkins, Felce, Mansell, de Kock, & Toogood, 1987; Mansell et al., 1987; McGill & Toogood, 1994; Totsika, Toogood, & Hastings, 2008; Totsika, Toogood, Hastings, et al., 2008), comprised guidelines and practical support for staff to assist resident engagement and deploy their attention contingent on activity engagement, together with integrated systems for (a) generating and delivering individual (person-centered) plans, (b) creating structured and semi-structured learning opportunities, and (c) developing Activity and Support Plans, and (d) maintaining quality through data recording and review. Researchers found this combination of procedures delivered improvements in levels of resident engagement both within and across individuals and services (Felce, 1989; Mansell & Beadle-Brown, 2012; Stancliffe et al., 2008; Totsika, Toogood, & Hastings, 2008; Totsika, Toogood, Hastings, et al., 2008). These early working methods evolved into two main ways of delivering Active Support, so two sets of resources are currently available. Jones et al. (2009) published a handbook describing a system of "Active Support" while Mansell, Beadle-Brown, Ashman, and Ockendon (2005) produced a manual for learning about Person-Centred Active Support or P-CAS. The two approaches are more similar than different, varying mainly in points of emphasis and the importance attached to activity planning and monitoring (Stancliffe et al., 2008).

The Development of Active Support

An early and significant change in Active Support occurred in the first experimental evaluation of the approach conducted by Jones et al. (1999) using a multiple baseline design. For the purpose of their study, these researchers produced six booklets describing the essential components of the Active Support Model (Jones et al., 1996a, b, c, d, e, f). The booklets corresponded closely with the original model, but procedural adaptations occurred when individual planning and structured teaching were omitted from intervention, and on-site Interactive Training (Toogood, 2008, 2010) was added.

Later, concern among another group of researchers about poor maintenance of Active Support interventions led Mansell et al. (2005) to develop Person-Centered Active Support (P-CAS). These authors wanted to (a) take account of increasing interest in person-centered approaches, (b) focus staff attention on the quality of the support they provided rather than on producing paper plans, and (c) respond to changes in staff training that meant materials had to be useful to individuals as well as to teams. Mansell and Beadle-Brown (2012) later suggested that P-CAS differed from preceding or alternate versions of Active Support by placing greater emphasis on (a) teaching staff principles and rationales rather than procedures, (b) teaching the importance of engagement and relationships at home *and* in the community, (c) why engagement is important and common excuses for not supporting it, (d) the primary importance of momentary support over planning and recording participation, (e) the importance of practice leadership to support implementation, (f) improving motivation by getting managers interested, and (g) aligning organizational priorities to promote rather than interfere with active support delivery.

The introduction of P-CAS profoundly influenced the way Active Support is viewed today. Individual (person-centered) planning, skills teaching and opportunity planning are now largely discounted or presented as approaches that work alongside Active Support and not fundamental to the model (Mansell et al., 2005; Mansell & Beadle-Brown, 2012). Jones et al. (2009), for example, describe the core components of Active Support as (a) interacting to promote resident participation, (b) using Activity and Support Plans, and (c) collecting data to help keep track. While this formulation preserves some of the planning and recording functions inherent in the early models, person-centered plans, opportunity and learning plans, behavior support plans, and communication plans, are explicitly described as *other approaches* that may be used *alongside* Active Support, and not as a part of it.

What Is Active Support?

Interacting to Promote Engagement

Both versions of Active Support focus on moment-to-moment interactions between staff and residents in relation to activity engagement, and both draw heavily on learning theory and applied behavior analysis in terms of task analysis, antecedent prompting and differential reinforcement. According to Mansell et al. (2005) the four principles that define Person-Centered Active Support are:

1. Seeing that every moment has potential for engagement and interaction,
2. Seeing that activities are presented little and often to manage demand,
3. Ensuring staff provide graded assistance to ensure success by matching support to need, and
4. Maximizing choice and control by supporting resident routines rather than staff routines.

The manual by Jones et al. (2009) suggests Active Support is fundamentally concerned with having staff:

1. Support engagement through activity planning and providing graded assistance,
2. Think in steps—seeing complex activities as components in a task analysis, and
3. Let the person know how they are doing by positively reinforcing engagement.

So, both versions of Active Support seek to make resident participation in activities more likely than passivity or behavior motivated by escape or avoidance. Staff achieve this by responding differentially to resident engagement, so that a person may be two or three times more likely to receive contact from staff when engaged in activity than when passive or engaged in challenging behavior.

Essentially, staff trained in Active Support *plan* opportunities for people with intellectual disabilities to take part in activities, supply the *motivation*, *support and assistance* they need to participate in activities successfully, and *evaluate* outcomes and make adjustments as required. The planning and monitoring functions are less prominent in P-CAS than in the Jones et al. model, which has an explicit technology for organizing the social environment to support resident engagement in activity. Working methods include (a) Activity and Support Plans, and (b) activity scripts to support personal routines.

Activity and Support Plans

Most activities in life occur on a regular basis and most households typically develop ways of completing them effectively and efficiently. In small community homes, Activity and Support Plans do a similar job after factoring in additional complexities associated with multiple occupancy, shift-based staff support, and the impact behavioral and cognitive impairments associated with intellectual disability have on resident capabilities.

Activity plans integrate a resident's personal routines with activities that occur regularly in the household. In multi-occupancy households, personal routines are synchronized (Felce, Jones, & Lowe, 2002) to form overarching plans that map activities to key times of the day or week. This framework of "anchored" activities typically brings order to the demand environment, making it more consistent, predictable and susceptible to resident control. Written plans also facilitate the deployment of staff to support individual residents in activities. Although the plans are written, the system is neither formal nor rigid. Conversations about which person will do what activity and with whom, most often take place over a meal or cup of coffee. Activity plans are not inflexible. Adjustments may be made on an ongoing basis, for example, as the allocation of support is discussed. There is space between anchored activities for spontaneity and for residents to choose what they want to do, and in what order they want to do them.

Activity Scripts

Most people have a preferred way of performing activities, such as washing dishes, and apply a standard to the things they do regularly that typically involves how often (e.g., 3–4 times daily), how well (e.g., standard of cleanliness), and under what conditions (e.g., soon after finishing a meal). When residents rely on staff for assistance to participate in activities, they are at risk of being subjected to staff preferences in place of their own. Moreover, when a team of staff is involved there may be several ways of doing each activity. This can become a problem when there is a high degree of variability in staff expectations and working methods that leads to resident passivity or behavior maintained by escape or avoidance. Activity scripts are a component of Active Support that provides part of the solution.

Activity scripts are a form of task analysis; they break down complex activities into component steps that correspond to individual and household preferences. Scripts are then written down for staff to follow every time the activity is done. Individual members of staff quickly learn the scripts so they are not obvious to the person or an observer. Scripts typically delineate a method, pace and standard based on an analysis of resident preference. The main aim is to ensure consistency in the way the resident is supported in doing the activity and that this does not change according to which member of staff is providing support. Scripts may also specify a frequency and standard for an activity and can include a risk assessment if necessary. Scripts cover personal routines, such as a morning schedule, as well as generic activities such as a mealtime. Systematic and consistent use of scripts by all staff helps individual residents to become more autonomous and independent within and across their routines.

The logic of scripts is that each staff member learns one way of carrying out everyday activities, instead of residents having to learn as many ways as there are staff. This avoids residents being inadvertently corrected by staff according to staffs' preferred way of doing things, and, as a consequence, becoming unnecessarily dependent on prompts or even task-averse. It seems intuitively more logical and sensible to expect marginal changes in the workplace behavior of staff (present for part of their life to do a job) than extensive change in the behavior of residents (present all of the time to live their lives). Moreover, staff ought to be capable of learning more rapidly and with less effort than would typically be the case for residents and, in the end, consistency makes the job of staff easier not more difficult.

Keeping Track: Monitoring Outcomes and Service Quality

Working methods in the Jones et al. (2009) version of Active Support provide for continuous monitoring and evaluation of resident activity and community presence. The data are basic, but can easily be supplemented with periodic observation or additional recording by staff if needed. Simple analyses provide real time pictures of the rate, type, temporal distribution and trends over time in activity engagement and community presence. These in turn provide estimates of program intensity, relevance, and balance, which can be adjusted and the effects evaluated with no additional effort.

Staff generate individualized personal data sets by adding a check mark to a printed list of activities whenever a resident contributes or takes part in an activity. Activity lists correspond with Activity and Support Plans and may be grouped into categories (such as food preparation, mealtime, making drinks and snacks) to aid interpretation. Recording charts known as the Participation Index usually span a week. For community presence, the datum is a measure of time. The number of time-based entries yields frequency data, which can be interpreted in relation to duration. These data may also be analyzed for temporal distribution or clustering of activities within and across weeks, and for evenness across types of community location and activities, e.g., leisure versus shopping versus visiting family and friends. Data recording is designed to minimize staff effort; hence only one entry is required per event. Staff can also monitor the rate and distribution of participation in activity within and across time and activity domains. Visual inspection quickly identifies missed opportunities, unbalanced schedules, highly variable and increasing or decreasing trends. Corrective action may be taken and the effects monitored.

In the P-CAS model, the Participation Index is not included as it is believed that this type of monitoring is a potential distraction from the proper implementation of Active Support based on moment-to-moment interaction (Mansell et al., 2005; Mansell & Beadle-Brown, 2012). It is well known, however, that observational data can provide a perspective different from verbal report and the opinions of staff. Individual members of staff are present for a fraction of a person's day and would find it difficult to sample a person's lived experience over much more than the duration of a shift or from a series of snapshots of shifts. Missed opportunities or overexposure to one type activity could go undetected indefinitely. Recently, a service that collected Active Support data routinely was able to demonstrate how, over a 6-year period, the quality and extent of a person's community presence, involvement and his relationships with others had developed in line with person-centered plans and targeted reductions in challenging behavior—a perspective that would have been impossible without continuous recording.

Active Support: Values and Philosophy

The philosophy underlying the Active Support Model is strongly person-centered and based on a small number of constructs. For example, everyone has the same human value, should expect to live as a contributing member of his or her community, deserves to receive support according to his or her needs, has a responsibility to sustain his or her own life as far as possible, is capable of development and growth, and is entitled to exercise personal autonomy and self-determination. Jones et al. (2009) express these values in terms of what most people have in common. They propose specifically that for most people it is important to:

1. Be part of a community,
2. Have good relationships with friends and family,
3. Have relationships that last,
4. Have opportunities to develop experience and learn new skills,
5. Have choices and control over life,
6. Be afforded status and respect, and
7. Be treated as an individual.

The Jones et al. list corresponds closely with the five service accomplishments delineated originally by O'Brien (1987) on the basis of Normalization theory. O'Brien listed the five essential service accomplishments as community presence, community participation (relationships), choice, competence, and status. The accomplishment of competence resonates particularly with the commitment in Active Support to promote opportunities for meaningful engagement. O'Brien defined competence as "the opportunity to perform functional and meaningful activities *with whatever level or type of assistance* that is required" (1987, p. 178, emphasis added). Active Support is fundamentally about providing the level and type of assistance a person needs to participate in activity and is one way, therefore of delivering the focused effort O'Brien said is needed in services if people with disabilities are to avoid being deprived of the expectations, opportunities, instruction and assistance necessary for increased competence.

Mansell et al. (2005) cited O'Brien's five service accomplishments in their training manual. They also referenced broader principles underpinning the development of intellectual disability services, such as civil rights, inclusion, independence and choice. Mansell and Beadle-Brown (2012) expanded on this analysis to include principles enshrined in the UN convention on the rights of persons with disabilities (United Nations, 2006), and the eight dimensions of the IASSID quality of life framework (Mansell & Beadle-Brown, 2012). They suggested Active Support impacts both the objective (e.g., participation extent) and subjective interpretations (e.g., the value of participation) of life conditions. The beneficial effects of Active Support span domains. So, while most conspicuously relevant to personal development, there may also be benefits and desirable outcomes associated with social inclusion, physical and emotional well-being, interpersonal relations, self-determination and rights. Active Support evaluations reflect this by capturing potential gains across several quality of life dimensions, as we discuss below.

A core value in Active Support is that, with the right type of help, everyone can participate in activities, and that participating in activity is good as this is a fundamental human right. Participation on its own, however, is not sufficient as a criterion for quality. Also important are (a) the type of activities people do, and (b) when, how and with whom they are done. In Active Support, activities have to be meaningful and functional, and what people do (also where, when, with whom and how) must promote images, expectations, and symbolic representations of people with disabilities that are positive. In short, the selection of activities has not only has to reflect the personal preferences of individuals with intellectual disabilities, but also must create and sustain people with intellectual disabilities in valued social roles (Wolfensberger & Thomas, 1983).

The relationship between Social Role Valorization and Active Support is apparent in two ways. On the one hand, a framework of values similar to those articulated in normalization theory (Wolfensberger, 1972) was convergent with values underpinning the development of the early working methods and their subsequent evolution into Active Support. On the other hand, systems of Active Support have been described as providing one way of translating socially important values and personally important agendas into action (e.g., Jones et al., 1999: Mansell et al., 2005) and of making policy aims a reality in people's lives (Mansell & Beadle-Brown, 2012).

An example of how Active Support translates values into action may be found in the way staff are trained in Active Support. Skilled staff minimize the need for inventing things for people with disabilities to do by inviting them to participate in the same sorts of things most other people do for most of the time. As a large part of most people's day is taken up with personal care activities and chores such as cooking, cleaning and shopping, these activities are incorporated into the daily schedules of people with intellectual disabilities. Active Support is not just about housework, but staff come to understand that people with intellectual disabilities have a responsibility like everyone else to participate in running their own lives—participating in activity is seen as one way of accomplishing this aim, and not a therapeutic intervention or token gesture. Equally, staff trained in Active Support understand that people's support needs change and so they learn to adjust what they do to suit each person's needs, preferences and capabilities at a given moment in time. The focus in Active Support is always upon what a person can do, rather than on what he or she cannot yet do. A further advantage is that these sorts of activity are, by definition, age- and culture-appropriate, image enhancing, and likely to enhance personal autonomy. Securing these outcomes depends on a social model of support in which individual members of staff behave as planners, enablers, and teachers. In Active Support, staff *plan* by organizing the residential environment to create opportunities for resident participation in everyday activities. They *enable* resident participation by providing assistance and bridging skill gaps where necessary. They *teach* by differentially reinforcing participation in activities and strengthening what a person can already do.

Active Support and Behavioral Technologies

A core value in Active Support is in its reliance on evidence-based procedures. The organizational and interpersonal technologies that define Active Support, including its staff training procedures, are derived directly from the field of Applied Behavior Analysis (ABA) (Cooper, Heron, & Heward, 2007). However, in the adult population, Active Support attaches more value to the momentary experience of performing an activity, such as preparing a meal, than to learning how to do it independently. The focus in Active Support, therefore, is on the here and now, rather than tomorrow or even further into the future. So, rather than wait for a person to master a vast array of complex skills through resource intensive teaching, when learning is a challenge, Active Support simply requires staff to provide more focused assistance when it is needed and less when it is not. This way, opportunities for engagement and social interaction are available immediately to the person regardless of the level of behavioral deficit or cognitive impairment. In some cases, this approach might mean that a member of staff performs a segment of an activity for the person, but then provides the opportunity and assistance for the person to do the rest.

Because everyone has some level of behavioral ability, the focus in Active Support is upon what a person can do already. The primary goal in Active Support is activity engagement rather than skill acquisition or learning. Nevertheless, many of the procedures used in Active Support are the same as those used to support learning outcomes (e.g., task analysis, prompting, shaping, fading and reinforcement).

The working methods are inherently behavioral and evidence-based. As enablers, for example, staff manage activity selection, preparation, presentation, pacing, sequencing, scheduling and map support where it is needed. In addition, staff break down complex activities into component steps (task analysis) and use graded levels of assistance (antecedent prompts) to enhance further the prospect of success. These are all examples of antecedent manipulations designed to maximize successful participation by lowering response effort, error, and the probability of evoking behavior maintained by escape or avoidance. In addition, staff seek to establish and maintain motivational contexts that bring engaging in activity firmly under appetitive control—so that people actually *want* to do it. This means staff attention is both an outcome and a source of reinforcement for other socially important behavior. Moreover, spending time with people whose communication skills are poorly developed can be difficult for staff and evoke avoidance behavior in them. Engaging in activities with residents provides at least three opportunities for interacting that are easier and mutually more rewarding. Residents and staff are able to interact when (a) deciding what they will do together, (b) discussing what is being done, and (c) talking about what they just did together. In these ways interaction becomes easier and more rewarding for staff as well as residents.

Learning About Active Support

Active Support training for staff typically comprises (a) elements of theory and values training, (b) work on developing Active Support materials, and (c) a focused learning event delivered through onsite coaching in the workplace. Staff first acquire knowledge of Active Support by studying a handbook (Jones et al., 2009) or training manual (Mansell et al., 2005), they learn basic principles and procedures, and develop activity scripts and plans, in a workshop tailored specifically to the staff and residents of the home. Finally, each member of staff takes part in a bespoke onsite training session with one or more practice tutors. It should be noted that, although broadly similar, there are differences between P-CAS and the Jones et al. training procedures. While the two approaches appear to deliver similar outcomes in terms of increased engagement, the approaches have not yet been compared for efficiency, effectiveness or acceptability, and the method Active Support trainers adopt is largely a matter of familiarity and personal preference. There is evidence to suggest that omitting either workshop or onsite training can result in no gain for residents (Jones et al., 1999; Totsika, Toogood, Hastings, & McCarthy, 2010).

Active Support Training

The relationship between ABA and Active Support is multilayered. At one level Active Support is a composite of evidence-based behavioral principles and procedures; at another, it uses behavioral technologies to teach behavioral principles and procedures to staff. In the services where Active Support procedures were developed, staff participated in a 10-day team-based induction program. Participants learned about basic principles and procedures from applied behavior analysis, about the concept and importance of engagement and social interaction, and how to organize and run every aspect of home and community life with the fullest possible involvement of residents. Senior staff then guided the work of less experienced team members using formal and informal systems of practice-based supervision and annual appraisal.

The behavioral performances of staff have been found to rest mainly in transacting support and assistance and reinforcing resident participation in activities. Staff behavior largely determines resident engagement, and, therefore, Active Support outcomes are largely dependent on staff performances, which are shaped through continuous training and performance feedback. Our experience suggests effective staff are likely to possess (a) a vocabulary to express and discuss core values, (b) a working knowledge of behavioral principles and procedures, and (c) the motor skills needed to support and assist resident engagement effectively.

Current training in Active Support is multimodal. The content and format of training are adjusted to suit the aim or purpose of training. So, for example, in the Jones et al. (2009) model, participants explore theory, values and principles in a facilitated practice-based participatory workshop. Skills for transacting support are then trained in formal on-site Interactive Training sessions and sustained through a less formal system of ongoing practice-based supervision within which more skilled or senior members of a staff team coach junior members. In addition, it has been noted that the density of trained staff and temporal distribution of training can influence the adoption and implementation of training in the workplace (Anderson, 1987; Landesman-Dwyer & Knowles, 1987). Active Support training schedules are therefore drawn up so that everyone on a team is able to participate in the same event. Workshop and onsite training events are scheduled to achieve maximum coverage within a compressed time frame, typically of 1 or 2 weeks.

Workshops

Active Support workshops are whole team events, tailored to the setting and with a person-centered focus on the residents of the home. Workshops are participatory and cover basic theory mainly through facilitated discussion. Workshops also develop product. At the end of a 1- or 2-day workshop following the Jones et al. (2009) model a team will have produced a ‘first draft’ Activity and Support Plan for each resident of the home to use, together with one or two activity scripts to trial in the onsite coaching sessions.

On-Site Coaching

Skills for transacting support are trained in-situ in coaching sessions led by Active Support trainers, e.g., in supervised practice sessions (P-CAS), or, as in the Jones et al. model, through more formally constructed Interactive Training sessions (Toogood, 2008, 2010). Coaching usually involves residents of the home engaging in activities and using materials that are ordinarily available at ordinary times of the day.

Interactive training procedures combine many features researchers consider essential for effectiveness (Toogood, 2010). For example, skills targeted for training are identified from an analysis of each staff’s observed baseline performance. Targeted skills are trained in the context within which they will be used. Coaching occurs in a continuous cycle of observation, rehearsal and feedback. Each staff serves as his or her own control and observational training data are used to evaluate the impact of training on the behavior of staff and related outcomes for residents (Jahr, 1998). Acceptability of the training procedures to staff is routinely assessed along with an analysis of training effectiveness and efficiency (Parsons, Reid, & Green, 1996; Toogood, 2008).

In broad terms, onsite training procedures in P-CAS are similar to those in interactive training, but P-CAS onsite training is less formal and has fewer observational performance measures than Interactive Training. Implementation, generalization, maintenance, and the further development of staff skills, are each addressed through practice leadership from senior members of the team (Mansell & Beadle-Brown, 2012).

Active Support and Supporting Organizational Context

Recent years have seen an increasing number of attempts at rolling out Active Support across provider organizations and service regions. These initiatives have drawn attention to a range of molar variables that fall under the general heading of organizational readiness (McVilly, Gelman, Leighton, & O’Nell, 2011). Issues span agency values and orientation, and the alignment of human resources policies and procedures, job descriptions, recruitment and retention policies, and supervision arrangements. Other variables include, but are not restricted to, staff deployment and ratios, job demarcation, the organization of housework and catering practices, health and safety policies and attitudes to risk management covering access to facilities in the home such as the kitchen, and access to community locations including shops and leisure facilities. Evaluating the organizational context and mapping organizational requirement for successful adoption of Active Support are relatively new additions to the list of questions on Active Support for which we do not yet have full and proper answers. We have reviewed whatever evidence is available, and drawn on our own experience to outline what we think are the important organizational aspects of Active Support in the later part of this chapter.

Research Evidence on Active Support Effectiveness

Approximately 30 years after Active Support’s inception in the demonstration projects (e.g., Felce, 1989), there are 16 published studies examining Active Support’s effectiveness in improving the quality of lives for residents of community homes. At the moment, all evidence is based on data from small community homes housing adults with an intellectual disability supported by paid staff. The context for Active Support implementation and evaluation has not changed since the very first demonstration projects (Felce, 1989; Mansell, McGill, & Emerson, 2001), but, about 10 years ago, evaluation data started emerging from countries other than the UK, mainly Australia, Taiwan, New Zealand (Chou et al., 2011; Graham, Sinnott, Snell, Martin, & Freeman, 2013; Koritsas, Iacono, Hamilton, & Leighton, 2008; Stancliffe, McVilly, Radler, Mountford, & Tomaszewski, 2010).

Engagement in daily living activities is the primary outcome for evaluating whether Active Support has made a difference in people's lives. In the following sections, we will review the centrality of activity engagement in Active Support research, and then we will summarize the evidence available on the model's effectiveness. For the latter, we will focus both on reviews published to date and on primary evaluation studies. Lastly, we will draw some conclusions to guide decision making for practitioners and researchers who are considering evaluating Active Support interventions.

Engagement in Meaningful Activity

Engagement in meaningful activities of daily life has remained the main focus of Active Support interventions regardless of variation in training approaches. The centrality of this outcome is due to its core function as a key driver of several quality of life dimensions: personal well-being, physical well-being, inter-personal relationships, rights, social inclusion (Felce, 1997; Schalock, 2004). Despite its importance, engagement in activities remains unacceptably low for many people with an intellectual disability whether at home or in services, whether adults or children (Axelsson, Granlund, & Wilder, 2013; Felce, Perry, & Kerr, 2011; Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009).

Does Active Support Work?

Three reviews have been published to date summarizing evidence from nine evaluation studies (Hamelin & Sturmey, 2011; Stancliffe et al., 2008; Totsika, Toogood, & Hastings, 2008). Two of the reviews (Stancliffe et al., 2008; Totsika, Toogood, & Hastings, 2008) were narrative syntheses of all the evaluation studies that had been conducted since the model's inception. They included data from early demonstration projects (Felce, 1989; Mansell et al., 2001), Jones' seminal studies in Wales, UK (Jones et al., 1999; Jones, Felce, Lowe, Bowley, Pagler, Gallagher, et al., 2001; Jones, Felce, Lowe, Bowley, Pagler, Stong, et al., 2001), evaluations from the Tizard Centre in the UK (Bradshaw et al., 2004; Mansell, Elliott, Beadle-Brown, Ashman, & Macdonald, 2002), and the first non-UK data from Australia (Stancliffe, Harman, Toogood, & McVilly, 2007). The third review was a systematic review of experimental evaluations of Active Support focusing on Jones et al. (1999) and Stancliffe et al. (2007) work (Hamelin & Sturmey, 2011).

The Stancliffe et al. (2008) and Totsika, Toogood, and Hastings (2008) reviews included largely the same pool of studies and reached similar conclusions. They concluded that available data indicated systematic improvements in the levels of activity engagement for residents and associated increases in the amount of time staff assisted residents to participate in activities. Findings also indicated that staff assistance became more effective in eliciting and maintaining resident engagement (Smith, Felce, Jones, & Lowe, 2002), while improvements in participation were also contingent on the greater availability of activities (Mansell et al., 2001). These reviews also concluded that the model's effect on other desirable outcomes was not clear. For example, there was insufficient evidence of longer-term improvements on adaptive skills, and inconclusive evidence on the direction of effect on challenging behavior. The Hamelin and Sturmey (2011) review focused solely on evidence from experimental studies and identified only two (i.e., Jones et al., 1999; Stancliffe et al., 2007) meeting this criterion as both had utilized a multiple baseline design. Two types of effect sizes for single-case designs indicated an effectiveness range from ineffective to highly effective for resident engagement and staff assistance. The authors concluded that the evidence indicated a promising model, as opposed to an evidence-based one. It is clear, however, that the conclusion was based on limited available data.

Following these reviews, seven recent studies have been published that included resident outcomes. These studies are different, though they all used group-designs with convenience sampling. Two studies included only post-training data (Mansell, Beadle-Brown, & Bigby, 2013; Mansell, Beadle-Brown, Whelton, Beckett, & Hutchinson, 2008), while the remaining five included baseline data, i.e., data obtained before Active Support was implemented (Beadle-Brown, Hutchinson, & Whelton, 2012; Chou et al., 2011; Koritsas et al., 2008; Riches et al., 2011; Stancliffe et al., 2010). Two of these studies also included follow up data obtained between 6 and 14 months following training (Chou et al., 2011; Koritsas et al., 2008). Only two studies included a control group (Chou et al., 2011; Mansell et al., 2008). Three studies obtained outcomes from staff-rated questionnaires and direct observations (Beadle-Brown et al., 2012; Mansell et al., 2008; Mansell et al., 2013), while the remaining four included data just from staff-rated questionnaires. Two studies were UK-based (Beadle-Brown et al., 2012; Mansell et al., 2008), one was from Taiwan (Chou et al., 2011), and the remaining were from Australia (Koritsas et al., 2008; Mansell et al., 2013; Riches et al., 2011; Stancliffe et al., 2010). The number of residents in the study samples was small (range from between 12 and 49 people), except for the two Mansell (Mansell et al., 2008; Mansell et al., 2013) studies that included larger samples ($N = 169$ and $N = 151$, respectively).

Change in resident *engagement* in activities was evaluated using either direct observations from trained researchers or questionnaires (mostly the Index of Participation in Domestic Life, IPDL; Raynes, Wright, Shiell, & Pettipher, 1994) completed by staff that knew the resident well. Six studies found significant improvements following Active Support either in the time residents' spent engaged in activities or in the number of domestic activities, variety of activities, and the number of activities done without assistance from staff. Two of the six studies (Beadle-Brown et al., 2012; Mansell et al., 2008) used both direct observations and the IPDL. While in both studies observed engagement (in social and nonsocial engagement which includes domestic activities) improved significantly, IPDL scores improved only in the Beadle-Brown et al. study. Outcomes from the seventh study (Mansell et al., 2013) could not indicate whether Active Support was effective or not, as the study did not include baseline data or a comparison group. Community homes in that study had adopted Active Support in the previous 10 years, and researchers aimed to compare homes' current operational levels. They observed high levels of engagement (about 51 % of the time residents were observed to participate in a social or nonsocial activity) and this was also the case for residents with lower adaptive skills (Mansell et al., 2013). This latter group participated in activities about 39 % of the time.

Staff contact with residents or *assistance* to participate in activities was only evaluated in three studies that used direct observations. Staff assistance was significantly higher in the Active Support group compared to the control group in the Mansell et al. (2008) study, while staff assistance significantly increased after Active Support implementation in the Beadle-Brown et al. (2012) study. In the Mansell et al. (2013) study, staff assistance was observed to be present 4 % of the time and staff contact 7 % of the time. These levels are considered low (e.g., assistance available only 2.4 min in every hour), so the high levels of activity participation in that study were most likely due to residents' higher ability skills (Mansell et al., 2013).

Changes in residents' *challenging behaviors* were assessed in five studies. In two studies, challenging behaviors did not change (Chou et al., 2011; Riches et al., 2011). In another two studies, there was a significant improvement in stereotypies and internalized behavior problems (Beadle-Brown et al., 2012; Stancliffe et al., 2010). In Koritsas et al. (2008) significant improvements in disruptive, self-absorbed and antisocial behaviors were present mainly at follow up. A reanalysis of observed challenging behavior data from the Jones et al. (1999) study indicated that most of the observed behaviors consisted of stereotypies (Jones et al., 2013). Decreases were observed in three out of five houses ($N = 11$ of 19) included in the 1999 study. Furthermore, there was a small, inverse relationship between increases in meaningful activity engagement and decreases in residents' challenging behaviors ($r=-0.37$; Jones et al., 2013).

The more recent Active Support evaluations included a wider range of outcomes than just engagement and challenging behavior. Of the four studies that assessed *adaptive skills*, three found significant improvements (Chou et al., 2011; Koritsas et al., 2008; Stancliffe et al., 2010). In the Riches et al. (2011) evaluation, there was no significant change in adaptive skills. In the three studies that measured resident *depression*, all found significant improvements for residents whose staff had received Active Support training (Chou et al., 2011; Riches et al., 2011; Stancliffe et al., 2010). There were also significant improvements in *choice* (residents having more opportunities to exercise choice in their daily lives) in three of the four studies that measured it (Beadle-Brown et al., 2012; Chou et al., 2011; Koritsas et al., 2008). Two studies that examined *community-related outcomes* reached mixed conclusions. In Chou et al. (2011), the group that received Active Support training experienced gains in community inclusion and contact with friends, but not in contact with family (but possibly because residents opted not to). In Riches et al. (2011) gains in community participation and social networks were not found.

Current Status of the Evidence Base

The evidence so far is systematic in highlighting gains in terms of resident participation in daily life activities, especially domestic activities. Where measured, staff assistance and contact increased following Active Support. The inclusion of a wider group of outcomes in recent studies allowed us to extend our knowledge of potential Active Support effects. Active Support seems to be associated with more permanent gains, as demonstrated by significant improvements in adaptive skills, suggesting perhaps that increased participation facilitates learning and practicing of new skills.

On the other hand, the recent data have not added much clarity on the direction of effects on challenging behavior. While some of the evaluation evidence suggests improvements for some topographies of challenging behavior, it seems unlikely that further similar research would be able to indicate overall effects of Active Support on challenging behavior. That is, we believe that it is not a question of more data, rather of different data. Simply collecting more data, either from observations or rating scales, is unlikely to provide more clarity in the absence of more detailed analysis on the functions of behavior and the interaction between functions and environmental modifications (either as a planned activity, or staff support). While it has been easier thus far to focus just on different topographies of behavior, the lack of conclusive evidence hints that effects may not be detectable at the topography-level, prompting us instead to consider behavior function. This proposal is supported by evidence from clinical case studies where Active Support resulted in substantial decreases in challenging behaviors (several topographies) when Active Support was accompanied by functional analyses of behavior and associated treatment of physical health problems (Jones et al., 2013; Toogood et al., 2009; Toogood, Boyd, Bell, & Salisbury, 2011).

The positive effects on mood and depression are also interesting. Although the evidence on mental health is still quite limited, positive effects may be expected to occur through increased participation and reduced inactivity, though this has not yet been demonstrated. Only Stancliffe et al. (2010) examined the relationship between changes in depressive symptoms and increases in domestic engagement, but found a low correlation ($r=0.24$). Active Support effectiveness on depression remains to be established, as available comparison group data also indicate spontaneous improvements over time (Chou et al., 2011). Finally, the consideration of resident outcomes related to community participation, inclusion, and social relationships is a welcome addition to the research evaluations, and will perhaps be important in future implementation, as services broaden their horizons from within the house to the wider community.

All the evidence reviewed above relates to the effectiveness of Active Support in improving residents' lives though increased participation in meaningful activities. While effectiveness is clearly important, so is acceptability from stakeholders in ensuring both take up and maintenance. Evidence from three studies from the UK and New Zealand indicates that residents, support staff, in-house supervisors and managers (Graham et al., 2013; Jones, Felce, Lowe, Bowley, Pagler, Gallagher, et al., 2001; Totsika, Toogood, Hastings, et al., 2008) value Active Support for what it can offer both to those who reside in community homes and to those who support them.

Implications for Future Evaluations of Active Support

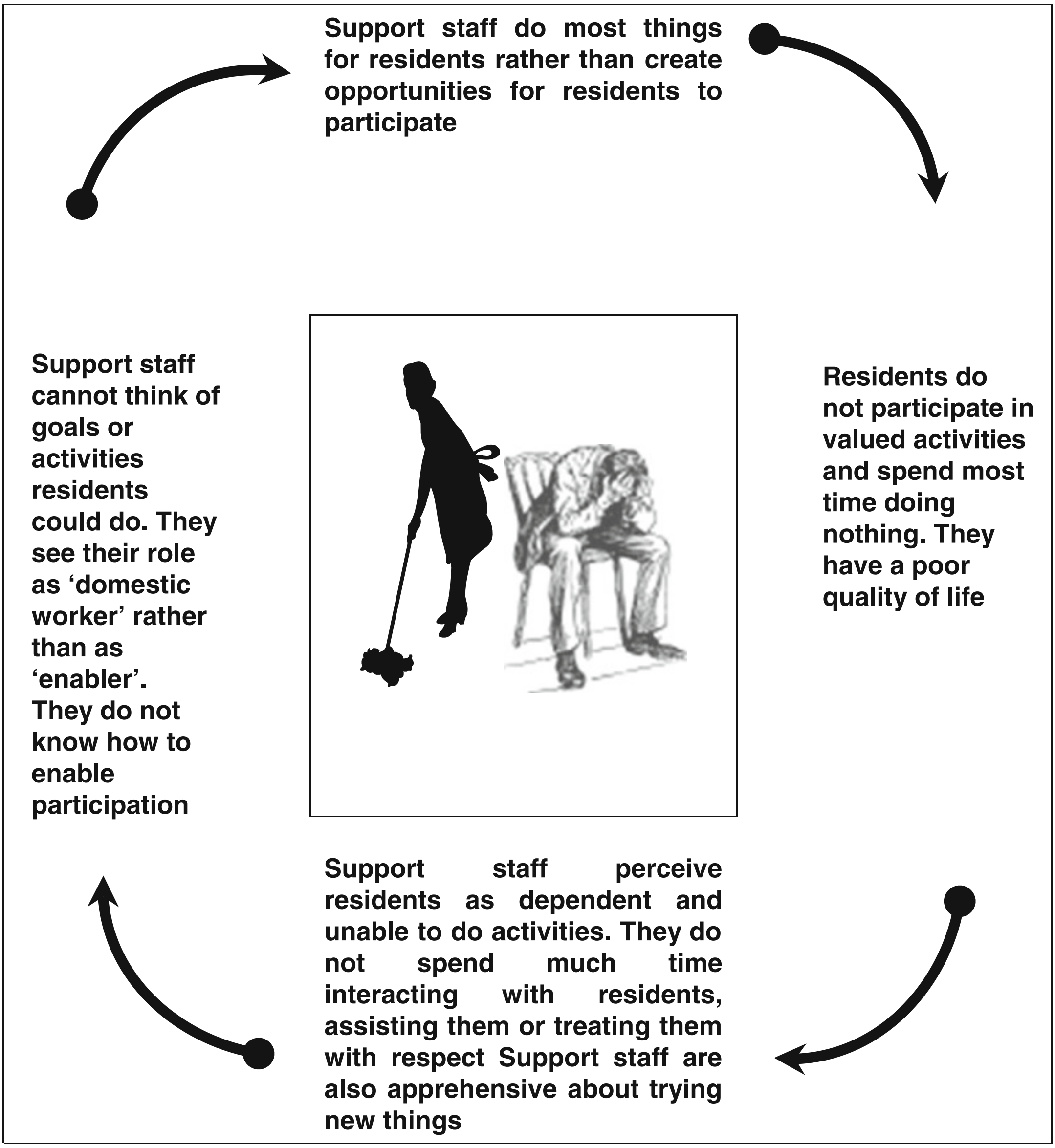
We believe that two important implications arise for future research. Active Support research is in need of some strong experimental studies at this stage. The evidence from uncontrolled, nonrandomized, and small-scale experimental studies is sufficiently encouraging to indicate that Active Support brings about gains in residents' daily experiences and quality of life. The next step in establishing the effectiveness of Active Support is a larger scale randomized trial.

The second implication relates to the number of outcomes included and the way they are measured. Over the years, Active Support evaluations appear more likely to include a wider range of resident-level outcomes and, at the same time, to rely more, if not exclusively, on staff-reported data. The focus on resident outcomes beyond domestic activities is crucial in helping to establish the true potential of Active Support, and in ensuring that Active Support is not just about housework. For the latter, we also need to ensure that our measures of participation or engagement remain broader than just domestic activities (i.e., measure several types of engagement). More importantly, however, we need to retain methodological rigor by using independently evaluated measures of engagement through direct observation. Direct observation remains the gold standard (Thomson, Felce, & Symons, 2000), helping to avoid over-reliance on a single source of informants (e.g., staff). Evidence suggests that staff reports show low levels of agreement on how much Active Support takes place (Mansell et al., 2013; Totsika, Toogood, Hastings, et al., 2008), suggesting that we cannot easily replace direct observation either for research evaluation or service audit purposes.

Implications for Service Values and Philosophy

The earlier description of Active Support emphasized the importance of values. This has a number of implications for services, the most obvious being a need for clear aims and a common values base in contemporary services. However, whilst this is a necessary condition, empirical evidence strongly suggests that this alone is insufficient (Emerson et al., 1999; Emerson & Hatton, 1994; Felce, Lowe, & Jones, 2002a, 2002b; Felce & Perry, 1995; Hewson & Walker, 1992; Jones et al., 1999; Jones, Felce, Lowe, Bowley, Pagler, Gallagher, et al., 2001; Jones, Felce, Lowe, Bowley, Pagler, Stong, et al., 2001; Stancliffe et al., 2008). Research on Active Support has demonstrated that although services may espouse the rhetoric of contemporary values, many fall far short of achieving them (Mansell et al., 2013). Indeed, many services operate a "hotel model," where support staff undertake all activities associated with running the household, leaving residents with little or nothing to do between external activities that may occur infrequently and are sometimes of unclear benefit to the person (Felce & Perry, 1995; Jones & Lowe, 2005). There is also some indication that people with the highest dependency and, therefore, in the greatest need of support, receive less staff attention and stimulation than their more able peers (Dailey, Allen, Chinsky, & Veit, 1974; Ducker et al., 1989; Grant & Moores, 1977; Jones et al., 1999; Lowe, Felce, & Blackman, 1996; Pratt, Bumstead, & Raynes, 1976), and that Active Support ensures that this is no longer the case (Ducker et al., 1989; Jones et al., 1999; Lowe et al., 1996; Totsika, Toogood, & Hastings, 2008; Totsika, Toogood, Hastings, et al., 2008). The hotel model is life wasting, rather than life enhancing, because it fails to engender residents' developmental growth or promote a good quality of life.

When support staff first start working with people with learning disabilities, they are often motivated by high ideals to improve residents' quality of life. However, many find themselves working in a hotel model, where they are not taught how to promote resident participation and may even be discouraged from doing so (Jones & Lowe, 2005). A reason for this may be that, in a hotel-model culture there is an inherent tendency to create false barriers concerning hygiene, health and safety, or to blame the residents' lack of ability, behavioral problems, choice to do nothing and so on. This denotes a failure to recognize basic service defects in the absence of structure and skill to support residents' participation in activity, skill development and experiential learning to make informed choices. This can result in a vicious circle of disempowerment that has a deleterious effect both on staff and on residents (Fig. 20.1).



Support staff do most things for residents rather than create opportunities for residents to participate

Residents do not participate in valued activities and spend most time doing nothing. They have a poor quality of life

Support staff perceive residents as dependent and unable to do activities. They do not spend much time interacting with residents, assisting them or treating them with respect Support staff are also apprehensive about trying new things

Support staff cannot think of goals or activities residents could do. They see their role as 'domestic worker' rather than as 'enabler'. They do not know how to enable participation

Fig. 20.1 A vicious circle of disempowerment in hotel models (Adapted from Jones & Lowe, 2005)

In contrast to this, Active Support can be seen as a set of practical person-centered actions consistent with O'Brien's five service accomplishments (O'Brien, 1987). O'Brien's motivation was to clarify the confusion over how values related to service outcome. His contribution has stood the test of time well and continues to provide both a strong anchor and steady compass in the stormy sea of service philosophy. Active Support combines these values with technology derived from Applied Behavior Analysis (Jones & Lowe, 2008; Mansell & Beadle-Brown, 2004) and, therefore makes a positive contribution in not only explaining what these values mean in practice but also providing effective methods to achieve them. In providing the structure and skills for support staff to become enablers, Active Support can also (reverse the inverse) change support staff attitudes and perception by establishing a virtuous circle of empowerment (Fig. 20.2).

As the virtuous circle gains momentum, support staff continually refine and individualize their approach as they successfully support residents to participate in a wider range activities for more of the time. This creates a dynamic whereby support staff develop a more positive understanding of the person which improves their communication and interaction. The relatively short time spent in the interactive aspect of Active Support training achieves this transformation far more efficiently and effectively than hours of theoretical values training can do. This is because theoretical

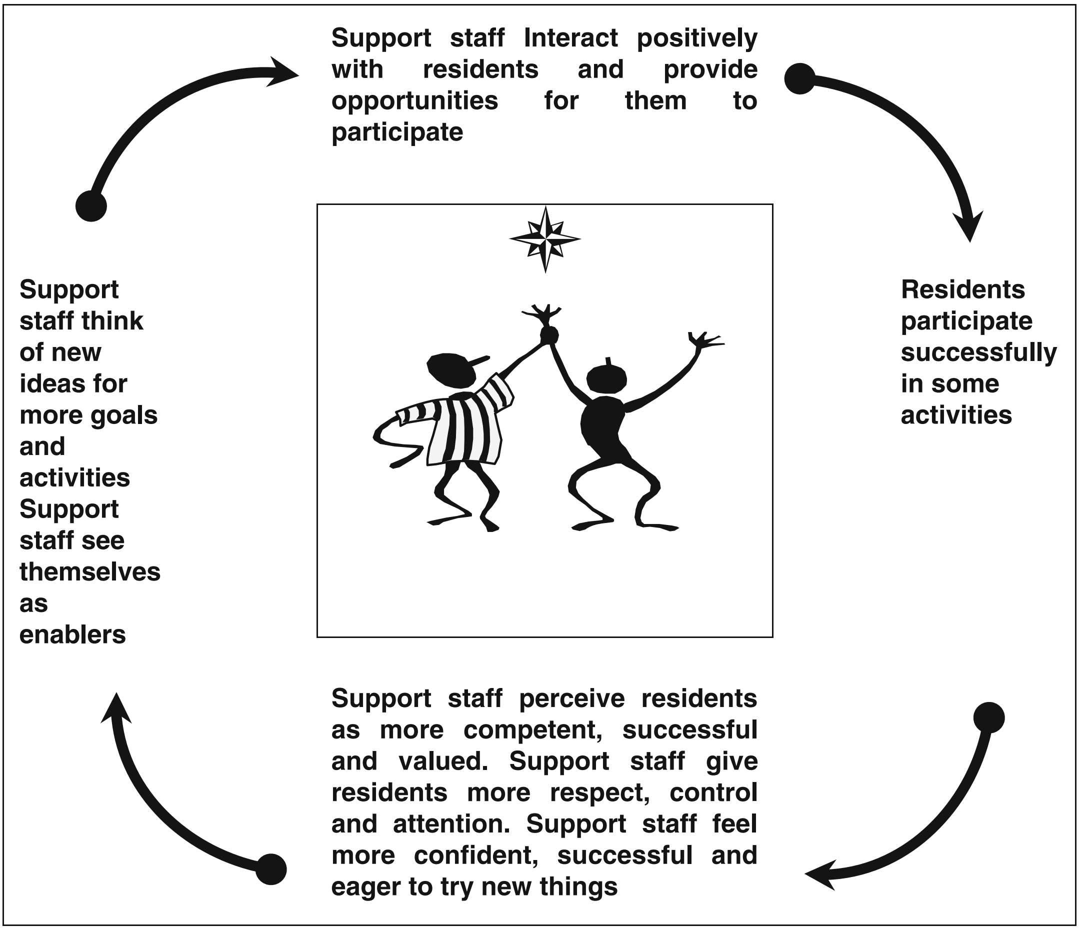


Fig. 20.2 A virtuous circle of positive interaction and empowerment (Adapted from Jones & Lowe, 2005)

training merely urges support staff to treat people with respect, dignity, promote choice participation and competency rather than shows them how to do this. In short, services must not only communicate their values and aims, but also move beyond this to give support staff the skills and tools to implement them in practice. It is not possible to achieve the five service accomplishments without promoting participation, as this is the key to inclusion and, therefore, central to the social model of disability. In our view, services should (a) embrace the values and aims from the five service accomplishments as the foundation for practice, (b) ensure that support staff actively support residents to participate in daily life as a key means of achieving these values in practice and (c) provide support staff with training in Active Support so that a culture is maintained where participation in activity is recognized as a key outcome and a quality of life indicator.

Implications for Service Design and Location

It is well established that small-scale, community-based services designed on typical domestic standards can more readily deliver the best outcomes in terms of residents' personal development and social inclusion (e.g., Chowdhury & Benson, 2011; Emerson & Hatton, 1996; Felce, 1993, 1996; Mansell & Beadle-Brown, 2010). The desirability of comfortable, well-equipped, homely environments tailored to individual resident needs hopefully requires little justification. However, research on Active Support has demonstrated that elements of the hotel culture be present in otherwise well-designed services, which represents a costly failure to take full advantage of the opportunities for personal development inherent in ordinary housing. The rationale for the ordinary house model was based not only on social equity but also on the accessibility of activities, both inside and outside the home, associated with the typical lifestyles enjoyed by most non-disabled people (Felce, de Kock, & Repp, 1986; Lowe & de Paiva, 1991a, 1991b; Lowe, de Paiva, & Felce, 1993). The underpinning philosophy of this model is that all activities of daily living (i.e., what we need to do to run our homes and look after ourselves) are culturally appropriate and valued activities because most people spend much of the time doing just that. Therefore, the model provides a rich source of readily available, meaningful opportunities for participation and skill development, which lead to positive self-esteem and social image, and thus has a very good fit with contemporary service values.

Research has demonstrated that, despite widespread adoption of the physical features of the community-based ordinary housing provision, the key factor that distinguishes successful services is what support staff do (Felce, 1993; Felce, Jones, et al., 2002). When support staff adopt the domestic worker role and mainly do domestic work without involving residents, this can displace their therapeutic role as support worker. Indeed, a key indicator of the hotel model is when residents are not supported to access their own kitchen or other utility areas because these are seen as the exclusive domain of support staff. Apart from the misguided concerns around health and safety referred to earlier, a further erroneous reason often proffered is that domestic chores are culturally devalued or not meaningful to the individual. This is a clear misunderstanding of the underpinning values. These issues are specifically targeted in Active Support training. Moreover, rather than avoiding risk and, therefore, opportunities for involvement, where risks are evident, these are managed to enable participation rather than used as a license for support staff to assume full control to the exclusion of residents. We recommend that:

1. Living environments should be person-centered and homely. A comfortable, well-equipped, ordinary house where residents have access to the usual variety of rooms and activities, taken for granted by most non-disabled people, is best.
2. Policy makers, commissioners and senior managers should ensure that these environments are used to full advantage: that is, the Active Support Model is fully implemented to

enable residents to enjoy the best possible quality of life.

3. Any adaptations in the physical environment should follow the least restrictive approach and be based on assessed individual need. Any restrictions should be viewed as exceptional and reviewed on a regular basis.

Organizational Policy and Procedures

Attention needs to be paid to wider aspects of organizational issues to foster the Active Support rather than the hotel model (Beadle-Brown et al., 2008; Clement & Bigby, 2007; Jones, Felce, Lowe, Bowley, Pagler, Stong, et al., 2001). Structure and routine are helpful aspects in most people's lives. Typically people develop their own preferred sequence of doing daily activities such as getting ready in the morning to go to work, and have additional structure to their days and weeks, such as doing certain activities on certain days, more leisure at the weekends and so on. Planning is part of an ordinary life, and the idiom "Failing to plan is planning to fail" has much truth.

Accommodation services are complex environments, with several residents who have different needs and interests, and numerous support staff who work different shifts and may see one another relatively infrequently. Given this complexity, it is surprising that structure and routine are often rejected as institutional and incompatible with community living in some contemporary services. However, a key difference between non helpful institutional routines and supportive environments is the extent to which routine and structure are person-centered and help people with intellectual disability not only to cope with but also get the best out of daily life, by enhancing richness of activity and increasing predictability which, in turn, increases personal control. In the hotel model, routines and structure exist predominantly for the convenience of support staff, with planning of resident activity being rudimentary at best and sometimes bordering on mythology (Felce, Jones, et al., 2002; Felce, Jones, Lowe, & Perry, 2003; Felce, Lowe, et al., 2002a, 2002b). For example, an activity timetable may exist, but often can be found only after an extensive search; it may cover only a small percentage of the time, may be out of date and may bear little resemblance to what residents actually do. In similar vein, support staff may firmly believe they provide support in consistent ways to each resident. A common example concerns personal care, particularly for those who require a high level of help and can be dependent on ten or more different support staff over a week. Often no written activity script can be produced, and support staff believe they all provide support in the same way so there is no need for one. A simple, but effective, exercise within Active Support training requires each support staff member to write a simple task analysis of exactly how they support a particular resident to do a specific activity. When they compare their different versions, major inconsistencies are often very apparent, often revealing to support staff previously undetected trigger points for the resident's challenging behavior.

Attention to developing the skills of existing support staff is more effective in achieving desired resident outcomes than adding more untrained support staff and this also has clear potential cost benefits (Felce et al., 1998; Felce et al., 2003; Felce, Lowe, Beecham, & Hallam, 2000; Robertson et al., 2004). Effectiveness can be further improved when this is combined with micro planning of resident activity and the clearer allocation of support staff to support this (Jones et al., 1999; Jones & Lowe, 2005; Stancliffe, Harman, Toogood, & McVilly, 2011).

Organizations should also avoid central purchasing of bulk supplies as this denies opportunities for residents to do their own shopping and become familiar with their local community. Internet grocery shopping may be useful at times, but can be a modern expression of institutional practice. In similar vein, employing catering or domestic support staff prevents residents from participating in these activities. The early model projects gave clear direction for support staff to never do any domestic activity without involving a resident.

Data driven practice, where evidence is explicitly used to inform decision-making is widely recommended as an essential element for continuous quality improvement at all organizational levels (Deming, 1986; La Vigna, Willis, Shaull, Abedi, & Sweitzer, 1994; Mawhinney, 1992; Sluyter, 2000). For example, organizations increasingly record incidents of challenging behavior and restrictive practice to inform organizational learning and underpin strategies for restraint reduction (Allen, 2011; Bullard, Fulmore, & Johnson, 2003; Huckshorn, 2004). The original versions of Active Support incorporated systematic recording to gather data on the frequency and scope of resident participation in activities and attainment of skills. This demonstrated the explicit emphasis on gains in adaptive behavior and overall personal development as desired resident outcomes and a dynamic, informed relationship between service inputs and outputs. Further, this focus was on positive quality of life outcomes rather than negative aspects. Unfortunately such coherence in data driven outcome measurement appears to be uncommon in contemporary services. We suggest services should ensure that:

1. Routines and structures are person-centered and helpful to residents rather than based on standard shift patterns designed for the benefit of support staff and the organization.
2. Support staff are trained in designing person-centered structures for planning resident activities at a micro level and routines that improve the consistency of support staff support and enhance residents' quality of life.
3. Particular attention is given to developing structure and routines for residents with the greatest dependence on support staff support.
4. Support staff function as support workers, i.e., support residents to participate in a wide range of activities, rather than do activities without involving residents.
5. Cleaners and cooks whose role is to do domestic work without involving residents are not employed.
6. Residents do their shopping and the central purchasing of most everyday items is avoided.
7. Data on residents' quality of life outcomes is gathered and used to inform decision making with individual residents and at other organizational levels.

Leadership

The effectiveness of any training in improving support staff performance is dependent on in-house supervisors helping support staff to implement in practice what they have learned in theory (Anderson, 1987; Jones, Blunden, Coles, Evans, & Porterfield, 1987). Research has highlighted the importance of Practice Leadership in ensuring the effective implementation of the Active Support model (Beadle-Brown et al., 2014; Hewitt et al., 2004; Jones, Felce, Lowe, Bowley, Pagler, Gallagher, et al., 2001; Larkin & Larkin, 1996; Sturmey, 1998). Practice leadership requires the first line in-house supervisor to understand the theoretical and practical aspects of the AS model and to lead by role modeling. Practice leaders should regularly work alongside support staff to support, observe and provide feedback to reinforce the desired support staff performance. This also allows them to problem solve any barriers to implementation. These elements form the core of interactive training (Toogood, 2008, 2010). Practice leadership in Active Support has many similarities with Positive Monitoring, a technique specifically designed for services for people with intellectual disabilities over 20 years ago and integral to the Nimrod project (Lowe & de Paiva, 1991a; Porterfield, 1987). However, administrative management that is more concerned with general bureaucratic aspects and distanced from day-to-day support staff practice is often the norm in many contemporary service settings and characterizes the hotel model. Embedding Active Support is achieved by developing practice leadership through in-house supervisors' involvement in Active Support training which enables them to develop support staffs' practical skills in positive interaction as an inherent component of the long-term managerial approach. We suggest that services should (a) adopt a strategic approach to developing practice leadership, (b) incorporate Positive Monitoring as a routine part of management practice, and (c) provide greater clarity in job descriptions at all levels to ensure that all roles are operationalized.

Conclusion

Although the term Active Support is used widely, it is not a homogenous or single entity. Rather, it is an organized set of principles, practices and procedures informed by a person-centered service philosophy and fundamental concern for how residents of small community homes and their staff use their time together. The main aim of Active Support is to create and sustain conditions in which staff act effectively as enablers, and residents are able to participate meaningfully in the ordinary activities of everyday life.

In this regard Active Support places a great deal of emphasis on what staff and staff teams do. Pivotal skills needed to implement Active Support effectively are the ability to:

1. *Plan* and then *create* opportunities for people with intellectual disabilities to take part in the natural flow or ordinary, everyday, life-defining activities,
2. Supply the momentary *motivation*, *support and assistance* individuals need to participate successfully in those activities, and
3. *Monitor*, *evaluate and adjust* expectations, opportunities and outcomes, together with the level and type of assistance provided in regard to the individual, the service setting, and across a service agency or provider organization.

In pursuing these aims, Active Support utilizes training interventions that typically combine elements of theory and values-based learning with developing Active Support materials and a focused learning event delivered through onsite coaching in the workplace. Maintenance is strengthened in the presence of ongoing practice leadership from in-house supervisors with support from their managers. It is important to note, however, that Active Support is not a panacea or quick fix to remediate poor quality or badly designed services. Active Support does not work in badly designed services that have strongly institutional characteristics, weak management or staff who have intractable attitudes that people with intellectual disabilities cannot develop or learn, or should not be involved in typical life experiences. These things also need to change. Reviewing services through the prism of Active Support can, though, highlight where change is required and what form it should take. For this to happen, organizational values, policies, and procedures need to be aligned to promote Active Support and be integrated into the management culture of the organization at all levels.

In reviewing the evolution of Active Support, we noted a thinning out of Active Support components. The rationale for locating individual planning, structured teaching, and semi-structured opportunity planning external to the Active Support Model is that each of these functions can be done in different ways and should therefore be coordinated with Active Support rather than considered a part of it (Mansell & Beadle-Brown, 2012). It has also been suggested that individual planning and skills teaching are logically and practically independent of Active Support. This is a moot point, however, as there is as yet no empirical evidence to support the argument one way or the other. It may be, for example, that systems of Active Support interact to improve the quality of staff insights, commitment and experience, and ultimately their interactions with residents. We simply do not know. The question of whether model components are integral or complementary may seem an unimportant one, except that ascribing a component as complementary implies that it may also be optional. Experience teaches us that delivering fully integrated systems of Active Support is likely to be more difficult for services than delivering system components selectively. It may be, then, that we need to proceed in a stepwise fashion, so that the bare bones of Active Support as currently presented represents a starting point for services and not an end goal.

In reviewing the research evidence on Active Support, findings were clear in systematically indicating increases in meaningful activity participation for residents of community homes. We noted, however, that the latest generation of Active Support evaluations is characterized by less reliance on direct observation as an evaluation method and a wider range of outcomes. As such, not all studies evaluated changes in staff behavior, but those that did reported significant improvements. In addition, the latest evidence suggested improvements in resident choice, mental health (depression), and adaptive skills. Evidence highlighted potential effects for stereotypies and internalizing behaviors, though clinical case study evidence indicated that Active Support can significantly reduce several different topographies when it is matched well to the behavioral function, and is accompanied by other interventions (e.g., treating medical problems).

An important feature of Active Support evaluation research is the lack of experimental rigor (Hamelin & Sturmey, 2011), with most studies relying on uncontrolled designs with convenience sampling. We believe that, following 15 group-design evaluations, the efficacy of Active Support remains to be demonstrated under conditions of tighter experimental control (such as in randomized trials), and should strive to retain the element of independent objective evaluation that direct observation can offer. At the same time, it is important to note that evidence of positive gains is now available from countries beyond the UK and for outcome areas beyond activity participation, suggesting the universality of the Active Support model, and its potential to bring about gains to broader quality of life domains. The challenge for the next generation of Active Support evaluations will be to strengthen experimental control while maintaining the resource intensive direct observations of resident engagement, and include secondary outcomes that examine whether Active Support benefits can be found in more than one domain of quality of life.

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Self-Determination and Choice

21

Michael L. Wehmeyer and Karrie A. Shogren

Introduction

Promoting the self-determination of adolescents and adults with intellectual disability has emerged as a best practice for a variety of reasons to be articulated in this chapter, among them the association between enhanced self-determination and choice opportunities with more positive quality of life and life outcomes for youth and adults with intellectual disability (Nota, Ferrrari, Soresi, & Wehmeyer, 2007; Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2015). Fundamentally, however, a focus on promoting self-determination has increased in importance in synchronicity with the emergence of greater civil rights protections and enhanced community and school inclusion for people with disabilities. It is not simply coincidence that the first mention of the rights of people with intellectual disability to self-determination was in a chapter written by Bengt Nirje (1972)—the Swedish philosopher who introduced the Normalization Principle—in a text introducing that same principle to a North American audience. In that chapter, Nirje argued that:

> One major facet of the normalization principle is to create conditions through which a [handicapped] person experiences the normal respect to which any human is entitled. Thus, the choices, wishes, desires and aspirations of a [handicapped] person have to be taken into consideration as much as possible in actions affecting him. To assert oneself with one's family, friends, neighbors, co-workers, other people, or vis-a-vis an agency is difficult for many people. It is especially difficult for someone who has a disability or is otherwise perceived as devalued. Thus, the road to self-determination is indeed both difficult and all-important for a person who is impaired (Nirje, 1972, p. 177).

It is also not coincidental that efforts to promote self-determination did not begin, despite Nirje's, 1972 call-to-action, until the early 1990s, when civil protections were in place and a vibrant self-advocacy movement focusing on empowerment and community inclusion was established (Wehmeyer, Bersani, & Gagne, 2000). Sixteen years after Nirje's initial call for the right to self-determination, Michael Ward, then the branch chief of the US Department of Education's Office of Special Education Programs, Secondary Education and Transition Services branch, and a person with personal experience with disability, wrote:

> While acquiring the personal characteristics which lead to self-determination is important for all people, it is a critical and often more difficult goal for people with disabilities. They must shatter the pervasive stereotypes which imply that they cannot, or perhaps should not, practice self-determination (Ward, 1996, p. 2).

Although separated by almost two decades, these writers make virtually the same point …

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even though self-determination is critically important for people with disabilities, they have limited opportunities to become self-determined. In the two decades between Nirje's call for self-determination and that of Ward, too little had changed in the lives of people with disabilities. However, much did change in the field of disability supports and in the way people with disabilities were perceived in these services and in society, as discussed momentarily, so that while Nirje's call for self-determination remained largely unheeded, the demands of Ward and his peers were attended to and are, slowly, being realized.

Normalization Principle

It is logical that the earliest call for self-determination within the field of intellectual disability occurred as a function of the articulation and implementation of the Normalization Principle. Scheerenberger (1987) suggested that no single categorical principle had ever had a greater impact on services for people with intellectual disability than did that of the Normalization Principle. In conjunction with the independent living movement, whose influence was felt most significantly by people with physical and sensory impairments, the Normalization Principle paved the way for greater community inclusion for people with intellectual disability and, ultimately, provided the foundation to focus on promoting self-determination.

Nirje (1969) explained that the normalization principle had its basis in "Scandanavian experiences from the field" and emerged, in essence, from a Swedish law on mental retardation, which was passed July 1, 1968. In its original conceptualization, the normalization principle provided guidance for creating services which "let the [mentally retarded] obtain an existence as close to the normal as possible" (Nirje, 1969, p. 363). Nirje stated:

> As I see it, the normalization principle means making available to the [mentally retarded] patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society (p. 36.).

Nirje (1969) identified eight facets and implications of the normalization principle:

1. Normalization means a normal rhythm of day.
2. Normalization implies a normal routine of life;
3. Normalization means to experience the normal rhythm of the year;
4. Normalization means the opportunity to undergo normal developmental experiences of the life cycle;
5. Normalization means that the choices, wishes and desires [of the mentally retarded themselves] have to be taken into consideration as nearly as possible, and respected.
6. Normalization also means living in a bisexual world;
7. Normalization means normal economic standards [for the mentally retarded];
8. Normalization means that the standards of the physical facility should be the same as those regularly applied in society to the same kind of facilities for ordinary citizens.

Scheerenberger (1987) noted that "at this stage in its development, the normalization principle basically reflected a lifestyle, one diametrically opposed to many prevailing institutional practices" (p. 117).

Independent Living, Self-Help, and Self-Advocacy Movements

Associated with the emergence of the Normalization Principal, and its associated changes in service delivery models, there emerged several self-help and independent living movements, beginning with people with physical disabilities and eventually adopted by people with intellectual disability in the formation of self-advocacy groups. Driedger (1989) pointed out that "many disabled people view their rights movement as the last in a long series of movements for rights—labor, blacks, colonized peoples, poor people, women—and now people with disabilities" (p. 1). Critical to this rights movement was the emergence of organizations organized and led by people with disabilities. Driedger suggested that three branches of the disabled people's movement have emerged since 1970: the independent living movement, consumer organizations, and self-help groups. The independent living movement, emerging almost in parallel with the Normalization Principle, focused on enabling people with disabilities to live as independently as possible in their communities. The movement was given considerable impetus in the USA when the Rehabilitation Act of 1973 allocated money to establish Independent Living Centers—consumer-controlled, cross-disability, nonresidential private nonprofit organizations that provide services that promote independence, productivity, and an enhanced quality of life for people with disabilities. The key to the success of CILs (Centers for Independent Living) was the fact that they were consumer controlled … people with disabilities providing assistance to other people with disabilities. Consumer organizations are similar to CILs, except they do not provide services and instead serve a monitoring and advocacy role. Concurrently, people with physical and other disabilities began to form self-help groups that focused on personal and rights-based advocacy.

In the 1980s, groups for people with intellectual disability began to emerge that emulated the structure and intent of existing self-help groups and that also provided a vehicle for personal advocacy and socialization. These groups became known as self-advocacy groups, and were organized and run by people with intellectual disability (Dybwad & Bersani, 1996). In 1990, leaders in the self-advocacy movement founded Self-Advocates Becoming Empowered (SABE), which provided a national presence for self-advocacy groups.

The importance of these consumer organized and controlled organizations on the emergence of a focus on self-determination cannot be underestimated. Not only did such organizations provide opportunities for greater independence and expand the desire for increased choice and control, they also provided the opportunity for people with disabilities to become informed, active advocates. These advocacy activities, concurrent with parental advocacy activities, eventually led to the passage of civil rights legislation, which has been equally important in the emergence of efforts to promote self-determination.

Civil Rights Protections

One of the most visible outcomes of the parent advocacy and, over the past two decades, the disability rights movement, have been the emergence of civil rights legislation protecting the rights of people with disabilities. Among the most visible of these protections is the Americans with Disabilities Act (ADA), signed into law in 1990. The ADA bans discrimination based on disability and gives people with disabilities civil rights protections equivalent to those provided to individuals on the basis of race, sex, national origin and religion in the Civil Rights Act of 1964. The ADA guarantees equal opportunity for people with disabilities in employment, public accommodations, transportation, state and local government services and telecommunication relay services. Of course a myriad of other civil and legislative acts focused on non-discrimination and equal access, from The Individuals with Disabilities Education Act to the Developmental Disabilities Act.

Changing Understandings of Disability and Support Models

In large measure because the aforementioned movements and actions that codified the community as the "place" where people with intellectual disability should live, learn, work, and play and because civil protections ensured equal access, there began to emerge biopsychosocial models of disability that emphasized the "fit" between a person's capacities and the demands of the environment. Lockstep with civil protections guaranteeing non-discrimination around the world, in the late twentieth Century the ways in which disability itself was understood began to change, thus facilitating a strengths-based approach (Buntinx, 2013). Such reconceptualizations began with the introduction of the

International Classification of Impairments, Disabilities, and Handicaps (*ICIDH*) (Wood, 1989; World Health Organization, 1980). The ICIDH situated disability within a framework of human functioning, describing the impact of health conditions on human functioning as resulting: (1) the "exteriorization of a pathology" in body anatomy and functions (e.g., as pertaining to intellectual disability, central nervous system and intelligence), (2) "objectified pathology" as expressed in the person's activities (e.g., adaptive behavior skills), and (3) the "social consequences of pathology" (e.g., participation in social life domains) (World Health Organization, 1980, p. 30).

Later, it was recognized that besides the impact of health condition factors (pathology), contextual factors (environmental factors, personal factors) are of pivotal importance for the understanding of human functioning and that limitations in human functioning are not necessarily linear or causal consequences of a pathology, but that human functioning should be conceived as multiple interactive processes where each factor can influence each dimension of functioning and each other factor either directly or indirectly (Wehmeyer et al., 2008). The ICIDH successor, the *International Classification of Functioning*, *Disability*, *and Health* (ICF; WHO, 2001), which removed "disability" from classifications of diseases, and placed it (and its understanding), within a model of typical human functioning. The ICF views "*Functioning*" as an umbrella term for all life activities of a person and encompasses body structures (anatomical parts of the body) and functions (physiological and psychological functions of body systems), personal activities (the execution of a task or action by an individual), and participation (involvement in a life situation). Limitations in functioning are labeled a "disability." Disability can result from any problem in one or more of the three dimensions of human functioning [body structures and functions, personal activities, participation]. The *health condition* of an individual can affect his or her functioning directly or indirectly in each or all of the three dimensions. Health condition problems are "disorders," "diseases," or "injuries," etc., as classified in the *International Statistical Classification of Diseases and Related Health Problems* (*ICD-10*) (WHO, 1999). The ICD-10 provides an etiological framework for health conditions affecting human functioning.

Finally, the ICF identifies *Contextual Factors* that include (a) environmental factors and (b) personal factors and that represent the complete background of an individual's life. They may have an impact on the individual's functioning and must also be considered in the evaluation of human functioning. *Environmental factors* make up the physical, social, and attitudinal environment in which people live and conduct their lives. *Personal Factors* are characteristics of a person such as gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experience (past life events and concurrent events), character style, individual psychological assets and other characteristics, all or any of which may play a role in disability at any level (Wehmeyer et al., 2008).

Essentially, the introduction of the ICIDH, which first conceptualized disability within the context of typical human functioning, and the ICF, which removed disability from taxonomies of disease and disorder, changed how disability, including intellectual disability, is understood using social-ecological or person-environment fit models. That is, disability itself is not a disease or a disorder existing within the person, but exists only in the gap between the person's strengths and capabilities and the demands of the environment or context. Intellectual disability, per se, is a disability manifesting as limitations in intellectual functioning (reasoning, planning, solving problems, thinking abstractly, comprehending complex ideas, learning quickly, and learning from experience) related to activity limitations, associated with participation restrictions, and eventually resulting from CNS impairments or specific etiological factors (Wehmeyer et al., 2008).

These social-ecological models of disability change the emphasis for intervention to reducing the gap between the person's capacities and the demands of the context by enhancing personal capacity and modifying the context, activity, or environment (Shogren, 2013; Wehmeyer, 2013a, 2013b). We emphasize these important changes in understanding (and nomenclature, as in the change from mental retardation to intellectual disability) as introductory to discussing issues pertaining to self-determination because, quite simply, it was only as such models of disability were introduced and began to be accepted, worldwide, that a focus on self-determination, and its concomitant focus on the importance of choice opportunities, could (and did) begin to take root. Promoting self-determination is part-and-parcel of changing understandings of disability; the focus on people with intellectual disability living, working, learning, and playing in their communities; and greater empowerment and self-advocacy.

The impact of the shift to a person-environment fit model involves an increased emphasis on the design of supports to enable a person to function within his or her context by efforts to increase personal capacity, modifications to the activity, task, context, or environment, and additional supports as necessary (Luckasson et al., 2002).

Supports are “resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and that enhance individual functioning” (Thompson et al., 2009, p. 135). Luckasson and Spitalnick (1994) suggested that “supports refer to an array, not a continuum, of services, individuals, and settings that match the person’s needs” (p. 88). First, supports have the unambiguous intent to enhance community integration and inclusion by enabling people to access a wide array of resources, information, and relationships. Second, supports are individually designed and determined with the active involvement of key stakeholders in the process, particularly the person benefiting from that support. Third, a supports model requires an active and ongoing evaluation of the ecological aspects of the “disability” (because the “disability” can only be defined within the context of the functional limitation and the social context) and efforts to design supports focus heavily on changing aspects of the environment or social context or providing individuals with additional skills or strategies to overcome barriers in those environments.

Self-Determination and Positive Psychology

The focus on self-determination in the lives of people with intellectual disability was among the first signs of a shift in research in psychology, in general, and research and practice in intellectual disability, particularly, toward strengths-based models of disability and intervention (Wehmeyer, 2013a, 2013b). Positive psychology involves the pursuit of understanding optimal human functioning and well-being and a prominent construct in positive psychology is self-determination (Ryan & Deci, 2000). Research in self-determination in positive psychology has focused primarily on the construct in the context of motivational psychology, and while research and theory in self-determination in special education was derived from this early work, most of the theoretical perspectives within the disability sphere have focused more broadly on self-determination as, in essence, a personality construct and less specifically on motivational aspects pertaining to self-determination. This leads us, in turn, to the need to define self-determination and describe the theoretical foundations for promoting greater self-determination.

Self-Determination: Its Genesis and Development

What Is Self-Determination?

Self-determination is a noun referring either to the determination of one’s own fate or course of action (a personal sense of the term) or to the rights of nations or groups of people to autonomy and self-governance (American Heritage Dictionary, 1992). The latter is the most common use of the term in the modern era, but the former is the oldest and, for our purposes, the most relevant. It refers, in some sense, to a quality or characteristic within a person who determines his or her own fate or course of action. The personal sense of the term emerged from the philosophical doctrine of determinism, which suggested that all action (including human behavior) is in some way *caused*. In the early twentieth century, as psychology emerged as a discipline distinct from philosophy, the notion of self-determinism was coopted to begin to understand personality development. Angyal (1941), in proposing the foundations for a science of personality, suggested that an essential feature of a living organism is its autonomy, where autonomous means self-governing or governed from inside. According to Angyal, an organism "lives in a world in which things happen according to laws which are heteronomous (e.g., governed from outside) from the point of view of the organism" (p. 33). Autonomous-determinism, or as it subsequently became, self-determination, refers to self- versus other-caused action.

Shogren, Wehmeyer, Palmer, Forber-Pratt, Little, and Lopez (2015) conceptualized self-determination as a general psychological construct within the organizing structure of theories of human agentic behavior. Human agentic theories "share the meta-theoretical view that organismic aspirations drive human behaviors" (Little, Snyder, & Wehmeyer, 2006, p. 61). An organismic perspective views people as active contributors to, or *agents* of, their behavior, An agentic person is the "origin of his or her actions, has high aspirations, perseveres in the face of obstacles, sees more and varied options for action, learns from failures, and overall, has a greater sense of well-being" (Little, Hawley, Henrich, & Marsland, 2002, p. 390). An agentic person engages in self-regulated and goal-directed *action*, they "plot and navigate a chosen course through the uncertainties and challenges of the social and ecological environments … continuously interpreting and evaluating actions and their consequences" (Little et al., 2002, p. 390). This continually evolving and actively monitored self-system gives rise to a sense of personal agency, or of the agentic self. The agentic self has a "sense of personal empowerment, which involves both knowing and having what it takes to achieve one's goals" (Little et al., 2002, p. 390).

Specifically, Shogren et al. (in press) propose *Causal Agency Theory* as a foundation upon which to build interventions to promote self-determination. Within the context of Causal Agency Theory, we define self-determination as a

> … dispositional characteristic manifested as acting as the causal agent in one's life. Self-determined *people* (i.e., causal agents) act in service to freely chosen goals. Self-determined *actions* function to enable a person to be the causal agent is his or her life.

A *dispositional characteristic* is an enduring tendency used to characterize and describe differences between people; it refers to a tendency to act or think in a particular way, but presumes contextual variance (i.e., socio-contextual supports and opportunities and threats and impediments). As a dispositional characteristic, self-determination can be measured, and variance will be observed across individuals and within individuals over time, particularly as the context changes (e.g., supports and opportunities are provided for self-determined action).

Broadly defined, *causal agency* implies that it is the individual who makes or causes things to happen in his or her life. Causal agency implies more, however, than just causing action; it implies that the individual acts with an eye toward *causing* an effect to *accomplish* a *specific end* or to *cause* or *create change*. Self-determined actions enable a person to act as a causal agent in their lives.

Organismic theories differentiate between self-determination as self-*caused* action and self-determination as *controlling* one's behavior. As Deci (2004) observed, "the concept of personal control … refers to having control over outcomes" (p. 23). Control is defined as "authority, power, or influence over events, behaviors, situations, or people" (VandenBos, 2007, p. 228). Self-determined action does not imply control over events or outcomes. Instead it refers to the degree to which action is self-caused; that is the degree to which behavior is *volitional* and *agentic*, driven by beliefs about the relationships between actions (or means) and ends.

Essential Characteristics of Self-Determined Actions

Self-determined *action* is characterized by three essential characteristics—volitional action, causal action, and action-control beliefs. These *essential characteristics* refer not to specific actions performed or the beliefs that drive action, but to the *function* the action serves for the individual; that is, whether the action enabled the person to act as a causal agent:

Volitional Action: Self-determined people act volitionally. Volition refers to making a conscious choice based upon one's preferences. Conscious choice implies intentionality; self-determined actions are intentionally conceived, deliberate acts that occur without direct external influence. As such, volitional actions are self-initiated and function to enable a person to act autonomously (i.e., engage in self-governed action). Volitional actions involve the initiation and activation of causal capabilities—the capacity to cause something to happen—and something to happen in one's life.

Agentic Action: An agent is someone who acts; a means by which something is done or achieved. Agency refers to action in the service of a goal. Self-determined people act to identify pathways that lead to a specific ends or cause or create change. The identification of pathways is a proactive, purposive process. As such, agentic actions are self-regulated and self-directed. Such actions function to enable a person to make progress toward freely chosen goals and respond to opportunities and challenges in their environments. Such actions involve agentic capabilities; the capacity to direct it to achieve an outcome.

Action-Control Beliefs: Self-determined people have a sense of personal empowerment; they believe they have what it takes to achieve freely chosen goals. There are three types of action-control beliefs: beliefs about the link between the self and the goal (control expectancy; "When I want to do ____, I can"); beliefs about the link between the self and the means for achieving the goal (capacity beliefs; "I have the capabilities to do _____"); and beliefs about the utility or usefulness of a given means for attaining a goal (causality beliefs; "I believe my *effort* will lead to goal achievement" vs. "I believe other factors—*luck*, *access to teachers or social capital*—will lead to goal achievement"). Positive action-control beliefs function to enable a person to act with self-awareness and self-knowledge in an empowered, goal-directed manner.

Socio-contextual Influences

People who are causal agents respond to challenges (opportunities or threats) to their self-determination by employing causal and agentic actions, supported by action-control beliefs. This leads to self-determined action that allows them to initiate and direct their behavior to achieve a desired change or maintain a preferred circumstance or situation. In response to challenges, causal agents use a *goal generation process* leading to the identification and prioritization of needed actions. The person frames the most urgent action need in terms of a goal state, and engages in a *goal discrepancy analysis* to compare current status with goal status. The outcome of this analysis is a *goal-discrepancy problem* to be solved. The person then engages in a *capacity-challenge discrepancy analysis* in which capacity to solve the goal discrepancy problem is evaluated. The person maximizes adjustment in capacity (e.g., acquires new or refines existing skills and knowledge) or adjusts the challenge presented to create a "just-right match" between capacity and challenge to optimize the probability of solving the goal discrepancy problem.

Next, the person creates a discrepancy reduction plan by setting causal expectations, making choices and decisions about strategies to reduce the discrepancy between the current status and goal status. When sufficient time has elapsed, the person engages in a second goal discrepancy analysis, using information gathered through self-monitoring to self-evaluate progress toward reducing the discrepancy between current and goal status. If progress is satisfactory, they will continue implementing the discrepancy reduction plan. If not, the person either reconsiders the discrepancy reduction plan and modifies that or returns to the goal generation process to reexamine the goal and its priority and, possibly, cycle through the process with a revised or new goal.

Development of Self-Determination

Self-determination develops across the life span, emerging as adolescents develop and acquire multiple, interrelated skills, referred to as component elements of self-determined action that enable the expression of the essential characteristics, including learning to make choices and express preferences, solve problems, engage in making decisions, set and attain goals, self-manage and self-regulate action, self-advocate, and acquire self-awareness and self-knowledge.

Self-determination is also an important contributor to the individuation process during adolescent development. Individuation refers to the process of moving from being primarily dependent upon others (for a child, typically his or her family), to being primarily dependent upon oneself; the "physiological, psychological, and sociocultural processes by which a person attains status as an individual human being and exerts him- or herself as such in the world" (VandenBos, 2007, p. 477).

Promoting the Self-Determination of People with Intellectual Disability

As noted at the onset of this chapter, promoting self-determination has become best practice in practices to support people with intellectual and developmental disabilities, particularly as it pertains to secondary education and transition services. In the early to mid-1990s, research examined the degree to which people with intellectual disability were self-determined and experienced opportunities to make choices in their lives (Stancliffe & Wehmeyer, 1995; Wehmeyer & Metzler, 1995). The absence of standardized measures of self-determination relevant to people with intellectual disability necessitated an initial focus on choice-making and choice opportunities, and a general consensus emerged from this research that people with intellectual disability experienced few opportunities to make choices in their lives (Stancliffe, 2001). Wehmeyer and Metzler (1995) found that people with intellectual disability experienced significantly fewer choice opportunities pertaining to where they lived, work and leisure activities, who they spent time with, and so forth. For example, in a sample of people without disabilities, 77 % indicated that they chose their current job, while Wehmeyer and Metzler found that only 11 % of people with intellectual disability made such choices. Similar discrepancies were found in relation to choices about where to live (46–6 %), opportunity to control one's own money (91–44 %), and choosing who to live with (59–9 %). Stancliffe and Wehmeyer (1995) found that choice opportunities varied for people with intellectual disability as a function of where a person lived, with people with intellectual disability who lived in their communities having significantly more choice opportunities than did people with intellectual disability living in congregate settings.

As measures of self-determination were developed and normed with people with intellectual disability, the research shifted to the broader question as to the relative self-determination of people with intellectual disability. Like research pertaining to the availability of choice making opportunities, this research found that people with intellectual disability were, in general, less self-determined than other people without cognitive disabilities (Wehmeyer, 1996). Wehmeyer and Bolding (1999, 2001) conducted matched-samples and follow-along studies that confirmed that the self-determination of people with intellectual disability was a function of the environments in which they lived and worked and that simply moving from a more restrictive (e.g., group home or sheltered workshop) setting to a community-based setting (supported living, supported employment) resulted in enhanced self-determination.

In all, this research confirmed that people with intellectual disability were less self-determined than many of their peers and that, in part, that was a function of limited choice opportunities available in congregate living and working settings prevalent at the time. Whether or not this relative lack of self-determination mattered was the focus of the next wave of research. Wehmeyer and Schwartz (1997) measured the self-determination of youth with intellectual disability as they exited high school, then followed up with them 1 year afterwards, determining a significant, positive correlation with self-determination status and more positive adult outcomes, including employment and community inclusion related outcomes. Wehmeyer and Palmer (2003) conducted a similar study, following up with youth with intellectual disability and learning disabilities 3 years post high school and, again, finding positive correlations between higher self-determination status and more positive adult outcomes.

Wehmeyer and Schwartz (1998) also found a significant positive correlation between the self-determination status of adults with intellectual disability and their self-reported quality of life. This linkage between higher self-determination and more positive quality of life has been found in subsequent studies as well (Lachapelle et al., 2005; Nota et al., 2007), as has the link between higher self-determination and more positive lifestyle satisfaction (Shogren, Lopez, Wehmeyer, Little, & Pressgrove, 2006).

The establishment of the importance of self-determination to people with intellectual disability, and the findings that people with intellectual disability were less self-determined than their peers, led to the development of interventions to promote self-determination, increase choice-making opportunities, and promote active involvement in educational and life planning activities. These interventions will be discussed in greater detail in a subsequent section, but several recent intervention studies contribute both to the determination of an evidence base for practice to promote self-determination and to knowledge about the importance of doing so, and warrant consideration at this point in the chapter.

Wehmeyer, Palmer, Shogren, Williams-Diehm, and Soukup (2012) conducted a randomized trial, control group study of the effect of multiple interventions to promote self-determination on the self-determination of high school students with intellectual disability or learning disabilities. Students in the treatment group received instruction using a variety of instructional methods to promote self-determination and student involvement in educational planning meetings over 3 years, while students in the control group received a placebo intervention. The self-determination of each student was measured using two instruments, including *The Arc's Self-Determination Scale* (Wehmeyer & Kelchner, 1995), discussed subsequently, across three measurement intervals (Baseline, After 2 Years of Intervention, After 3 Years of Intervention). Using latent growth curve analysis, Wehmeyer and colleagues found that students with disabilities who participated in interventions to promote self-determination over a 3-year period showed significantly more positive patterns of growth in their self-determination scores than did students not exposed to interventions to promote self-determination.

In a follow-up study of the treatment and control group students from Wehmeyer, Palmer et al. (2012), Shogren et al. (2015) investigated employment, community access, financial independence, and independent living outcomes 1 and 2 years after leaving school. Results indicated that self-determination status at the end of high school predicted significantly more positive employment, career goal, and community access outcomes. Students who were self-determined were significantly higher in all of these areas. These two studies study provided causal evidence that promoting self-determination results in enhanced self-determination, and that enhanced self-determination results in more positive adult outcomes, including employment and community inclusion.

Wehmeyer, Shogren, et al. (2012) conducted a switching replication, randomized trial control group study on the impact of a multicomponent intervention, the *Self-Determined Learning Model of Instruction* (SDLMI, see subsequent section for implementation description) on student self-determination. Data on self-determination using multiple measures was collected with high school students with intellectual disability or learning disabilities in both a control and treatment group. Wehmeyer and colleagues examined the relationship between the SDLMI and self-determination using structural equation modeling. After determining strong measurement invariance for each latent construct, these researchers found significant differences in latent means across measurement occasions and differential effects attributable to the SDLMI. This was true across disability category, though there was variance across disability populations. In other words, instruction using the SDLMI resulted in enhanced self-determination. Next, Shogren, Palmer, Wehmeyer, Williams-Diehm, and Little (2012) reported findings from a cluster or group randomized trial control group study examining the impact of the SDLMI on student academic and transition goal attainment and access to the general education curriculum for students with intellectual disability and learning disabilities. Students in the treatment group had significantly higher levels of goal attainment and access than their peers in the control group.

A recent randomized-trial study by Powers et al. (2012) also provided causal evidence of the effect of promoting self-determination on community inclusion. Powers and colleagues implemented the TAKE CHARGE intervention with youth in foster care who were receiving special education services, including students with intellectual disability. The TAKE CHARGE process involves in-situ coaching of youth to promote self-directed goal setting, mentoring, and parental support. Powers et al. conducted a randomized trial study of TAKE CHARGE. The intervention yielded moderate to large effect sizes at post-intervention and at 1 year follow-up in student self-determination, a measure of quality of life, and youth utilization of transition services. Further, youth in the intervention group completed high school, obtained employment, and were living in the community at higher rates than were students in the control group.

Evidence-Based Practices to Promote Self-Determination

It is worth noting that the research supports the efficacy of efforts to promote self-determination for positive outcomes. Algozzine, Browder, Karvonen, Test, and Wood (2001) conducted a meta-analysis of single subject design research and a second meta-analysis of group design studies from any study that had attempted to teach skills related to component elements of self-determination (e.g., choice making, decision making, problem solving, goal setting and attainment, self-advocacy). Algozzine and colleagues found that when students with disabilities were provided instruction to promote such component elements, students were successful in acquiring such skills. The median effect size across 100 group intervention comparisons from group design studies was 1.38 (Cohen's *d*), while interventions evaluated using single subject designs had a median percentage of nonoverlapping data (PND, a rubric analyzing how many data points in a graph were higher than baseline measures) was 95 %. Both of these suggest robust effects, with a Cohen's *d* interpreted as a moderate to large effect, and a PND of 95 % indicating a large effect.

A second meta-analytic study examining the evidence in the self-determination literature was conducted by Cobb, Lehmann, Newman-Gonchar, and Alwell (2009). Cobb and colleagues conducted a narrative metasynthesis of the literature pertaining to efforts to promote the self-determination of students with disabilities. A metasynthesis consists of a narrative summation of both narrative reviews and more standard meta-analytic studies. Cobb et al. synthesized findings from seven existing meta-analyses, finding positive impacts from such interventions and that, perhaps not surprisingly, there were greater positive effects from multicomponent interventions.

Self-Determination Assessments

There are two assessments that have been developed specifically for use with people with intellectual disability, each described in this section.

The Arc's Self-Determination Scale

The Arc's Self-Determination Scale (SDS, Wehmeyer & Kelchner, 1995) is a 72-item self-report measure based on the research by Wehmeyer and colleagues. A total of 148 points are available on the scale, with higher scores indicating higher levels of self-determination. An overall self-determination score, as well as subscale scores for each of four essential characteristics of self-determined behavior—autonomy, self-regulation, psychological empowerment, and self-realization—can be calculated. The SDS was developed and normed with 500 adolescents with cognitive disabilities (students with intellectual disability and students with learning disabilities; Wehmeyer, 1996). Subsequent research (Shogren et al., 2008) has verified the proposed theoretical structure of The Arc's Self-Determination Scale, (i.e., four related, but distinct subscales [autonomy, self-regulation, psychological empowerment, and self-realization] that contribute to a higher-order self-determination construct). The SDS was demonstrated to have adequate reliability and validity in the measurement of self-determination for adolescents with cognitive disabilities (see Wehmeyer, 1996 for details about reliability and validity). An adult self-report version of The Arc's Self-Determination Scale was determined to be reliable and valid (Wehmeyer & Bolding, 1999) and has been used, among other things, to evaluate the effect of interventions to promote self-determination and self-regulated problem solving on employment-related outcomes (Wehmeyer, Lattimore, et al., 2003).

The Minnesota Self-Determination Scales

The second assessment is, in reality, a suite of assessments. The *Minnesota Self-Determination Scales* involve four self-report scales are intended for use with adults with intellectual disability, and particularly by residential staff supporting people with intellectual disability. All are administered by personal interview using a pictorial response sheet, a picture item booklet, and an interview record booklet with directions for the interviewer and written scale questions (Wehmeyer, Abery, Mithaug, & Stancliffe, 2003). For each scale item, the picture booklet contains a black and white drawing showing the main idea(s). Prior to presenting the scale items proper, all self-report editions include combined pictorial and text materials explaining the purpose and content of the scale, the response format, and one or two practice items. Response alternatives are illustrated on a pictorial response sheet, and the individual with a disability may respond verbally or by pointing to one of the alternatives depicted.

There are five scales, all but one of which have self-report and residential staff report versions. All these scales contain written instructions and are completed as pencil and paper assessments (Wehmeyer, Abery, et al., 2003). The first is the *Exercise of Control Scale* (Abery, Elkin, Smith, Springborg, & Stancliffe, 2000a, 2000b), which assesses the degree of control exercised by the focus person over a variety of aspects of life and who most often supports/makes this decision. The second set of measures is the *Decision-Making Preference Scale* (Abery, Elkin, Smith, Springborg, & Stancliffe, 2000c, 2000d), evaluates who the focus person would *like* to decide about various issues, regardless of the current reality about who actually decides. The third set of measures is the *Importance Scale* (Abery, Elkin, Smith, Springborg, & Stancliffe, 2000e, 2000f), which evaluates how important various aspects of life are to the focus person. This yields an index of *importance*. The item content is essentially identical to the *Decision-Making Preference Scale* except that the general question and the response alternatives differ.

These three scales—Exercise of Control, Decision-Making Preference, and Importance—are combined to generate a *self-determination index score*. The fourth measure is the *Skills, Attitudes, and Knowledge Scale* (Abery, Elkin, Smith, Springborg, & Stancliffe, 2000g, 2000h), which measures, as its name suggests, skills, attitudes and knowledge pertaining to self-determination. The final measure in the *Minnesota Self-Determination Scales* suite is the *Self-Determination Environment Scale* (Abery, Elkin, Smith, Springborg, & Stancliffe, 2000i), which evaluates the degree to which the adult's self-determination is supported in the settings in which he/she spends time. This is the one measure for which there is no self-report version.

Interventions to Promote Self-Determination

We limit the discussion of interventions to promote self-determination to those for which there is an evidence base. Virtually all of these are school-based interventions, though there is some work with adults with intellectual disability that will be briefly highlighted. We would also note that, although we will not go into any detail, the Algozzine et al. (2001) meta-analysis discussed previously examined instructional efforts to promote component elements of self-determined behavior (e.g., goal setting and attainment, decision making, choice making, problem solving, self-advocacy) on outcomes in those areas. There are not many single-component-element interventions (e.g., focused on decision making only or focusing on goal setting and attainment only) that have been widely evaluated with people with intellectual disability. Among the most promising of these narrower intervention efforts is the *ESCAPE-DD* curriculum (Hickson & Khemka, 2013), which teaches youth and young adults with intellectual disability a decision-making process that enables them to make better decisions in circumstances that involve peer pressure or that constitute risk for personal abuse. In truth, ESCAPE-DD, like other interventions to be discussed, is a multicomponent intervention, incorporating instruction on problem solving as part of the decision-making process. There is, however, a need to develop and evaluate interventions focused on specific component elements of self-determined behavior.

Self-Regulation and Student-Directed Learning Strategies

One class of interventions that has been shown to be effective with people with intellectual disability across multiple instructional domains involve self-regulation or student-directed learning strategies. Self-regulation is the process of setting goals, developing action plans to achieve those goals, implementing and following the action plans, evaluating the outcomes of the action plan, and changing action plans if the goal was not achieved (Mithaug, Mithaug, Agran, Martin, & Wehmeyer, 2003). The skills associated with self-regulation enable students to examine their environments, evaluate their repertoire of possible responses, and implement and evaluate a response (Whitman, 1990).

Student-directed learning strategies involve teaching students strategies that enable them to modify and regulate their own behavior (Agran, King-Sears, Wehmeyer, & Copeland, 2003). The emphasis in such strategies is shifted from teacher-mediated and directed instruction to student-directed instruction. Research in education and rehabilitation has shown that student-directed learning strategies are as successful, and often more successful, as teacher-directed learning strategies, and these strategies are effective means to increase independence and productivity. A variety of strategies have been used to teach students with disabilities how to manage their own behavior or direct learning. Among the most commonly used strategies are picture cues and antecedent cue regulation strategies, self-instruction, self-monitoring, self-evaluation, and self-reinforcement. These are briefly introduced next (see Mithaug et al., 2003, for a comprehensive treatment of student-directed learning strategies).

Picture cues and antecedent cue regulation strategies involve the use of visual or audio cues that students use to guide their behavior. Visual cues typically involve photographs, illustrations, or line drawings of steps in a task that support students to complete an activity that consists of a sequence of tasks. Audio cues include prerecorded, taped directions or instructions that the students can listen to as they perform a task. Emerging technologies, such as handheld computers, provide new and potentially powerful vehicles to deliver visual or auditory cues to learners. Picture cues and antecedent cue regulation strategies have been used to teach individuals with intellectual disability complex work task sequences and to promote on-task behavior and independent work performance (Agran et al., 2003; Mithaug et al., 2003).

Self-instruction involves teaching students to provide their own verbal cues prior to the execution of target behaviors. Students and adults with intellectual disability have been taught to use self-instruction to solve a variety of work problems, to complete a multistep sequences and to generalize responding across changing work environments (Wehmeyer et al., 2007).

Self-monitoring involves teaching students to observe whether they have performed a targeted behavior and whether the response met whatever existing criteria were present. Teaching students self-monitoring strategies has been shown to improve critical learning skills and classroom involvement skills of students with intellectual disability (Agran et al., 2005; Hughes et al., 2002) as well as to promote access to the general education curriculum for students with intellectual disability (Agran, Wehmeyer, Cavin, & Palmer, 2008, 2010; Wehmeyer, Hughes, Agran, Garner, & Yeager, 2003). Woods and Martin (2004) found that teaching supported employees to self-manage and self-regulate work tasks improved employers' perceptions of the employee and improved work performance.

Self-evaluation and *self-reinforcement* involve teaching the student to compare his or her performance (as tracked through self-monitoring) with a desired goal or outcome and to administer consequences to themselves (e.g., verbally telling themselves they did a good job). Self-reinforcement allows students to provide themselves with reinforcers that are accessible and immediate. Given access to self-administered reinforcement, behavior change may be greatly facilitated and both procedures have been shown to improve generalization of learning (Agran et al., 2003).

Student Involvement in Educational and Transition Planning

Closely related to efforts to promote student self-regulation and student-directed learning—as well as efforts to promote self-advocacy, goal setting, and related component elements of self-determined behavior—are efforts to promote active student involvement in educational and transition planning activities. There are a number of such instructional programs and packages. Test et al. (2004) conducted an extensive review of the literature pertaining to student involvement and determined that students across disability categories can be successfully involved in transition planning, and a number of programs, including those mentioned subsequently, are effective in increasing student involvement. Three such planning efforts have evidence of their efficacy with students with intellectual disability.

Whose Future Is It Anyway?

Whose Future is it Anyway? (WFA, Wehmeyer et al., 2004) is a student-directed process to support students with intellectual disability to learn skills that enable them to meaningfully participate in transition planning meetings during their high school years (though can be used at the middle school level). The WFA process consists of 36 sessions introducing students to the concept of transition and transition planning and enabling students to self-direct instruction related to (1) self- and disability-awareness; (2) making decisions about transition-related outcomes; (3) identifying and securing community resources to support transition services; (4) writing and evaluating transition goals and objectives; (5) communicating effectively in small groups; and (6) developing skills to become an effective team member, leader, or self-advocate.

The materials are student-directed in that they are written for students as end-users. The level of support needed by students to complete activities varies a great deal. Some students with difficulty reading or writing need one-to-one support to progress through the materials; others can complete the process independently. The materials make every effort to ensure that students retain this control while at the same time receiving the support they need to succeed.

Section 1 (Getting to Know You) introduces the concept of transition and educational planning; provides information about transition requirements in IDEA; and enables students to identify who has attended past planning meetings, who is required to be present at meetings, and who they want involved in their planning process. Later, they are introduced to four primary transition outcome areas (employment, community living, postsecondary education, and recreation and leisure). Activities throughout the process focus on these transition outcome areas. The remainder of the sessions in this first section discuss the topic of disability and disability awareness. Students identify their unique characteristics, including their abilities and interests. Participants then identify unique learning needs related to their disability. Finally, students identify their unique learning needs resulting from their disability.

In the second section (Making Decisions), students learn a simple problem-solving process by working through each step in the process to make a decision about a potential living arrangement and then apply the process to make decisions about the three other transition outcome areas. The third section (How to Get What You Need, Sec. 101) enables students to locate community resources identified in previous planning meetings that are intended to provide supports in each of the transition outcome areas. Section 4 (Goals, Objectives, and the Future) enables learners to apply a set of rules to identify transition-related goals and objectives that are currently on their IEP or transition planning form, evaluate these goals based on their own transition interests and abilities, and develop additional goals to take to their next planning meeting. Students learn what goals and objectives are, how they should be written, and ways to track progress on goals and objectives.

The fifth section (Communicating) introduces effective communication strategies for small-group situations, such as the transition planning meetings. Students work through sessions that introduce different types of communication (e.g., verbal, body language) and how to interpret these communicative behaviors, the differences between aggressive and assertive communication, how to effectively negotiate and compromise, when to use persuasion, and other skills that will enable them to be more effective communicators during transition planning meetings. The final section (Thank You, Honorable Chairperson) enables students to learn types and purposes of meetings, steps to holding effective meetings, and roles of the meeting chairperson and team members. Students are encouraged to work with school personnel to take a meaningful role in planning for and participating in the meeting.

Students are encouraged to work on one session per week during the weeks between their previous transition planning meeting and the next scheduled meeting. The final two sessions review the previous sessions and provide a refresher for students as they head into their planning meeting. Wehmeyer and Lawrence (1995) conducted a field tested of the process, providing evidence of the impact of the process on student self-determination, self-efficacy for educational planning, and student involvement. Wehmeyer, Palmer, Lee, Williams-Diehm, and Shogren (2011) conducted a randomized-trial, placebo control group design to study the impact of intervention with the WFA process on self-determination and transition knowledge and skills, finding that instruction using the WFA process resulted in significant, positive differences in self-determination when compared with a placebo-control group, and that students who received instruction gained transition knowledge and skills. Similarly, Lee et al. (2011) conducted a randomized-trial study of the impact of the WFA process both with and without the use of technology, and determined significant gains in self-determination and transition knowledge and skills as a function of instruction with WFA.

The Self-Directed IEP

The *ChoiceMaker Self-Determination Transition Curriculum* (Martin & Marshall, 1995) consists of three sections: (1) Choosing Goals, (2) Expressing Goals, and (3) Taking Action. Each section contains from two to four teaching goals and numerous teaching objectives addressing six transition areas. Included are: (1) an assessment tool; (2) Choosing Goals lessons; (3) the Self-Directed IEP, and (4) Taking Action lessons. This third component, the Self-Directed IEP (SDIEP) teach students the leadership skills they need to self-direct their IEP meeting. Students learn 11 steps for leading their own planning meeting, including stating the purpose of the meeting, introducing meeting attendees, reviewing their past goals and progress, stating new transition goals, summarizing goals, and closing the meeting by thanking attendees. Martin et al. (2006) conducted a randomized trial control group study of the SDIEP and determined that students who received instruction using the SDIEP, including students with learning disabilities and students with emotional and behavioral disorder, (a) attended more IEP meetings; (b) increased their active participation in the meetings; (c) showed more leadership behaviors in the meetings; (d) expressed their interests, skills, and support needs across educational domains; (e) and remembered their IEP goals after the meeting at greater rates than did students in the control group, who received no such instruction. Seong, Wehmeyer, Palmer, and Little (2015) conducted a randomized-trial placebo control group study of the SDIEP, finding that instruction using the process resulted in enhanced self-determination and transition knowledge.

TAKE CHARGE for the Future

TAKE CHARGE for the Future (Powers et al., 1996) is a student-directed, collaborative model to promote student involvement in educational and transition planning. The model is an adaptation of a validated approach, referred to as *TAKE CHARGE*, to promote the self-determination of youth with and without disabilities (Powers, Turner, Matuszewski, Wilson, & Phillips, 2001). *TAKE CHARGE* uses four primary components or strategies to promote adolescent development of self-determination: (1) skill facilitation, (2) mentoring, (3) peer support, and (4) parent support. The process introduces youth to three major skills areas needed to take charge in one's life: (1) achievement skills, (2) partnership skills, and (3) coping skills. Youth involved in the *TAKE CHARGE* process are matched with successful adults of the same gender who experience similar challenges, share common interests, and are involved in peer support activities throughout (Powers et al., 1998). Parent support is provided via information and technical assistance and written materials.

TAKE CHARGE for the Future uses the same set of core strategies to enable learners with disabilities to participate in their planning meeting. Students are provided self-help materials and coaching to identify their transition goals; to organize and conduct transition planning meetings; and to achieve their goals through the application of problem solving, self-regulation, and partnership management strategies. Concurrently, youth participate in self-selected mentorship and peer support activities to increase their transition focused knowledge and skills. Their parents are also provided with information and support to promote their capacities to encourage their sons' or daughters' active involvement in transition planning. Powers et al. (2001) conducted a control-group study and found that the *TAKE CHARGE* materials had a positive impact on student involvement. As discussed previously, Powers and colleagues (2012) conducted a randomized-trial study of TAKE CHARGE for the Future with youth in foster care who were receiving special education services, including students with intellectual disability. Instruction with the intervention yielded moderate to large effect sizes at post-intervention and at 1-year follow-up in student self-determination, a measure of quality of life, and youth utilization of transition services. Also, youth in the intervention group completed high school, obtained employment, and were living in the community at higher rates than were students in the control group.

Self-Determined Learning Model of Instruction

All of the above interventions are intended to promote self-determination by activing engaging students in educational or transition planning An evidence-based multicomponent intervention that incorporates the elements of student-directed learning, self-regulated problem solving, and goal setting and attainment is the *Self-Determined Learning Model of Instruction* (SDLMI; Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000). The SDLMI has been validated with students across multiple disability categories as effective for promoting educational goal attainment, enhancing self-determination, and promoting access to the general education curriculum.

Implementation of this model consists of a three-phase instructional process. Each instructional phase presents a problem to be solved by the student. The student solves each problem by answering a series of four *Student Questions* per phase that students learn, modify to make their own, and apply to reach self-set goals. Each question is linked to a set of *Teacher Objectives*, and each instructional phase includes a list of *Educational Supports* teachers can use to teach or support students to self-direct learning. Model components are depicted in Table 21.1.

The Student Questions are constructed to direct the student through a problem-solving sequence in each instructional phase. The four questions differ in each phase, but represent identical steps in the problem-solving sequence: (1) identify the problem, (2) identify potential solutions to the problem, (3) identify barriers to solving the problem, and (4) identify consequences of each solution. These steps are the fundamental steps in any problem-solving process and they form the means-end problem-solving sequence represented by the Student Questions in each phase and enable the student to solve the problem posed in each instructional phase (*What is my goal*? *What is my plan*? *What have I learned*?). The Student Questions are written in first-person voice in a simple format with the intention that they are the starting point for discussion between the teacher and the student. In essence, teachers use each Student Question as a teaching prompt to teach and support students to answer the question in ways that are indicated in the Teacher Objectives. Although some students will be able to become self-directed in posing and answering the questions, others will likely need ongoing support from teachers to answer each question. That is fine, in that the intent of the SDLMI is not that students become independent learners (though that would be a good outcome), but that students remain at the center of the process and are actively engaging, to the greatest extent they are able to do so, in self-regulated problem solving to set and attain goals. So it does not matter if the student does or does not read or can or cannot answer questions independently, but instead that teachers are doing all they can to keep the student involved in and at the center of the process. The Educational Supports simply provide recommendations for teachers as to what instructional strategies they might use to enable students to answer questions.

Several studies have established causal evidence for the efficacy of the SDLMI, beginning with the quasi-experimental study conducted by Wehmeyer, Palmer, et al. (2000). Table 21.2 provides a summary of quasi-experimental and single-subject design studies of the SDLMI. Several recent studies have provided causal evidence of the effects of instruction using the SDLMI. As previously described, Wehmeyer, Shogren, et al. (2012), conducted a switching replication, randomized trial control group study to establish the efficacy of the SDLMI to promote self-determination. Shogren et al. (2012) implemented a cluster randomized trial control group study to establish the efficacy of the SDLMI on student academic and transition goal attainment and access to the general education curriculum for students with intellectual disability and learning disabilities. These findings extended findings from Lee, Wehmeyer, Soukup, and Palmer (2010), who in a smaller RCT also found that implementation of the SDLMI promoted student access to the general education curriculum.

Two variants of the SDLMI have been developed and evaluated. The first, the *Beyond High School* (BHS; Wehmeyer, Garner, Lawrence, Yeager, & Davis, 2006) model, incorporates the SDLMI and the *Whose Future is it Anyway*? processes into a multistage model to promote self-determination and goal attainment forstudents with intellectual disability in post-secondary education settings. The first stage of the BHS model is designed to enable students to establish short- and long-term goals based on their own preferences, abilities, and interests. First, students are involved in targeted instruction teaching them to self-direct planning and decision making specific to the transition process. This could be accomplished through multiple informal or formal strategies and methods that prepare students to participate in or direct their educational planning process, such as

Table 21.1 Self-determined learning model of instruction phases, problems to solve, student questions, teacher objectives, and educational supports (Wehmeyer & Palmer, 1999)

Phase	Problem to solve	Student question	Teacher objectives	Educational supports
Phase 1	What is my goal?	What do I want to learn?	• Enable Students to identify specific strengths and instructional needs.	• Student self-assessment of interests, abilities and instructional needs. • Awareness training
			• Enable students to communicate preferences, interests, beliefs, and values.	• Choice-making instruction. • Problem-solving instruction. • Decision-making instruction
			• Teach students to prioritize needs.	• Goal setting and attainment instruction.
		What do I know about it now?	• Enable students to identify their current status in relation to the instructional need.	
			• Assist students to gather information about opportunities and barriers in their environments.	
		What must change for me to learn what I don't know?	• Enable students to decide if action will be focused toward capacity building, modifying the environment, or both.	
			• Support students to choose a need to address from the prioritized list.	
		What can I do to make this happen?	• Teach students to state a goal and identify criteria for achieving goal.	
Phase 2	What is my plan?	What can I do to learn what I don't know?	• Enable student to self-evaluate current status and self-identified goal status.	• Self-scheduling • Self-instruction • Antecedent cue regulation • Choice-making instruction
		What could keep me from taking action?	• Enable student to determine plan of action to bridge gap between self-evaluated current status and self-identified goal status.	• Goal-attainment instruction • Problem-solving instruction • Decision-making instruction • Self-advocacy and assertiveness training
		What can I do to remove these barriers?	• Collaborate with student to identify most appropriate instructional strategies.	• Communication skills training • Self-monitoring

(continued)

Table 21.1 (continued)

Phase	Problem to solve	Student question	Teacher objectives	Educational supports
			• Teach students needed student-directed learning strategies.	
			• Support student to implement student-directed learning strategies.	
			• Provide mutually agreed upon teacher-directed instruction.	
		When will I take action?	• Enable student to determine schedule for action plan.	
			• Enable student to implement action plan.	
			• Enable student to self-monitor progress.	
Phase 3	What have I learned?	What actions have I taken?	• Enable student to self-evaluate progress toward goal achievement	• Self-evaluation strategies
				• Choice-making instruction
		What barriers have been removed?	• Collaborate with student to compare progress with desired outcomes.	• Goal-setting instruction
				• Problem-solving instruction
				• Decision-making instruction
		What has changed about what I don't know?	• Support student to reevaluate goal if progress is insufficient.	• Self-reinforcement strategies
				• Self-recording strategies
			• Assist student to decide if goal remains the same or changes.	• Self-monitoring
			• Collaborate with student to identify if action plan is adequate or inadequate given revised or retained goal.	
			• Assist student to change action plan if necessary.	
		Do I know what I want to know?	• Enable student to decide if progress is adequate, inadequate, or if goal has been achieved.	

those discussed previously. Next, students were taught to self-direct the transition goal-setting, action planning, and program implementation process using the *SDLMI*, again discussed previously. Once students learn this self-regulated learning process, they apply the first part of the *SDLMI* (*What is my goal?*) to identify goals in key transition areas, including employment, independent living, recreation and leisure, and postsecondary education.

Table 21.2 Quasi-experimental or single subject design studies of *SDLMI* (from Wehmeyer & Palmer, 2007)

Study	Design	Subjects	Dependent variables	Outcomes
Wehmeyer, Palmer, et al. (2000)	Pre–post no control group	40 HS students: 13 w/ MR, 17 w/ LD, 10 w/ EBD	SD, GAS, goal skills, locus of control	Progress on 80 % of educational goals, enhanced SD and perceptions of control.
Agran, Blanchard, and Wehmeyer (2000)	Delayed multiple baseline across groups	19 MS/HS students w/ severe MR	GAS, % correct on transition goals linked to functional needs	Students attained transition related goals using model.
McGlashing-Johnson, Agran, Sitlington, Cavin, and Wehmeyer (2003)	Multiple baseline across subjects	4 HS students with severe MR	% correct on job tasks, GAS	
Palmer and Wehmeyer (2003)	Pre–post no control group	50K-3rd grade students: 21 w/ LD, 6 w/ MR, 5 w/ Speech Impairments, 2 w/ OHI, 16 w/ Dev Delay	Goal attainment and skills	Students achieved goals at greater than expected level and acquired goals knowledge and skills.
Palmer, Wehmeyer, Gipson, and Agran (2004)	Interrupted time series w/ switching replication	22 MS students with MR	SD, Problem solving skills, GAS	Students able to achieve goals linked to general education curriculum using model
Agran et al. (2010)	Multiple-baseline across subjects	3 MS students with moderate MR	Academic goals linked to district standards	Students mastered skills linked to standards in science, geography.

The second stage of the BHS model involves convening a student-directed, person-centered planning meeting that brings together other stakeholders in the instructional process to work with students to refine goals, as needed, to support the student as he or she implements the second phase of the *SDLMI* (*What is my plan*?) and to enable the student to provide informed consent with regard to implementation of the instructional program. During the final stage of the BHS model, the student, with supports identified from the second stage, implements the plan, monitors his or her progress in achieving the goal, and evaluates the success of the plan, making revisions to the goal or the plan as warranted. This is accomplished using the strategies and questions comprising the third phase of the *SDLMI*. Palmer, Wehmeyer, Shogren, Williams-Diehm, and Soukup (2012) conducted a randomized control trial study of the BHS process with 109 students with intellectual disability enrolled in post-secondary education, finding that students involved with the BHS process had more positive self-determination related outcomes than their peers in the control group.

A second offshoot of the SDLMI is the *Self-Determined Career Development Model* (SDCDM; Wehmeyer, Lattimore, et al., 2003). Wehmeyer and colleagues modified the SDLMI to focus on career and employment goals for youth and adults with disabilities, using the same self-directed problem solving process to promote vocational and employment outcomes. The conceptual framework and process for The SDCDM is identical to that of the SDLMI but has a career and employment emphases. In each phase, facilitators assist participants to address a problem that is solved by answering four questions. Through all phases, participants engage in activities that enable them to set a job or career goal, develop a plan to meet that goal, and adjust their plan (if needed) to meet that goal. In addition to the questions, each phase also contains a list of objectives that serve as guidelines for facilitators. That is, the list of objectives provides facilitators with a means to accurately gauge what is being taught and what the person should be learning. Each phase also has a list of employment supports that facilitators may use if they find they need additional instructional methods for the participant. Wehmeyer, Gotto, and McVeigh (2012) are engaged in a randomized-trial study of the effect of the SDCDM on self-determination and employment related outcomes for adults with intellectual disability.

Conclusion

Promoting the self-determination of youth and adults with intellectual disability has become best practice in education and rehabilitation for a variety of reasons, as described in this chapter. The research shows that people with intellectual disability are less self-determined than their peers with other disabilities and without disabilities, and suggests that this discrepancy is a function of the lack of opportunities many people with intellectual disability have to learn and practice skills related to self-determination. The research is clear that given adequate instruction and supports, people with intellectual disability can become more self-determined, and that being self-determined is linked, causally, to more positive school and adult life outcomes, as well as higher quality of life and lifestyle satisfaction. There are several assessment and instructional processes that have been shown to be valid with youth and adults with intellectual disability. Though much progress has been made in efforts to promote self-determination since Michael Ward wrote about this need in 1989, there remains much work yet to be done.

Authors' Note The Arc's Self-Determination Scale is available for free online at http://www.ou.edu/content/education/centers-and-partnerships/zarrow/self-determination-assessment-tools.html. The authors' are in the initial stages of validating a new measure of self-determination, called the Self-Determination Inventory-Self-Report version (Shogren et al., 2014), that includes items from The Arc's Self-Determination Scale, but expands assessment to include domains identified by Causal Agency Theory. When field testing is completed, potentially by mid to late 2015, the measure will be available at http://www.self-determination.org. The Minnesota Self-Determination Scales can be obtained by contacting Brian Abery at the University of Minnesota, Rehabilitation Training Center on Community Living (http://rtc.umn.edu/rtc/). The *Whose Future is it Anyway*? materials can be downloaded in PDF format online for free at http://www.ou.edu/content/education/centers-and-partnerships/zarrow/self-determination-education-materials/whos-future-is-it-anyway.html. The SDCDM process and information about the model can be found online at http://www.ngsd.org/

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Telehealth

22

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Introduction

According to the Institute of Medicine (2012), telehealth is, in part, the provision of healthcare via the use of electronic and telecommunication technologies. For applied behavior analysts (herein referred to as behavior consultants), telehealth provides for substantially increased opportunities to deliver effective and empirically validated procedures to clients, the client's family, and other care providers. As one example, Wacker (2013) presented a case example, Jace (described later in this chapter), of how telehealth can be conducted in the homes of young children with autism spectrum disorders. During this talk at the annual conference of the Association for Behavior Analysis International, videos showing the child and his mother working together on a behavior treatment plan were presented. The videos first showed the child completing a task demand that involved putting blocks in a bucket. His mother sat near him on the couch and gave directions and prompts as needed. After he completed the task, he requested a play break with his mother by pressing a microswitch that when pressed activated a prerecorded message. The child and mother repeated this play-work routine several times, while the mother appeared to be talking to herself. However, the camera then zoomed in on the fireplace, which was across the room from the couch. A laptop was sitting open on the mantle, and on the screen of the laptop was the live image of a behavioral consultant who was coaching the mother through the procedures and providing feedback and praise. Thus, via telehealth, this mother had her own private consultation from a highly skilled behavior consultant

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regarding the behavior management program she was conducting with her child. This occurred in her home without either her or the behavior consultant having to travel, which in turn, substantially reduced the amount of generalization that was needed for her to implement the program since she was already conducting the program in her home.

This example shows how we have incorporated telehealth into our outpatient clinical and research programs at the Center for Disabilities and Development (CDD), The University of Iowa Children's Hospital. In this chapter, we provide a brief history of the evolution of our services. We first describe our outpatient clinic, the biobehavioral service (BBS), including a description of in vivo in-home coaching delivered to families. We next describe how we utilized telehealth to provide applied behavior analytic services in both clinic and home settings, and how other disciplines and other highly trained behavior consultants have used telehealth to deliver services. We conclude the chapter with step-by-step recommendations for using telehealth as part of a clinical practice.

History of Outpatient and Community-Based Behavioral Assessment and Treatment Programs

Our telehealth program is a part of the services we provide through the BBS outpatient clinic (Northup et al., 1991). This clinic was developed in the mid 1980s to provide functional analyses (FAs; Iwata, Dorsey, Slifer, Bauman, & Richman, 1994) and reinforcement-based treatments to individuals with developmental disabilities who engaged in severe problem behavior such as self-injury or aggression. A large focus of the clinic has always been consulting with families and other care providers. However, the distance that many of the families had to travel made it difficult to provide the intensity of individualized coaching that some parents needed to effectively manage problem behavior in their homes. In addition, parents frequently had to wait for 3 or more months to be seen in the clinic as the demand for behavioral services in Iowa continued to exceed the availability of those services (Wacker et al., 2013b). This was especially distressing with very young children whose self-injury or other severe problem behavior was just emerging. To complicate matters further, practitioners with skills in applied behavior analysis have historically been located mostly in a few of the university or urban areas of the state, leaving many families without the behavior analysis services they needed for their child. In response to these challenges, we sought to extend the clinic model through the delivery of in vivo in-home and telehealth-based services to assessment and treatment of severe problem behavior.

Home-Based Services

Beginning in the early 1990s, we received funding from the National Institute of Child Health and Human Development (Wacker & Berg, 1992) to work with parents in their homes to conduct FAs of their young (up to 6 years of age) children's problem behavior and to then implement functional communication training (FCT; Carr & Durand, 1985) to reduce problem behavior in their homes. During this project, behavior consultants drove to the families' homes and coached the parents during weekly 1-h sessions to conduct the assessment and treatment procedures. All of the children had developmental disabilities and most had problem behavior maintained by negative reinforcement. Harding, Wacker, Berg, Lee, and Dolezal (2009) provided a summary and case example of the specific FCT procedures used by the parents. In general, treatment consisted of two steps: (a) the child was given a direction by the parent to complete a small task such as to stack blocks or to point to a picture in a book, and (b) after the task was completed, a communication card and/or device such as a microswitch was presented to the child, who could then request an enriched break to play. Thus, task completion produced the card/device from the parent, and touching the card/device produced an enriched break to play with the parent.

The initial results of this project (Wacker et al., 1998) showed that parents could conduct these assessment and treatment procedures with good success when they received on-site and real-time coaching from a skilled behavior consultant.

The majority of the children participating in the project showed at least an 80 % decrease in their problem behavior within a few months and the rated acceptability (Reimers, Wacker, Cooper, & DeRaad, 1992) of the procedures by the parents was very high. Even greater reductions in problem behavior occurred in subsequent projects (Wacker, Berg, & Harding, 1996, 2000), and positive findings of the generalization (Berg, Wacker, Harding, Ganzer, & Barretto, 2007) and maintenance (Wacker et al., 2011) achieved with this in vivo in-home coaching model further convinced us that an in-home approach to assessment and treatment, with every session conducted by parents, could be highly successful with real-time coaching occurring as the parents conducted the sessions. However, there were two major problems with this approach if conducted as a service delivery program. First, it was limited to families living within a 100-mile radius of the clinic (Wacker et al., 2013a). Thus, unless a large increase in behavior consultants became available very quickly in local geographic areas, many families who lived outside of this radius would remain unable to access these types of services for managing their child's behavior at home. Second, in-home services were expensive to provide, primarily due to the travel time of the behavior consultant, and insurance reimbursement was often too low to allow clinicians to provide necessary ongoing services. Therefore, a more efficient approach to providing these services was required. The emergence of telehealth technology offered the opportunity to address some of the delivery barriers associated with both the clinic and in vivo in-home approaches.

Telehealth-Based Services

As summarized by Lee et al. (2015), the University of Iowa Hospitals and Clinics have been providing limited telehealth services since the mid 1990s. Behavior consultants began providing telehealth consultation to local pediatricians and school teams in 1996, when the University of Iowa's National Laboratory for the Study of Rural Telemedicine received a grant from the US National Library of Medicine (Kienzle, 2000). Part of this grant was used to fund projects that evaluated the effectiveness of telehealth, and BBS staff received one of those projects. Most of this project was devoted strictly to consultation, meaning that school or healthcare teams reviewed cases with BBS staff and then implemented the procedures locally without real-time guidance from the behavior consultants.

Barretto, Wacker, Harding, Lee, and Berg (2006) extended the procedures when they showed that FAs could be conducted effectively via telehealth. The telehealth system utilized an existing secure, fiber optic cable system, which connected the CDD to high schools, hospitals, and other government agencies in Iowa. Barretto et al. (2006) conducted FAs with two children, one in a school by a school team and one in a department of human services office by a foster parent and a physical therapist. There was no easy way to communicate between the sites, and so the local professionals and parent conducted a phone call with BBS staff prior to the assessment, and BBS staff held up signs indicating what should occur next and/or breaks were taken so that further discussion could occur by phone. Despite these major limitations, social functions were identified for both children. These results were replicated with other children in other locations with positive results occurring most of the time. Thus, rather than simply consulting on a case, the behavior consultants were able to observe the care provider conducting sessions with the child and to provide feedback as soon as it was needed.

These successful clinical demonstrations led Wacker et al. (2013a, 2013b) to further evaluate the efficacy of conducting both FAs and FCT via telehealth through a grant funded by the National Institute of Mental Health (Lindgren & Wacker, 2009). In this funded project, behavior consultants at the CDD coached parents to conduct FAs and FCT in regional pediatric clinics located near their homes (but over 200 miles, on average, from the CDD). These clinics were connected to the CDD via a secured videoconferencing system. They used this system to conduct the exact same FA and FCT procedures as had been conducted in the in-home project (FA plus 2-step FCT program) with 20 young children diagnosed with autism spectrum disorder. Social functions were identified for 18 of the 20 children. In a subsequent study, 17 children (13 from the original group plus four additional children) received FCT. Problem behavior was reduced by an average of 93.5 %. This reduction in problem behavior was equivalent to that achieved in the in vivo in-home project (or from our CDD clinic studies; Asmus et al., 2004), but was much less costly and much more convenient for the participating families.

Although telehealth delivery was more convenient for clinicians and for families living substantial distances from our clinic in Iowa City, families still needed to drive an average of 15 miles to the regional pediatric clinics, and they still needed to generalize the procedures to their homes. Given the positive outcomes achieved by parents both in their homes with in vivo coaching and in regional pediatric clinics with remote real-time coaching, Lindgren and Wacker (2011) conducted these exact same procedures via telehealth directly in the homes of the children and their families using Skype™. We are currently in the last year of this project, and the behavioral results to date have been equivalent to those obtained in the previous projects. Social functions have been identified for most children's problem behavior, treatment results for most children show at least 90 % reduction in problem behavior, and the parents can implement the procedures with good fidelity (Suess, Romani, et al., 2014), even though all coaching is conducted via telehealth and there is the possibility of equipment problems (Lee et al., 2015) and other concerns (Suess, Kopelman, et al., 2014) that can affect the fidelity of the procedures. Parent ratings of acceptability have remained very high throughout all of the telehealth projects.

In the following sections, we describe both the in-clinic and in-home telehealth procedures we conducted through our clinic and funded projects. Most of our programs are currently funded through grants, but we are gradually beginning to integrate the use of telehealth into our BBS clinic. We do not anticipate that telehealth will replace in vivo (home and clinic) programs, but we do anticipate that telehealth will be increasingly used to augment our other clinical and research programs. In our view, the question is not whether we will be using telehealth in the future, but rather how to identify the conditions under which it can be best used.

Description of Treatment or Training Approach

Clinic-to-Clinic Telehealth Model

Model Description

The clinic-to-clinic project (Lindgren & Wacker, 2009) was the team's first large-scale attempt to replicate the procedures (FA plus FCT) first conducted in vivo in the family's home (Wacker et al., 1998, 2011) through telehealth. Therefore, the procedures used during this project (Wacker et al., 2013a, 2013b) were conducted as similarly as possible to the procedures from the in-home project. Participants were young children ages 2–6 years who were diagnosed with autism spectrum disorder and who engaged in problem behavior. Behavior consultants were located at the CDD (host site) and parents, their child, and a parent assistant were located at one of five participating regional pediatric clinics (remote site) located within 50 miles of the family's home. The regional pediatric clinic site and the CDD site were connected through a secure videoconferencing system. Assessment and treatment procedures were conducted during 1-h weekly consultations by the children's parents with live coaching from the behavior consultants.

In this section we provide a step-by step description of the procedures used in this project and we highlight the modifications we made from the in-home in vivo model to the telehealth clinic-to-clinic model.

Step One: Determining Equipment Needs

The regional pediatric clinics had preexisting high speed internet and videoconferencing capabilities. As part of this project, the CDD had a four-station telehealth center that connected to the regional clinics by a firewall-protected virtual private network. Emblaze-VCON vPoint HD was used as the videoconferencing and video recording software because it allowed for conducting real-time (synchronous) telehealth and recording of all sessions for subsequent data collection. Further specifications of the technology used in the clinic-to-clinic model are described in more detail by Wacker et al. (2013b) and Lee et al. (2015). Prior to beginning the project, the behavior consultants became acquainted with the videoconferencing hardware (i.e., windows-based PC, webcam, and headphones with microphones) and software (i.e., videoconferencing and video recording). They also conducted various test runs and recordings to ensure that the teleconferencing and video recording technology were working properly prior to conducting evaluations in the telehealth center.

Step Two: Initial Meetings

Parent Assistant Training

Parent assistants were hired to provide on-site support to the parents as needed during the telehealth consultations. The parent assistants' children received care at the clinics, but the parent assistants had not received specific training in behavior analysis prior to this project. Parent assistants were hired to work about 8-h per week.

The behavior consultants provided two, 1-h training presentations to the parent assistants. These presentations were done via telehealth and also served to train the parent assistants on the technology. One presentation reviewed the principles of behavior analysis, and the second one reviewed the specific procedures of the project (FA and FCT). The parent assistants received a manual that described the project's procedures and timelines in detail. The parent assistants had duties prior to, during, and after each telehealth visit. Prior to the visit, the parent assistants arranged the clinic room to ensure safety, made sure all materials needed for the session were available, and met remotely with the behavior consultant to review the plan for the visit. During the visit, they assisted the parent by continuing to make sure materials were available and preventing the children from eloping or climbing on the tables, and they assisted the behavior consultant with troubleshooting technology issues. After the visit, the parent assistant met with the behavior consultant to review the results from the visit and plan for the next visit.

Parent Training

Prior to beginning telehealth visits with the child, the behavior consultant met remotely with the parent for 1 h to provide training to the parent on the project's procedures. Parents also received a manual with descriptions of the procedures and were asked to read the procedures prior to implementing them. Parents were not expected to remember how to implement the procedures on their own as they received live coaching throughout the sessions in the same way as provided during the in vivo in-home project (Harding et al., 2009).

Initial Assessments

Three assessments (parent interview, daily behavior record, preference assessment) were conducted prior to beginning the FA and FCT. The purpose of these assessments was to obtain information about the child's target problem behavior (behavior of focus during the FA and FCT, which usually included self-injury, aggression, and/or property destruction), to develop hypotheses regarding the function of the target behavior, and to identify stimuli to utilize during the assessments. These three assessments were conducted during the first parent meeting and the first telehealth visit with the child.

Parent Interview

During the first parent meeting, in addition to reviewing the procedures, the behavior consultant interviewed the parent. During this interview, the parent was asked to describe the behaviors of concern and how these behaviors impacted their day-to-day lives. Based on this information, the team developed response definitions and gauged the severity of the child's target problem behavior. In addition, we asked the parents about the child's overall behavior and communication skills. This interview also provided the behavior consultant with important information on the parents' communication skills and overall comfort with the telehealth equipment.

Daily Behavior Record

The behavior consultant asked the parent to collect a daily behavior record of the target behaviors for 1-week until their next meeting. This assessment served two main purposes. First, it helped to develop hypotheses regarding the function of the child's problem behavior and therefore assisted in designing the FA conditions for that child. Second, it prompted parents to consider the function of their child's problem behavior.

Preference Assessment

The behavior consultant asked the parent about toys/activities the child liked, and the degree to which the child needed adult assistance to engage in those activities. An array of five to six of these activities was then used during a free operant preference assessment (Roane, Vollmer, Ringdahl, & Marcus, 1998) that was conducted during at least three, 5-min sessions. The highly preferred items were used during the free play and tangible conditions of the FA, and the less preferred activities were often used during the escape condition.

Step Three: Evaluation Procedures

Functional Analysis

Sessions during the FA were conducted similarly to those described in the in vivo in-home projects (Wacker et al., 1998, 2011), with a few procedural and logistical changes.

Before the Child Arrived

The behavior consultant initiated a telehealth call to the parent assistant 10–15 min prior to the parent and child arriving in the clinic. The behavior consultant then guided the parent assistant in ensuring the clinic space was safe and ready for conducting the sessions. The behavior consultant and parent assistant ensured that all materials needed for the sessions were available in the room except for ones the parent was bringing from home.

Coaching the Parent and Providing Feedback

The behavior consultant provided live coaching during the session to the parent as described in Harding et al. (2009). This included providing prompts such as when the parent should reinforce target behaviors and providing descriptive feedback regarding the fidelity of those procedures.

Conducting Sessions

One control (free play) and three test (social attention, escape, tangible) conditions were typically included in the FA (Wacker et al., 2013b). One difference in the FA procedures compared to the in vivo in-home project was that three to nine consecutive free play conditions were conducted initially to assist the child and parent to become comfortable with the telehealth technology and the clinical space. We continued to conduct free play sessions until zero or near zero occurrences of problem behavior occurred. For most children, three to four free play sessions were sufficient. After the test conditions were begun, the order of the sessions was counterbalanced. Inclusion in the project required that the child's problem behavior was maintained, at least in part, by social functions.

Functional Communication Training

Prior to beginning FCT, the behavior consultant, parent assistant, and the parent had a meeting to discuss the FCT procedures. FCT involved teaching the child to comply with a request (which increased via demand fading) and then mand for an enriched 1–2 min break. The parent was asked to practice FCT in his/her home daily for 10–15 min and report on the practice sessions to the behavior consultant at the beginning of the next telehealth appointment.

Benefits, Challenges, and Hints for Clinic-to-Clinic Telehealth

Benefits

The two primary benefits of conducting services via telehealth from clinic-to-clinic was that the vast majority of the children displayed at least a 90 % decrease in problem behavior, and parents rated the treatment as highly acceptable. Very few of these children could have been served in either our clinics or our in-home treatment project because of geographical constraints (e.g., distance, cost). Other benefits included:

1. *Cost Effectiveness*. In comparison to the in vivo in-home project, the decreased travel time for behavior consultants resulted in an overall threefold reduction in the cost of delivering effective behavioral assessment and treatment to children who displayed problem behavior.
2. *Efficiency and Increased Access*. The decreased travel time to families' homes increased the efficiency of the behavior consultants. This resulted in their ability to see more children during the same period of time.

Challenges

Very few concerns arose during the implementation of the clinic-to-clinic telehealth project. However, as with any service delivery model, there are various potential problems and limitations to consider, including:

1. *Access*: Although the pediatric clinics were closer to the children's homes, the families still had to travel to the local clinic. The travel may pose obstacles for certain families and may therefore limit their ability to utilize this service. For example, families who did not own vehicles had to identify transportation on a weekly basis to the clinic, and families who had limited funds had difficulty paying up front for the gas money to come to the clinic. Additionally, families who had other children had to secure childcare for siblings or one of the parents had to stay home. These obstacles may result in session cancellations or the families' inability to participate in this service delivery model.
2. *Generalization*: Although the parent was coached to implement the intervention with good fidelity in clinic, they still needed to implement it in the natural setting (e.g., home, community) without support, which may result in treatment fidelity errors.

Hints

Throughout our experiences on this project, we identified several strategies and tips that were beneficial, could have been beneficial, or should have been considered when beginning the project. Based on these experiences, the following hints should be considered when developing a telehealth service.

1. *Immediate Feedback*: We used a real-time telehealth model in which the behavior consultant observed the parent as the parent was conducting a session with his/her child. This allowed for immediate feedback, which likely increased the overall fidelity of the procedures. If the telehealth sessions had instead been recorded and stored for later viewing by the behavior consultant, the delayed feedback may not have been as effective.
2. *Capability to Control Camera*: When conducting clinic-to-clinic telehealth, it is more likely that the technology connecting the clinical settings has higher capabilities than technology used in the home since it may be used by multiple providers, from different specialties, and for multiple clients. Enhanced technology comes with various benefits such as the remote capability to control the camera in the host location. When conducting behavioral assessment and intervention, this is a great benefit because the individuals at the remote site (e.g., parent, parent assistant) do not have to worry about the camera positioning and can focus on following the behavior consultant's directions. In addition, if the child moves away from the camera's view, the behavior consultant can easily track the child's movements.
3. *Number of Sessions per Visit*: Despite scheduling 1 h for each telehealth visit, we were able to conduct only three to six sessions (lasting 5 min each) per appointment. The lower than expected number of sessions was due to the need to touch base with parents and remind them of procedures at the beginning of the session, provide feedback to parents after the sessions, and prompt the parent assistant and parent to prepare for the next session.
4. *Child Sensitivity to Consultation*: Several of the children in our project were highly sensitive and responsive to the behavior consultant coaching his/her parent. Children who were vocal sometimes responded to behavior consultant inquiries and coaching (e.g., saying, "No" or engaging in problem behavior when the behav-

ior consultant instructed the parent to place a demand on his or her child even though the parent had not yet made the request). In these cases, we implemented various modifications such as using bug-in-the-ear systems, turning off the behavior consultant's camera, limiting the in-session coaching, and talking with the parent pre- and post-session by phone.

Case Examples The following two case examples (Mel and Newt) are representative of the procedures and results from our clinic-to-clinic telehealth project. Both children's demographic information and FCT data were included in summary tables in Wacker et al. (2013a).

Mel. Mel was a 30-month-old boy diagnosed with autism spectrum disorder, mixed-receptive-expressive language disorder, and developmental delay. His target problem behavior consisted of self-injurious behavior (e.g., head banging, hitting head with hard objects, hand biting), aggression (e.g., head butting), and property destruction (e.g., throwing items). Mel was nonvocal, and his communication consisted of walking toward the items he wanted (e.g., approaching mother's bag, walking toward door). Mel attended a preschool classroom for 3 h every day. Mel's father lived halfway between the CDD and the local pediatric clinic, and his mother lived approximately 88 miles away from the CDD and a few minutes from the local clinic where they received telehealth consultation. Mel and one or both of his parents attended weekly 1-h telehealth visits for approximately 4 months.

During Mel's first telehealth appointment, the behavior consultant coached the parent to conduct three free play sessions, which also served as the stimulus preference assessment. Although Mel engaged with some toys, he persistently approached his diaper bag, which contained lollipops. Given the absence of consistent toy play, the lollipops were selected as Mel's highest preferred stimulus. Mel did not engage in target problem behavior during the initial three free play sessions. In addition, he did not attempt to approach the screen on which the behavior consultant's image was projected and did not seem to respond (e.g., move toward, look up) when the behavior consultant coached his parents. Therefore, the behavior consultant proceeded with the FA. During the next two, 1-h telehealth visits, the behavior consultant coached Mel's parents to conduct eight FA sessions within a multielement design. The sessions were 5 min in length and the order of the sessions was counterbalanced. The results of the FA, shown in Figure 22.1, identified that Mel's problem behavior was maintained by access to tangibles, specifically the lollipops that his parents carried in their bags. During FCT, Mel was required to walk to the work table when his parents showed him a work card, and to place his lollipop in an empty container called his "safe spot" (safe, meaning the lollipop would not be thrown away or taken by others). He then had to complete two requests (e.g., put blocks in a bucket) independently and without problem behavior prior to being able to mand by signing "more" for access to his lollipop. With one exception, Mel's target problem behavior decreased immediately and remained low during all sessions (Figure 22.2; FCT 2). The demand requirement was then increased to ten requests per session, and problem behavior remained low (Figure 22.2; FCT 10).

The main concern experienced with telehealth in this case was due to the severity of Mel's self-injurious behavior. His self-injury was severe and required that the behavior consultant prepare the parents and the parent assistant carefully to block and protect Mel from hurting himself. We have found that for children with more severe challenging behavior, it is imperative to prepare the parent and the parent assistant ahead of time to maintain the safety of all parties involved. During our clinic-to-clinic telehealth project, we did not have to terminate participation for any child due to severity of his/her challenging behavior.

Newt. Newt was a 36-month-old boy diagnosed with autism spectrum disorder whose target problem behavior was aggression (e.g., pushing, hitting), self-injurious behavior (e.g., head banging), and property destruction (e.g., swiping items, throwing items). Newt had limited functional communication and attended an early childhood special education preschool classroom. Newt and

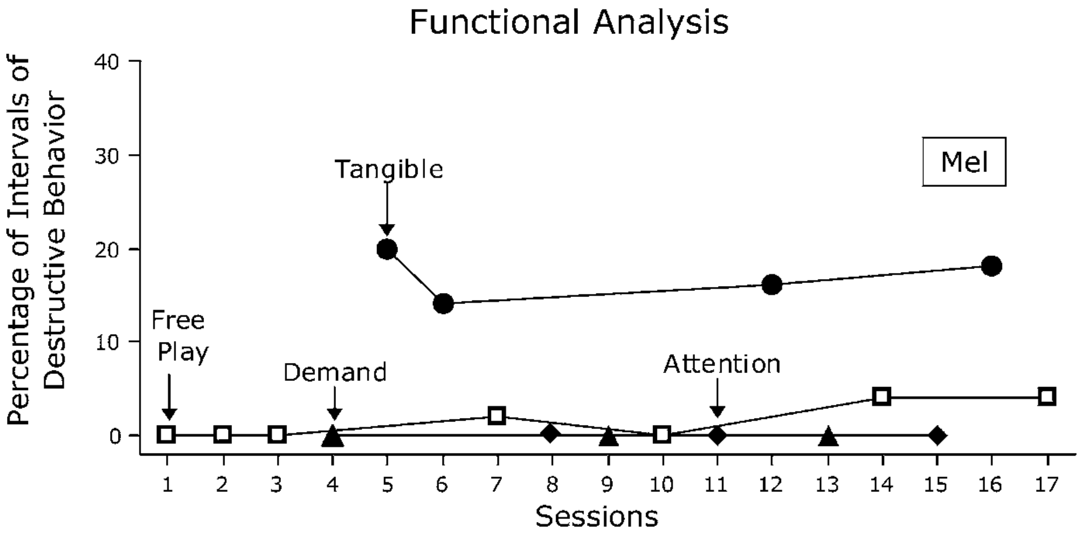

Fig. 22.1 Results of the functional analysis completed via telehealth with Mel during his enrollment in the clinic-to-clinic telehealth project

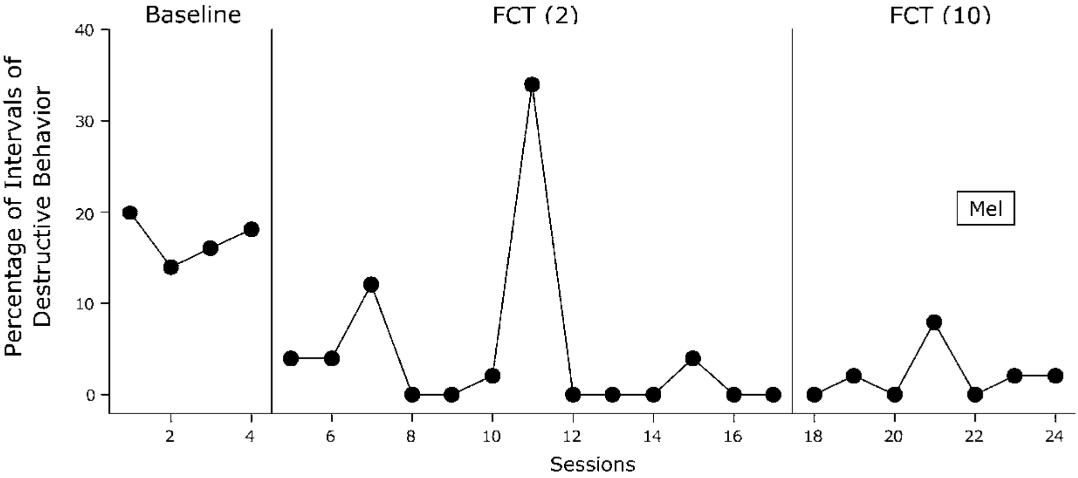

Fig. 22.2 Results of functional communication training conducted via telehealth with Mel during his enrollment in the clinic-to-clinic telehealth project

his family lived approximately 95 miles away from the CDD where the behavior consultants were located and approximately six miles from their local pediatric clinic where they received telehealth consultation. Newt and his mother attended weekly 1-h telehealth visits for approximately 4 months during the course of this project.

Newt was one of the last participants enrolled in the clinic-to-clinic telehealth study. Thus, the behavior consultant and parent assistant did not always have to call each other prior to Newt arriving in the clinic for the telehealth visits. During the first parent meeting, the parent assistant, Newt's mother, and the behavior consultant met to discuss the goals and procedures of the project, interview the parent, explain the daily behavior record, and ask about Newt's preferences. The parent assistant faxed the daily behavior record forms to the behavior consultant for review prior to the next meeting. During Newt's first telehealth appointment, the behavior consultant coached the parent to conduct three free play sessions, which also served as the free operant stimulus preference assessment. Newt did not engage in problem behavior during these sessions, seemed comfortable in the environment, did not attempt to approach the screen, and did not seem sensitive to the behavior consultant coaching his mother.

During the next three 1-h telehealth visits, the behavior consultant coached Newt's mother to conduct 13 FA sessions within a multielement design. The parent responded very well to coaching. The only concern that occurred was during the escape condition, in which the behavior consultant had to remind the parent several times to make sure she had enough materials to complete the demand and to prevent Newt from having access to his preferred item before completing the tasks requested. The results of the FA showed that Newt's problem behavior was maintained by access to tangibles and escape from demands. FCT required Newt to walk to the work table and complete one demand (i.e., putting blocks inside a bucket) before being able to mand for an enriched break with his toys and parent attention. Newt manded by pressing a microswitch with a picture card attached to it. After an initial increase, Newt's problem behavior decreased to zero. The task demands were then increased to ten tasks per session, and problem behavior remained low.

The biggest problem we experienced with telehealth in this case was poor fidelity during demands. This mother needed the continued support of the parent assistant to conduct the FCT procedures with good fidelity.

As shown in these case examples, telehealth can serve as a very effective delivery system for behavioral assessment and treatment procedures. Although some problems with fidelity occurred, the parents were still able to achieve notable reductions in problem behavior. The biggest problem with conducting telehealth in regional pediatric clinics was that the families still needed to drive to a clinic and to generalize the procedures from the clinic setting to their homes.

Clinic-to-Home Telehealth Model

Model Description

The clinic-to-home project (Lindgren & Wacker, 2011) was initiated following the successful demonstration that parents can be coached remotely to conduct FA plus FCT in a clinic setting via telehealth. One of the primary objectives of the clinic-to-home telehealth project was to directly compare outcomes (e.g., reduction in problem behavior, cost, treatment acceptability) with the in vivo in-home and clinic-to-clinic telehealth models. The procedures used during this project (Suess, Romani, et al., 2014) were similar to those of the previously described projects (Wacker et al., 1998; 2013a, 2013b). Participants were young children ages 2–7 years who were diagnosed with autism spectrum disorder and who engaged in problem behavior. Behavior consultants were located at the CDD (host site), and parents conducted sessions in their homes (remote site). Assessment and treatment procedures were conducted during weekly 1-h telehealth visits by the children's parents with live, remote coaching from the behavior consultants. In this section, we provide a brief overview of the procedures used in this project with a focus on modifications needed to adapt the clinic-to-clinic telehealth model to the home setting.

Step One: Determining Equipment Needs

At the time of enrollment, our technology support staff contacted the parents to determine their equipment needs in order to participate in the project (refer to Lee et al., 2015, for specific equipment requirements). Parents were loaned a Windows-based laptop, webcam, and Ethernet cable if they did not already own the necessary equipment to participate. In order to meet each of the parents' equipment needs, we created an equipment lending pool from which the equipment was checked-out to the parents free of charge; the parents then returned the equipment at the end of their participation in the project. The laptops were equipped with Skype™ (video conferencing software) and Debut (video recording software). Internet service was also provided to the parents if they did not have broadband service or if the speed of the internet service was not sufficient for the telehealth visits (refer to Lee et al., 2015, for recommended internet requirements). Support for internet service was then discontinued when participation in the project ended.

After the parents received the equipment in the mail, a technology meeting was completed to ensure compatibility with the telehealth system being used at the CDD and to familiarize the parents with how to use Skype™ (Lee et al., 2015). The technology meeting was approximately 1 h and involved our technology support staff contacting the parents via telephone to provide initial instructions on how to operate the computer and ended by testing the Skype™ connection.

Step Two: Initial Meeting

The week following the technology meeting, the behavior consultant held a 1-h parent meeting via Skype™. The parent meeting began by the behavior consultant providing an overview of function-based assessment and treatment procedures used in the project (Suess, Romani, et al., 2014). The parents also received a manual describing the project's procedures. The behavior consultant then interviewed the parent to determine the current behaviors of concern. At the end of the parent meeting, the behavior consultant and parent determined the room in the home (e.g., bedroom, kitchen, family room) in which the FA and FCT were going to be conducted and set a day and time at which the subsequent telehealth visits would occur.

Step Three: Evaluation Procedures

Functional Analysis

Parents were coached to conduct the FA within a multielement design, and all test conditions were counterbalanced. Unlike in the clinic-to-clinic telehealth project, parent assistants were not present during the FA, and parents conducted all sessions without any "hands-on" support in their home. Prior to each weekly telehealth visit, the behavior consultant spent a few minutes talking with the parent about how the sessions would be conducted, making sure that appropriate materials were present, and that the room was set up to conduct the analysis. FA sessions were conducted very similarly to the clinic-to-clinic model, including the addition of extra free play sessions, conducted consecutively at the beginning of the FA, until near zero occurrences of problem behavior occurred. All FA sessions were recorded using Debut for subsequent data collection and analysis.

Functional Communication Training

Prior to beginning FCT, the behavior consultant and parent met to review the FCT procedures, which again involved teaching the child to comply with a request and to then mand for an enriched 1–2 min break. The parent was asked to practice the FCT in their homes daily for 10–15 min and to record their practice sessions using Debut on the laptop. The behavior consultant and the parent briefly discussed the prior week's practice sessions at the beginning of the next telehealth appointment.

Benefits, Challenges, and Hints for Clinic-to-Home Telehealth

Benefits

There appear to be several potential benefits to the delivery of in-home behavioral services via telehealth.

1. *Treatment Effectiveness*. Outcome data indicated that the mean reduction in problem behavior for participants in the clinic-to-home telehealth project was 97 %.
2. *Cost Effectiveness*. There was a significant decrease in average cost per child per week compared to in vivo delivery of behavioral services in the home.
3. *Accessibility, Convenience, and Productivity*. By eliminating both the need for consultants to travel to the home and for families to travel to a clinic, clinic-to-home telehealth resulted in increased accessibility and convenience compared to the traditional in-home project or the clinic-to-clinic telehealth project. The average distance from Iowa City for families in the clinic-to-home telehealth project was over 116 miles. By eliminating travel barriers, many families were able to participate in the telehealth project who would have been previously ineligible due to geographical con-

straints. Furthermore, because services were delivered in the home, families did not have to travel to a clinic for weekly sessions.

4. *Generalization*. Similar to the in vivo in-home model, the FA and FCT procedures were conducted by parents in their own homes. This greatly reduced the need for parents to generalize the procedures, and the consultants could observe any naturally occurring barriers (e.g., more than one family dog was in "time out" during sessions).
5. *Treatment Acceptability*. Parent ratings of treatment acceptability remained high. This suggests that, regardless of the specific delivery system utilized, most parents have found the FA plus FCT approach to treatment to be very acceptable.

Challenges

The following is a list of practical considerations for practitioners to consider with in-home telehealth service delivery based upon our experiences.

1. *Technical Challenges*: Use of telehealth technology resulted in occasional technical problems related to connectivity, hardware, and software that did not exist when behavioral consultants provided in vivo consultation in the home. In a few instances, sessions could not be conducted at the scheduled time or data were lost due to technical difficulties. See Lee et al. (2015) for additional information about the types of challenges encountered and for technical guidelines for practitioners interested in providing services via an in-home telehealth service delivery model.
2. *Implementation Considerations*: Prior to conducting FA plus FCT in the home, behavior consultants needed to consider several practical issues that could influence assessment and treatment outcomes. These included (a) equipment needs (e.g., Did the parent have internet service? Did they own a secure and reliable webcam and computer?), (b) the safety of the child and parent in the room where the evaluation was to be conducted (e.g., Was there furniture that could be knocked over? Were potentially dangerous materials present?), (c) whether target behaviors were observable via telehealth (e.g., What happened if the child moved around quickly or left a defined space?), (d) who would be involved in the telehealth sessions (e.g., If the participating child had siblings, would they be present in the room?), (e) how the child would respond to the equipment (e.g., Did a Bluetooth® device need to be used to provide bug-in-the-ear coaching to the parent? Were additional free play sessions needed to be conducted to help the child adjust to the camera?), (f) the severity of problem behavior (e.g., If a child engaged in severe problem behavior, would we reinforce less severe behaviors that were part of the same response class?), and (g) how coaching would be delivered (e.g., setting up time with the parent prior to conducting sessions to discuss procedures to provide feedback during sessions if fidelity errors were committed, and to review results at the conclusion of the sessions). See Suess, Romani, et al. (2014) for information about how parents were oriented to conduct in-home telehealth.
3. *Insurance Reimbursement*. The procedures described in this chapter were conducted as part of federally funded research projects. Although the results strongly indicate that telehealth is a feasible model for conducting behavioral assessment and treatment, variability currently exists with respect to insurance reimbursement for telehealth services and especially for in-home telehealth services.

Hints

The following is a list of hints to consider when developing a clinic-to-home telehealth service.

1. *Advanced Preparation*. As described above, there are several variables unique to telehealth delivery of behavioral services in the home compared to in vivo delivery that can influence outcomes. Although it is impossible to anticipate all variables in advance, we encourage practitioners to carefully consider and resolve likely challenges to minimize difficulties that occur during sessions. It was particularly important for the behavior consultants to have the ability to troubleshoot simple technology

issues (e.g., issues with audio and video) that occurred when using Skype™.

2. *Immediate Feedback*: Similar to the clinic-to-clinic model, immediate feedback was provided to parents across all sessions, which likely increased treatment fidelity. We recommend that behavioral consultants correct errors when they occur instead of waiting until after a video of the session has been observed.
3. *Information Technology* (*IT*) *Support*. Before beginning to deliver services through telehealth, it will be important to select appropriate equipment and to ensure that IT support will be available to address any connectivity, hardware, and software issues that arise as well as issues related to protection of privacy and data storage and retrieval.
4. *Number of Sessions per Visit*: Similar to clinic-to-clinic telehealth, we completed slightly fewer sessions per visit in the clinic-to-home telehealth project than in the in vivo in-home project. Time spent checking in with the parent at the beginning of the session, conducting additional free play sessions to help the child adjust to the telehealth equipment, reminding the parent of procedures prior to sessions, and providing feedback after the sessions all contributed to the greater amount of total time needed to complete the FA.
5. *Child Sensitivity to Consultation*: A few of the children were aware of and overly responsive to the behavior consultant coaching their parent via telehealth. Similar to the clinic-to-clinic telehealth project, we implemented modifications such as using Bluetooth® audio technology, turning off the behavior consultant's camera, limiting the live in-session coaching, and talking with the parent pre- and post-sessions on the phone.

Case Examples The following two case studies (Jace and Billy) describe procedures used during the clinic-to-home telehealth model. For Jace, the first case example, we emphasize the procedures conducted during the telehealth appointments. Jace's data were previously published in Suess, Romani, et al. (2014). For Billy, we emphasize the various challenges encountered and our solutions to address those challenges throughout our experiences with Billy and his mother.

Jace. Jace was a 31-month-old boy diagnosed with autism spectrum disorder and intellectual disability. Jace's mother conducted all telehealth sessions. Jace's home was located 3 miles from the CDD.

At the time of enrollment, the behavior consultant conducted a brief phone interview to determine his parents' equipment needs. Specific information was obtained regarding access to a computer, internet service, and other technology materials (e.g., webcams, Ethernet cables). This information was important to determine whether the equipment currently in the home would be sufficient for telehealth services.

After receiving the needed telehealth equipment, the behavior consultant held the technology meeting with the mother to orient her to Skype™ and other specific features of the computer (e.g., Internet Explorer). The behavior consultant also ensured that Skype™ was using the external webcam provided for her instead of the internal webcam on the computer to ensure the highest quality visual image. Finally, the behavior consultant helped the mother connect the Ethernet cable from the computer to the internet modem. Connecting the Ethernet cable proved difficult for her, even with descriptive feedback from the behavior consultant. Thus, the behavior consultant instructed her to move the external webcam so the behavior consultant could see the modem and computer to facilitate more specific support.

The purpose of the second telehealth visit was for the behavior consultant to deliver a didactic training during a 1-h meeting. The primary behavioral concerns were self-injurious behavior (e.g., head banging), aggression (e.g., pulling hair and biting), and property destruction (e.g., throwing items). Jace did not have an effective form of communication and only occasionally used gestures (e.g., pointing).

The FA began the following week. The behavior consultant began preparing for this visit (and all subsequent visits) about 10–15 min prior to the scheduled appointment time. During this setup period, the behavior consultant prepared notes to record general behavioral observations during the visit and also logged onto Skype™ to check the internet connection and webcam. After establishing a connection, the behavior consultant guided the mother to make sure the living room was safe, to move some items (e.g., picture frames), and to create barriers to block Jace from running out of the living room and to prevent the family dog from entering the room.

A series of free play sessions were first conducted to evaluate Jace's level of reactivity with having the behavior consultant coach his mother via Skype™ and to conduct free operant preference assessments. Prior to the beginning of free play, and before each subsequent test condition of the FA, the behavior consultant provided a detailed vocal description of each test condition. For example, the behavior consultant described free play by saying something similar to, "During free play, allow Jace to play with his toys. Provide as much attention to him as you can and try to avoid making requests. Allow Jace to direct the play."

Test conditions of the FA were then alternated with additional free play sessions, with problem behaviors occurring during the tangible and escape sessions. His mother frequently had to move closer to the computer in order to hear the behavior consultant delivering feedback, which in turn affected the procedural fidelity of the FA. Thus, the behavior consultant began using nonverbal modes of feedback. For example, if the behavior consultant was coaching the mother to deliver physical guidance, the behavior consultant modeled taking his own hand to complete the task. Other technology problems occurred intermittently during the FA, likely due to a slow or delayed internet connection. These problems occasionally required the mother to reestablish the Skype™ connection with the behavior consultant. Technology problems never precluded sessions from being conducted.

As described by Wacker et al. (2011) a brief extinction baseline was then conducted to measure the persistence of Jace's problem behaviors during extinction. During extinction sessions, his mother delivered instructions to him to complete tasks. Elevated levels of problem behavior were observed during the extinction baseline.

Following the extinction sessions, the behavior consultant prepared treatment materials, which included a microswitch and play and work picture cards, and sent these to the parent. At the next telehealth visit, the behavior consultant reviewed the treatment procedures with Jace's mother. For example, the behavior consultant coached her on how to replace the work materials with the microswitch after Jace complied with her instruction. This meeting ended after approximately 1 h.

FCT treatment began the following week. Jace's mother and the behavior consultant briefly reviewed the task analysis for Jace's FCT treatment before beginning sessions. At one point, Jace ran away from his desk and out of camera view. After that session, his mother and the behavior consultant were able to discuss environmental modifications (i.e., moving a chair in front of the entrance to the kitchen) to prevent similar situations from occurring. After consistently low levels of problem behavior occurred during the initial treatment sessions, we probed sessions at the terminal treatment goal of completing ten tasks in a 5-min session. Jace continued to engage in near zero levels of problem behavior. In comparison to baseline, Jace's problem behavior was reduced by 100 %.

Billy. Billy was a 61-month-old boy diagnosed with autism spectrum disorder. He also had an extensive medical history as he was born premature at 24 weeks. His home was located 78 miles from the CDD. Billy and his mother participated in the telehealth sessions. Problem behaviors targeted during the FA and FCT were self-injury (e.g., head hitting), aggression (e.g., hitting, kicking, scratching), and property destruction (e.g., throwing items). Billy communicated using phrase speech. Billy and his mother participated in weekly telehealth sessions for approximately 4 months.

We interviewed Billy's mother to determine her equipment needs. She had access to a desktop computer and had internet service established in the home. Her desktop computer was too old to use for the project. Thus, a laptop computer and other needed equipment (webcam and Ethernet cable) were shipped to her. The current internet service in the home was judged to be sufficient for telehealth. She did not know how to use a computer and expressed concern about her ability to use the computer. For this reason, we had her come to the CDD to have the initial technology meeting to show her how to turn the computer on and off, connect to the internet, and create a Skype™ account. To teach her how to use Skype™, our technology support staff called her at her home and gave her step-by-step directions over the phone on how to log on to Skype™ and connect with the behavior consultant. We had the mother practice logging on to Skype™ a few times before the first telehealth visit. When the telehealth visits began, the behavior consultant called her on the phone to help her make the Skype™ connection.

Following an interview, the living room was chosen for conducting the procedures because the computer could be connected directly to the cable modem, which provided the most optimal internet connection. The computer and webcam were placed on a chair near the open floor space in the living room, which allowed the behavior consultant to observe Billy playing with toys and completing task demands. His mother arranged for another adult to be in the home to watch the other children while she participated in the telehealth visits.

During the initial free play sessions of the FA, Billy seemed comfortable with the behavior consultant coaching his mother via Skype™ as he played appropriately with the toys and did not approach the computer screen. One problem that occurred during the attention condition involved Billy eloping from the living room when his mother diverted her attention. Given that the behavior consultant could not see Billy when he eloped from the room, the behavior consultant instructed his mother to neutrally guide Billy back to the living room. Billy continued to engage in elopement during the attention condition. Elopement was then added as a target problem behavior. Two technology problems also occurred during the FA. The first problem involved a delay between the audio and video feeds. When this problem occurred, the behavior consultant often continued conducting the sessions. However, on occasion the behavior consultant had to have Billy's mother restart Skype™ because the delay was too disruptive and was compromising the fidelity of the sessions. The second problem involved losing the Skype™ connection all together. When the connection was lost, the behavior consultant and mother reestablished the video call when the internet connection improved and resumed conducting the session. Similar technology problems were encountered throughout Billy's participation; however, these problems never precluded sessions from being conducted. A total of 15 sessions were conducted in the FA, and the results suggested that Billy's problem behavior was maintained by escaping demands and gaining access to toys and attention.

Prior to starting treatment, the behavior consultant held a brief meeting via Skype™ to explain the FA and extinction baseline results and to describe the FCT procedures to the mother. The materials (e.g., play and work picture cards) needed for treatment were then mailed to her. During the subsequent telehealth visit, the behavior consultant instructed her on how to set up play and work areas of the room prior to beginning FCT. During FCT, Billy was directed to complete a small amount of work and then to mand for a break to play with the toys. Demand fading was used to increase the work requirement to access reinforcement (i.e., completing two, four, or ten demands per 5-min session). During one of the initial treatment sessions, Billy eloped from the living room and hid in the kitchen pantry when he was directed to complete work. Given that an attention function was identified in the FA, the behavior consultant did not want the mother providing attention by following Billy into the kitchen. Therefore, the behavior consultant instructed her to stay in the living room, repeat the task directive, and provide high quality attention when Billy returned to the living room and sat in the work area. The behavior consultant also had the mother move to the opposite side of the work area in order to block Billy from eloping from the room during subsequent treatment sessions. In addition to managing elopement, there were times when the behavior consultant could not see Billy in the work area. To fix this problem, the behavior consultant had the mother relocate the computer and webcam so that the behavior consultant had a wider view of the living room. To help his mother be more organized and consequently implement the treatment procedures with better fidelity, the behavior consultant provided vocal prompts (e.g., "Do you have your work and play picture cards ready?") for her to get her materials ready prior to the start of an FCT trial. FCT was implemented for 32 sessions across eight telehealth visits. Billy's problem behavior was reduced by 100 % by the end of treatment.

Outcome and Procedural Approach Summary

As summarized in Table 22.1, results from Mel, Newt, Jace, and Billy showed that problem behavior was maintained by positive reinforcement (Mel) or a combination of positive and negative reinforcement (Newt, Jace, and Billy), and was reduced by at least 76 % when FCT was implemented by the parent. Treatment acceptability remained high across parents and telehealth projects. These results are representative of the overall results obtained for the majority of children enrolled in both telehealth projects.

As displayed in Table 22.2, procedural components remained relatively similar across all of our service delivery models. Each model required slight modifications in the step-by-step process such as determining equipment needs for the in vivo in-home service versus the clinic-to-clinic or clinic-to-home service. In addition, several challenges were experienced with the telehealth models, which required the development of practical solutions. For example, at times a lot of coaching from the behavior consultant was needed to increase the parent's procedural fidelity or to modify the environment. Given that these challenges are likely to be inevitable when the behavior consultant cannot be physically present, effective solutions need to be carefully considered, developed, and implemented. These solutions can include actions such as having a support person (like a parent assistant) available to show the parent how to conduct a procedure, using visual cues that can be moved in front of the webcam to show the parent exactly what to do, and having a highly skilled behavior consultant coaching and modifying procedures at the moment problems arise. In addition, technical issues, insurance reimbursement issues, and generalization issues need to be considered when using telehealth as a service delivery model.

Regardless of whether behavior analytic services were directly delivered by a trained behavior consultant in the home or via telehealth in a clinic or home setting, clinically meaningful reductions in problem behavior were observed for the majority of children and parents' ratings of treatment acceptability were high. Other benefits as well as limitations were noted specifically for each model, such as

Table 22.1 A summary of assessment and treatment results for Mel, Newt, Jace, and Billy

	Assessment		Treatment					Time
Case examples	Identified FA function(s)	Mean % of problem behavior in baseline	Function(s) targeted for treatment	Mean % of problem behavior at the end of treatment	% Reduction in problem behavior	Number of visits during treatment	Final TARF rating (scale 1–7; 7 = highly acceptable)	Total length of time in project
Mel	Tangible	17 %	Tangible	1 %	92 %	6 visits	6.5	~4 months
Newt	Escape and tangible	14 %	Escape and Tangible	3 %	76 %	9 visits	7	~3 months
Jace	Escape and tangible	9 %	Escape and Tangible	0 %	100 %	4 visits	6	~3 months
Billy	Escape, tangible, and attention	36 %	Escape and Tangible	0 %	100 %	8 visits	5	~3 months

Table 22.2 A summary of the procedural steps, benefits, challenges, and hints across service delivery models

	In vivo in-home model	Clinic-to-clinic model	Clinic-to-home model
Step 1: Determining equipment needs	• Recording devices: video cameras	• Equipment for both clinic sites: computers, webcams, headphones with microphones, video conferencing software, video recording software, Internet connection	• Equipment for both clinic and home sites: computers, webcams, headphones with microphones, video conferencing software, video recording software, Internet connection
		• Test runs of equipment and software	• Training on how to operate the equipment
Step 2: Initial meetings	• Parent interview	• Parent assistant training	• Parent training
	• Daily behavior record	• Parent training	• Determine location of sessions in home
	• Preference assessment	• Parent interview	• Parent interview
		• Daily behavior record	• Daily behavior record
		• Preference assessment	• Preference assessment
Step 3: Evaluation procedures	• Functional Analysis	• Functional Analysis	• Functional Analysis
	• Functional Communication Training	• Functional Communication Training	• Functional Communication Training
Benefits	• Decreases in problem behavior	• Decreases in problem behavior	• Decreases in problem behavior
	• High treatment acceptability	• High treatment acceptability	• High treatment acceptability
	• Naturalistic setting	• Cost effectiveness	• Cost effectiveness
		• Increased access and efficiency	• Increased accessibility, convenience, and productivity
			• Naturalistic setting
Challenges	• Access	• Access	• Technical challenges
		• Generalization of procedures	• Implementation considerations
			• Insurance reimbursement
Hints		• Immediate feedback	• Advanced preparation
		• Capability to control camera	• Immediate feedback
		• Number of sessions per visit	• IT support
		• Child sensitivity to consultation	• Number of sessions per visit
			• Child sensitivity to consultation

increased access and efficiency when using either telehealth model, decreased needs for training for generalization when using the in vivo in-home or clinic-to-home models, and the need for increased free play sessions when FAs were conducted via telehealth. These findings suggest that both in vivo and telehealth delivered services have merit for addressing challenging behaviors and that clinicians should consider multiple variables when determining which approach to utilize.

Review of Approach and Research Illustrative of this Approach

Telehealth-based services have been provided in Iowa for the past 20 years, but it has only been within the last 10 years that our use of this technology has evolved from providing consultation to the delivery of behavior analytic assessments and treatments with real-time coaching from behavior consultants. Expanding how telehealth is delivered has evolved in new and innovative ways. However, telehealth-based services have been available for at least 40 years (American Telemedicine Association, 2015) and were even predicted as early as 1925 by Hugo Gernsback, a radio and publishing pioneer (Novak, 2012).

In the scientific literature, peer-reviewed articles on telehealth appeared in 1975 (based on a literature search in the PsychINFO and ERIC databases using the search terms *telehealth* or *telemedicine* or *telemental health* or *telebehavioral health* across all domain categories including all text, author, title, subject terms, source, abstract, and ISSN). The appearance of peer-reviewed articles on telehealth in 1975 supports the American Telemedicine Association's claim that telehealth-based services have been present for at least 40 years. Our search yielded 3655 telehealth entries between the years 1975 and 2015. When narrowing this search, 86 % of those articles were published during the last 10 years (2005–2015), which is why telehealth "feels" new and innovative. Telehealth-based services cover all aspects of healthcare, ranging from general parent training (e.g., Wade, Oberjohn, Conaway, Osinska, & Bangert, 2011) to providing highly specific treatments such as imagery-based treatments for breast cancer survivors (e.g., Freeman et al., 2015). The connection from a telehealth-based center (host site) to a remote site has included settings such as other clinics (e.g., Southard, Neufeld, & Laws, 2014), schools (e.g., Reynolds & Maughan, 2015), and homes (e.g., DelliFraine & Dansky, 2008), with the location between these sites ranging from within the same facility (e.g., Machalicek, O'Reilly, Chan, Lang, et al., 2009) to extremely rural areas (e.g., Dailey & Stanfa-Brew, 2014). In the following sections, we describe applications of telehealth-based services in selected areas of healthcare to illustrate the range of research being conducted. We then describe current research using telehealth-based services within the field of applied behavior analysis outside of our current projects. Finally, we describe several current research and clinical applications of telehealth-based services in the field of applied behavior analysis, based on recent interviews we conducted with active researchers and practitioners.

Applications of Telehealth-Based Services Across Healthcare

Much of the current research in telehealth focuses on demonstration of the feasibility of service delivery in a particular field or using a particular method. For instance, several studies focused on the feasibility and accuracy of providing screening or consultation to patients who presented to a clinic with referral for specific concerns or for routine care. The concerns or care addressed in these studies varied across the healthcare field, and included mental health (Southard et al., 2014), ocular health (Maa, Evans, DeLaune, Patel, & Lynch, 2014), and speech, language, and hearing health (Ciccia, Whitford, Krumm, & McNeal, 2011). One selected study evaluated the effectiveness of providing an evidence-based parent training program via telehealth (Reese, Slone, Soares, & Sprang, 2012). Another selected publication discussed the benefits and limitations of utilizing telehealth with military personnel in need of care regarding mental health concerns while deployed in a combat environment (Dailey & Stanfa-Brew, 2014).

For those studies evaluating the feasibility and accuracy of providing screening or consultation via telehealth, results have been generally positive. For example, Southard et al. (2014) showed that for patients who presented to a rural hospital emergency room (ER) for various mental health concerns (e.g., attempted suicide, nonspecific pain) resulting in a mental health consultation, various dependent measures improved when telehealth was provided from a community mental health provider located 15–35 miles away from the rural ER. The specific benefits were: (a) the reduced amount of time from the ordered consult to consultation from the community mental health provider, (b) the reduced amount of time from the patient's arrival in the ER to consultation from the community mental health provider, and (c) the reduced length of the hospital stay from arrival to discharge. Similarly, National Public Radio (NPR) recently released a story (Feibel, 2015) about Houston firefighters connecting with doctors using a video chat application to assess the immediacy of a visit to the ER during 911 house calls. By connecting with doctors via telehealth, the medical concern could be assessed and triaged to the appropriate clinic such as an outpatient primary care clinic rather than the ER.

Ciccia et al. (2011) and Maa et al. (2014) have also evaluated the feasibility and accuracy of screening individuals for concerns related to their respective specialty fields when those screenings are conducted via telehealth. Ciccia et al. (2011) showed that speech, language, and hearing screening via telehealth for children up to 6 years old was feasible, reliable, and strongly supported by the families. Specifically, pure tone hearing screening, speech-language screening, and Distortion Product Otoacoustic Emissions (DPOAE) screening were found to be 100 % reliable across screenings administered in-person compared to those administered via videoconferencing. An additional screening, typanometry, was administered and shown to be 84 % reliable across the different modes of administration. Similarly, Maa et al. (2014) found a high correlation between face-to-face ocular exams and tele-eye exams for detecting common ocular diseases (i.e., cataract, macular degeneration, glaucoma) in elderly patients.

Another area of healthcare research has focused on the effectiveness of delivering evidence-based practices via telehealth. Reese et al. (2012) implemented the *Group Triple P Positive Parenting Program* (Turner, Dadds, & Sanders, 2002) via telehealth with low socioeconomic status families from the Appalachian region of Kentucky where children were experiencing behavioral, emotional, or family problems. Results showed that the children's externalizing behaviors decreased, the parent's distress levels decreased, and the parent's skills and self-efficacy increased, suggesting that this evidence-based group parenting program can be implemented successfully via telehealth.

Dailey and Stanfa-Brew (2014) discussed how a telehealth service delivery model was utilized in combat environments. They discussed that in combat environments, behavioral health officers or the patient have to travel across dangerous areas to receive service in person, and this travel is often time-consuming. By using telehealth to deliver services to military personnel, lengthy travel delays were avoided, physical security risks were mitigated, and experts were available for facilitating care for psychiatric emergencies more immediately.

Overall, the use of telehealth as a service delivery model throughout healthcare has been shown to be an effective and feasible option for providing a range of services to individuals and families with a variety of concerns.

Applications of Telehealth-Based Services Across Applied Behavior Analysis

The first generation of telehealth research in applied behavior analysis focused on two major themes: (a) the effectiveness and feasibility of behavior analytic procedures and outcomes (Machalicek, O'Reilly, Chan, Lang, et al., 2009; Wacker et al., 2013a, 2013b), and (b) delivery of consultation and training for service providers and parents in behavior analytic procedures (Fisher et al., 2014; Frieder, Peterson, Woodward, Crane, & Garner, 2009; Gibson, Pennington, Stenhoff, & Hopper, 2010; Hay-Hansson & Eldevik, 2013; Heitzman-Powell, Buzhardt, Rusinko, & Miller, 2014; Machalicek et al., 2010; Machalicek, O'Reilly, Chan, Rispoli, et al., 2009; Suess, Romani, et al., 2014). Studies on the effectiveness and feasibility of delivering behavior analysis via telehealth have demonstrated that behavior analytic procedures can successfully be implemented in real-time while expert practitioners are not physically present. For example, Machalicek, O'Reilly, Chan, Lang, et al. (2009) evaluated the effects of behavior intervention plans on challenging behavior that were developed based on the results of FAs conducted via telehealth and showed that challenging behavior decreased when that behavior intervention plan was implemented. These results suggested that the results of FAs obtained via telehealth can be just as useful for treatment development as the results obtained from FAs conducted in vivo.

Behavior analytic studies on the use of telehealth have often focused on consultation and training with an emphasis on providing training in behavior analytic principles and procedures to service providers and parents. For example, Fisher et al. (2014) evaluated a 40-h online training program for behavioral technicians that included online modules and scripted role-plays. The online modules consisted of the participants accessing the material within each module and passing a multiple-choice quiz with 80 % accuracy prior to proceeding to the next module. Role-plays were situated at various points within the module training and consisted of opportunities to practice the skills covered in a particular module while receiving real-time coaching and feedback. Participants in this study were randomly assigned to an immediate treatment group or a wait-list control group. In this preliminary study, results showed that those receiving the online training program implemented the procedures correctly and mastered the majority of skills taught following the training, whereas little change occurred for those in the control group, suggesting that training provided through the use of telehealth technology can be effective. Similar results were obtained with parents in a study conducted by Heitzman-Powell et al. (2014), in which parents received online training and real-time coaching and feedback when implementing behavior analytic procedures with their children with autism spectrum disorder.

Other studies have focused on real-time coaching and feedback, either prior to or during the implementation of a behavior analytic assessment or intervention procedure. For example, Gibson et al. (2010) evaluated the effects of a behavioral treatment (FCT) on challenging behavior (elopement) displayed by a preschool-aged child with autism spectrum disorder, with all intervention training and consultation provided via telehealth prior to the implementation of the intervention. Specifically, the authors provided training via telehealth to the teachers and teacher assistants on how to implement the FCT procedures. Total training time was 45 min and consisted of the consultants modeling the FCT procedure, coaching the teachers and teacher assistants through a series of role-plays, and providing feedback. Following this training, the school personnel's implementation of the intervention was shown to occur with high fidelity, and the student's challenging behavior was shown to decrease.

Training has also been provided during the implementation of behavioral assessments and interventions. For example, Machalicek, O'Reilly, Chan, Rispoli, et al. (2009) and Machalicek et al. (2010) demonstrated that pre-service teachers and licensed teachers implemented preference assessments and FAs, respectively, with accuracy when receiving real-time coaching and feedback via telehealth. Similarly, Hay-Hansson and Eldevik (2013) showed that real-time coaching and feedback via telehealth was effective when training service providers to conduct discrete trial training with children with autism spectrum disorder.

The overall findings of telehealth as a service delivery and training model for behavior analytic procedures are positive: it is both effective and feasible. Behavior analytic studies on telehealth have noted numerous benefits including (a) the effectiveness of this service delivery model in training direct service providers and parents (Fisher et al., 2014; Frieder et al., 2009; Gibson et al., 2010; Hay-Hansson & Eldevik, 2013; Heitzman-Powell et al., 2014; Machalicek et al., 2010; Machalicek, O'Reilly, Chan, Rispoli, et al., 2009), (b) an alternative method for providing supervision and training (Fisher et al., 2014; Hay-Hansson & Eldevik, 2013), (c) increased savings related to time and money for direct service providers, parents, and behavior analytic specialists (Fisher et al., 2014; Gibson et al., 2010), (d) increased access to service and specialist support (Gibson et al., 2010; Heitzman-Powell et al., 2014; Machalicek, O'Reilly, Chan, Lang, et al., 2009; Machalicek, O'Reilly, Chan, Rispoli, et al., 2009), (e) increased abilities of direct service providers and parents in implementing behavior analytic procedures (Frieder et al., 2009; Heitzman-Powell et al., 2014), and (f) decreased occurrence of observer effects (Gibson et al., 2010).

Although there are a number of benefits to providing behavior analytic services via telehealth, there are also many challenges that have been noted that need to be considered when developing or conducting behavioral services via a telehealth model, including: (a) poor video quality such as blurred screens or changing light conditions that are incoming from windows (Hay-Hansson & Eldevik, 2013), (b) technical difficulties such as internet instability, lack of technology advances in rural areas, or insufficient internet speed to transmit high quality video and audio streams (Frieder et al., 2009; Gibson et al., 2010; Hay-Hansson & Eldevik, 2013; Heitzman-Powell et al., 2014), (c) equipment capabilities such as webcams that can pan and zoom so that child movement is easily captured or data collection methods that are not labor intensive (Frieder et al., 2009), (d) comfort with the use of technology including comfort with the presence of cameras and recording devices or comfort with troubleshooting technology issues (Frieder et al., 2009; Gibson et al., 2010), (e) coaching skills such as the ability to effectively use verbal communication when visual strategies such as modeling are not possible (Heitzman-Powell et al., 2014), and (f) administration issues such as personnel time constraints or policies and permissions that allow for internet-based video consultations (Frieder et al., 2009; Gibson et al., 2010).

Current Research and Clinical Applications of Telehealth-Based Services in Applied Behavior Analysis

The initial behavior analytic studies on telehealth have demonstrated the effectiveness and feasibility of using telehealth to train service providers and parents to assess and treat a variety of target behaviors. This has led to an increased use of telehealth by behavior consultants, much of which is too new to be available in the published literature. For this reason, we contacted colleagues across several sites to determine the work that is currently being conducted using telehealth. The colleagues and sites contacted included Drs. Wayne Fisher and Kevin Luczynski at the University of Nebraska Medical Center's Munroe-Meyer Institute, Dr. Stephanie Peterson at Western Michigan University, Dr. Jennifer McComas at the University of Minnesota, and Dr. Nathan Call at the Marcus Autism Center and Emory University. We contacted these colleagues because their current work represents a range of services from research to clinical practice and focuses on the training and supervision of direct service providers or the provision of services by highly trained behavior consultants.

Drs. Fisher and Luczynski have extended their first generation research from evaluating the effects of a 40-h remote-training program for behavior technicians (Fisher et al., 2014) to evaluating the outcomes of early intervention programming for children with autism spectrum disorder that is delivered by newly trained behavior technicians throughout the state of Nebraska who receive real-time (synchronous) coaching and delayed (asynchronous) feedback via telehealth from certified behavior analysts (W. Fisher, personal communication, March 5, 2015; K. Luczynski, personal communication, March 20, 2015). Dr. Peterson is training community mental health agency staff across the state of Michigan to conduct behavioral assessments and treatments with children with an autism spectrum disorder who engage in problem behavior (S. Peterson, personal communication, March 9, 2015). This training consists of didactic training, behavioral skills training, and real-time coaching for six predetermined behavioral assessment and treatment skills. The telehealth evaluations being conducted by Drs. Fisher, Luczynski, and Peterson are funded by research programs from the Department of Defense (Drs. Fisher and Luczynski) and the Michigan Department of Health (Dr. Peterson).

Dr. McComas is conducting feasibility and effectiveness research with girls who have Rett Syndrome and engage in self-injury (J. McComas, personal communication, March 5, 2015). This population was chosen because the prevalence of this syndrome is rare, and providing services to these individuals in-person is often precluded because of the distance from service providers. Telehealth appears to be a viable option for providing services to a broader number of girls with this syndrome, and the effectiveness of this approach is currently being studied. Dr. Call is conducting a 10-week (2-h per week) clinical service funded by a contract from the Georgia

State Department of Behavioral Health in which highly trained behavior consultants coach care providers in real-time via telehealth regarding how to conduct behavioral assessment and treatment procedures with children who engage in severe problem behavior (N. Call, personal communication, March 18, 2015). This service is an extension to already established services at the Marcus Autism Center in which in-person behavioral assessments and treatments are conducted in the clinic, homes, and community. With the in-person services, travel is constrained to a 50-mile radius. Thus, telehealth appears to be a viable option for expanding these established services to individuals and families across the state of Georgia.

Across all of these research and clinical endeavors, results to-date have been positive for behavior analytic training and supervision of staff and care providers and for direct intervention provided via telehealth. Similarly, positive results have been achieved in other healthcare disciplines, with the combined results supporting the continued use and evaluation of telehealth services. Based on this review and our own results, we make the following practice recommendations.

Practice Recommendations

Although telehealth provides a variety of benefits including increased access and efficiency of services, it is our impression that telehealth may not be beneficial or best practice in all situations. For example, a few children in our clinic-to-home telehealth project engaged in a level of problem behavior that was deemed unsafe for remote evaluation and treatment. In these cases, the behavior consultants felt more comfortable providing the services in vivo where they could physically help control the situation. Thus, service provided via telehealth was discontinued, and in vivo services were initiated. Similarly, we have struggled to obtain satisfactory treatment results with children whose problem behavior is maintained by automatic reinforcement. To match children to the treatment most likely to be effective, we provide a step-by-step decision tree of issues to consider when choosing between service delivery models. If telehealth is the chosen service delivery model, we provide a step-by-step checklist of recommendations for practitioners to consider when determining the equipment needs, determining the initial setup of the service, and determining the service's procedures. These recommendations are based on the collective experiences from our projects, our colleague's publications and current projects, and the literature we have reviewed. In addition to our recommendations, we suggest that the reader also reference the American Telemedicine Association's guidelines for video-based online mental health services (2013) as they provide additional clinical, technical, and administrative guidelines.

Choosing Between Service Delivery Models

The selection of the most appropriate model of care can be facilitated by using a series of initial questions to ask when choosing between the in vivo (in-clinic or in-home), clinic-to-clinic, and clinic-to-home service delivery models. These questions are illustrated in Figure 22.3 to assist with decision-making.

1. Is the presenting problem one that can be assessed and treated safely via telehealth? For example, we frequently assess and treat severe forms of self-injury maintained by automatic reinforcement or conduct extinction procedures as part of a treatment package that may induce more severe forms of problem behavior. In these cases, judgment by a highly trained behavior consultant is required to maintain the safety of the child and care providers, as studies have not been conducted on the feasibility and effectiveness of providing service for these issues via telehealth.
2. Is accessibility to equipment and an internet connection with the remote site sufficient? Some families do not have access to equipment that is suitable for telehealth and some rural locations continue to have inadequate internet connections. Additionally, most

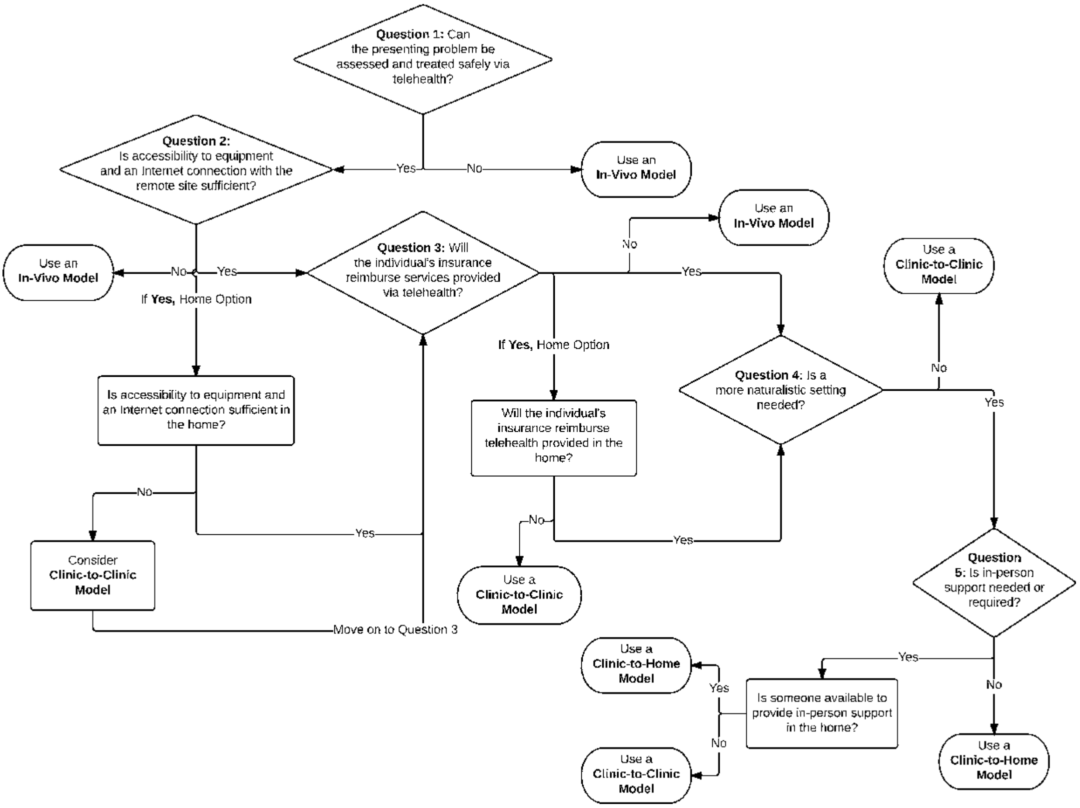

Fig. 22.3 A decision-making model for choosing between service delivery models

telehealth services do not have the capability of providing computer equipment or paying for internet service. For this reason, we are developing an equipment lending program within the CDD.

3. Will the individual's insurance reimburse for services provided via telehealth? Insurance reimbursement may depend on whether the telehealth setting is an approved site. Often, home settings are not considered approved sites. However, insurance reimbursement is continuously evolving so it is important to keep up to date on the current state of telehealth reimbursement.
4. Is conducting the assessment and treatment in a more naturalistic setting such as a home beneficial? One benefit of our in-home projects compared to the clinic projects was that parents did not have to generalize the treatment procedures to their home because they were already being trained within that environment on how to respond to their children's problem behavior.
5. Is in-person support needed or required? Is someone available to provide in-person support (e.g., direct service provider, family member, neighbor) in the home? In behavior analysis, some services such as discrete trial training include a direct service provider conducting the procedures in vivo, whereas other services such as assessments and treatments for problem behavior may only need someone to provide childcare to siblings. Additionally, in-person support may be beneficial for such situations as those described above, making telehealth a feasible option if problem behavior becomes severe and warrants additional in-person support.

Step-by-Step Checklist of Recommendations for Practitioners

After determining that telehealth service delivery is most appropriate, several steps warrant consideration when developing the service. Within these steps, we provide areas for consideration and additional tips or questions to ask when developing a telehealth service. This checklist is summarized in Table 22.3. Specifics of these recommendations will depend upon the type of service provided via telehealth. For example, if only face-to-face consultation is provided, a wide-angle camera is not necessary. In contrast, a wide-angle camera is necessary for services that attempt to capture large motor movements such as a child running around a room.

Step One: Determining Equipment Needs

Consider what equipment is needed to achieve adequate audio and video quality for both telehealth sites (host site and remote site). Is the remote site required to have equipment (e.g., computer, tablet, smartphone) or will the host site maintain an equipment lending library? Are Ethernet cables needed? Are external webcams or wireless cameras needed? Is Bluetooth® technology needed for audio communication? What videoconferencing software will be used? Please see Lee et al. (2015) for specific equipment recommendations.

1. Consider what internet service plans and connections are needed. Is the remote site required to have an internet connection or will the host site pay for the service? What are the optimal bandwidth speeds needed to obtain the audio and video quality desired? This is likely to depend on the purpose of the telehealth service (e.g., consultation versus assessment) and the videoconferencing software being used.
2. Familiarity with the equipment and programs is needed to troubleshoot general technology problems with the audio and video inputs for both telehealth sites. Is an IT support person needed? IT support will likely be needed

Table 22.3 A checklist of recommendations for practitioners when developing a telehealth service

Steps	Consideration	Additional tips/questions
Determining Equipment Needs	1. Equipment needs to achieve adequate audio and video quality for both sites	• Is the remote site required to have equipment or will the host site provide it? • Are Ethernet cables needed? • Are external webcams or wireless cameras needed? • Is Bluetooth® technology needed? • What videoconferencing software will be used?
	2. Internet service plans and connections needed	• Is the remote site required to have an Internet connection? • What are the optimal bandwidth speeds for the desired audio and video quality?
	3. Familiarity with the equipment and programs to troubleshoot general technology problems	• Is an IT support person needed?
	4. Other issues related to equipment	• Does the equipment and software programs need to maintain confidentiality? • Is recording software needed to capture the telehealth session? • Does the service provider need the ability to move the camera remotely? • Will firewall systems block the connection? • Is overall cost a concern?

(continued)

Steps	Consideration	Additional tips/questions
Determining the Initial Setup of Telehealth Service	1. Initial technology meeting to learn how to use, test, and troubleshoot any initial problems with the equipment	• Are task analyses of how to connect with the host telehealth site necessary?
	2. Logistics of providing telehealth	• What room will be used for the telehealth visits?
		• Does the room chosen, maintain safety of all individuals present?
		• Does the room chosen provide enough space for the purpose of the telehealth visits?
		• Docs the room chosen provide sufficient Internet connection?
		• Does the room chosen provide access to or limit materials?
		• Can the room be used consistently for telehealth visits?
		• Is there a place in the room for the equipment for maximum viewing abilities?
	3. Who will be involved in visits	• Can the same person be available for weekly visits?
		• Is a support person needed to run interference with siblings, etc.?
		• Is a support person needed during the procedures?
	4. Meeting prior to beginning procedures to set up room and orient to the service	• What needs to be removed (i.e., dangerous items), setup (i.e., play and work areas)?
		• Where should the webcam be placcd webcam to obtain the best view of the room?
		• What general procedures should be discussed for subsequent telehealth visits?
	5. Developing a plan for connecting	• Who should initiate the telehealth contact?
		• What are the procedures and who is responsible if the telehealth contact is not made?
		• What procedures should occur when the Internet connection is lost during a visit?
	6. Benefits of an initial in-person meeting	
Determining the Telehealth Service's Procedures	1. Preparing for a visit	• What abilities does the practitioner need to successfully conduct telehhealth visits?
		• What data collection procedures need to be conducted?
		• What are the goals of the visit?
		• How many sessions need to be conducted?
		• What types of conditions need to be conducted?
		• What materials does the practitioner need?
		• What precautionary measures need to be considered?
		• What termination criteria need to be developed?
	2. Starting a visit	• Docs check-in with the individual need to occur?
	3. Procedures during a visit	• Describe general procedures to the parents prior to the start of each session.
		• Try to avoid deviating from the protocol or procedures while conducting sessions.
		• Keep calm if technology problems arise during the telehealth visit.
		• Provide the individual with immediate praise and feedback during sessions.
		• Provide more detailed feedback at the end of the sessions.
		• Be one step ahead of the individuals during the session.
	4. Procedures at the conclusion of a visit	• At the end of the telehealth visit, briefly review results, describe what to expect in subsequent visits, and describe any homework needed.
	5. Follow-up procedures	• Send an e-mail with updates on results and reminders of upcoming visits

when initially starting the telehealth service and for troubleshooting more significant technology problems.

3. Consider other issues related to the equipment. Do the equipment and software programs need to maintain confidentiality to comply with HIPAA and FERPA compliance rules? Is recording software needed to capture the telehealth session? Does the service provider need the ability to move the camera remotely? Will firewall systems block or slow the connection? Is overall cost a concern?

Step Two: Determining the Initial Setup of Telehealth Service

Several recommendations are provided when initially setting up a telehealth service. Many of these recommendations can be combined into one or two meetings with participants at the remote site.

1. Consider having an initial technology meeting with the individual to help them learn how to use, test, and troubleshoot any problems with the equipment. Are task analyses of how to connect with the host telehealth site necessary?
2. Consider the logistics for providing the telehealth service to the remote site. What room will be used for the telehealth visits? When working with children, it is often helpful to have a room that can be closed to prevent the child from eloping from the room. Other specific questions to consider include the following. Does the room chosen maintain safety of all individuals present? Does the room provide enough space for the purpose of the telehealth visits? Does the room provide sufficient internet connection speeds to support optimal audio and video streams? Does the room provide access to materials needed for the visits, and limit access to materials in need of restriction? Can the room be used consistently for telehealth visits? Is there a place in the room for the equipment to be placed to maximize viewing capabilities?
3. Consider who will be involved in the telehealth visits. Can the same person be available for weekly visits? Is a support person needed to supervise siblings, etc.? Is a support person needed during the procedures?
4. Consider having a meeting with the individual to set up the room and orient them to the telehealth service. What needs to be removed (i.e., dangerous items) and set up (i.e., play and work areas)? Where should the webcam be placed to obtain the best view of the room? What general procedures (e.g., expectations, individual roles) should be discussed for subsequent telehealth visits?
5. Develop a plan with the individual regarding the telehealth connection. Who should initiate the telehealth contact? What are the procedures and who is responsible if the telehealth contact is not made within a specified time period? What procedures should occur when the internet connection is lost during the telehealth visits? It is often helpful to exchange phone numbers so that both parties can communicate with each other in case technology problems arise at the start of the telehealth visit or if the internet connection is lost and cannot be re-established while conducting telehealth sessions.
6. Consider whether an initial in-person meeting is beneficial.

Step Three: Determining the Telehealth Service Procedures

1. Consider the necessary steps for preparing for a telehealth visit. This preparation is very important for making the telehealth visit go smoothly. What abilities does the practitioner need to possess to conduct telehealth visits successfully? What data collection procedures (e.g., live recording, recorded and scored later) need to be conducted? What are the goals of the visit? Specifically, how many sessions need to be conducted? What types of conditions need to be conducted? What materials does the practitioner need? What precautionary measures need to be considered? What termination criteria need to be developed?
2. Consider the procedures conducted at the start of a telehealth visit. Does check-in with the individual need to occur? Check-in may consist

of asking about how things have been going since the last visit, summarizing the results to date, and summarizing the objectives for the visit. This may be beneficial in building rapport with an individual, especially if an in-person introduction did not occur.

3. Consider the procedures to be conducted during the telehealth visit. Describe general procedures to the participants prior to the start of each session so they understand what they need to do. The directions should be simple and clear for parents to understand. Avoid using jargon. Try to avoid deviating from the protocol or procedures while conducting sessions. Making several procedural changes during the telehealth visits will likely make the visit seem more chaotic. Keep calm if technology problems arise during the telehealth visit. Make the decision if the session will continue despite the technology problems, or if the session needs to be stopped to address the technology problem before continuing on with the visit. Provide the individual with immediate praise and corrective feedback during the sessions. These phrases should be brief to avoid disrupting the parents from conducting the procedures. Provide more detailed feedback at the end of the sessions to help parents learn how to implement the procedures differently in subsequent sessions. Be one step ahead of the individuals during the session. This may involve giving warnings about upcoming procedures, helping them keep track of where the materials are placed in the room, and instructing on where to position themselves and the child.
4. Consider the procedures conducted at the conclusion of the visit. At the end of the telehealth visit, briefly review results from the current visit, describe what the parents should expect to do in the subsequent visit, and describe any homework that needs to be completed prior to the next visit.
5. Consider the follow-up procedures. For example, an email may be sent with an update on the results to date and a reminder of the date and time of the upcoming visit.

Summary

Telehealth can be an effective service delivery model for a variety of concerns that traditionally have been addressed in-person by professionals in their clinic offices or classrooms. Telehealth provides an alternative to this in-person model with the greatest benefits including increased access and efficiency and decreased costs. Although telehealth can be effective and feasible, it is unlikely that telehealth will replace traditional in-person models. Rather, telehealth can serve as a supplement to traditional service models or as an alternative service option when both traditional and telehealth models are equally effective. Given that these models are all reasonable options for delivery of behavioral services, it becomes imperative that practitioners weigh the benefits and challenges when choosing a service delivery model. Similarly, it is important for researchers to continue evaluating the conditions under which telehealth is most effective in order to inform clinical decision-making in practice.

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Skills Training for Parents with Intellectual Disabilities

23

Maurice A. Feldman and Munazza Tahir

Introduction

This chapter presents an evidence-based approach for the assessment and training of parenting skills in persons with intellectual disabilities (ID). Note that the formal diagnostic term, “intellectual disabilities” is used throughout this chapter, but we also include parents with borderline intellectual and cognitive difficulties, because much of the literature includes parents with IQs between 70 and 80. Research clearly shows that parents with ID can improve child-care skills and parent–child interactions through behavioral skills training with corresponding benefits to their children (Feldman, 1994; Wade, Llewellyn, & Matthews, 2008). Nonetheless, parents with ID are at increased risk of having their children removed from the home because of concerns, justifiable or not, of the potential for child maltreatment, particularly child neglect (Booth, Booth, & McConnell, 2005; Llewellyn, McConnell, & Ferronato, 2003; McConnell, Aunos, Feldman, & Prasad, 2011; Taylor et al., 1991). As a group, their children may be at risk for developmental, behavioral, and school problems (Feldman & Walton-Allen, 1997/2002), although many children fare well (Collings & Llewellyn, 2012; Granqvist, Forslund, Fransson, Springer, & Lindberg, 2014). Ineffective parenting skills training could lead to the removal of the child, as it is often assumed that because of the parent’s ID, he/she is incapable of benefiting from training, rather than that the training was not effective (Feldman & Aunos, 2010). Therefore, it is incumbent upon the parent trainer to accurately identify skills in need of improvement and then utilize efficacious interventions to reduce risk of child maltreatment and the breakup of the family. Indeed, parent education interventions using behavioral skills training, as described in this chapter, have been associated with substantial decreases in child removal from the home concomitant with objective increases in parenting skills (Feldman, Case, & Sparks, 1992; Feldman, Sparks, & Case, 1993). This chapter provides an overview of the rationale and description of the most researched and established program for parents with ID—the Step-by-Step parenting assessment and training model (Feldman, 1998; Feldman & Case, 1993), presents research supporting this and similar models, and ends with practice recommendations.

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Contextual Model

While the focus of this chapter is parenting skills training, it is important to recognize that many contextual factors, besides training techniques used, may influence parenting behaviors and response to intervention (Feldman, 2002; Feldman & Aunos, 2010). The contextual model (called a "parenting interactional model" in our previous work, Feldman, 2002; Feldman & Aunos, 2010) underlies the Step-by-Step approach. The model incorporates ecological (Belsky, 1993; Bronfenbrenner, 1989) and behavior analytic principles (Cooper, Heron, & Heward, 2007) to identify internal and external factors affecting parenting behaviors and the most effective way of measuring and teaching parenting skills. A parent trainer working with parents with ID should consider these contextual variables when designing assessment and intervention plans.

Behavior does not occur in a vacuum. In order to understand why some parents lack parenting skills or appear not to cooperate with services, it is crucial to determine the specific "context" or ecological niche within which each family is functioning (Belsky, 1993; Bronfenbrenner, 1989). Context refers to a combination of the current events/experiences that surround that individual and the past history of that individual (Morris, 1988). To understand current (parenting) behavior, an ecological perspective pinpoints risk and resilience variables while a behavior analytic perspective identifies motivating operations that have reinforcer value-altering and behavior-altering effects (Michael, 2000). Motivating operations indirectly increase (establishing operation) or decrease (abolishing operation) frequency of certain behaviors due to their influence on the effectiveness of a reinforcer (Michael, 2000). Wahler (1980) provides an elegant example of the impact of contextual influences on parenting behavior. He found that the insular mothers were more likely to follow a behavioral program for their children if the mothers had positive interactions with friends earlier that day (establishing operation) and less likely to follow the program when they had negative interactions with family or workers (abolishing operation).

As elucidated in the interactional model presented in Feldman (2002) and Feldman and Aunos (2010), contextual factors influencing parenting behaviors and response to interventions include (but are not limited to): parental history (e.g., childhood abuse and trauma, stigmatization, parenting role models, prior experience with childcare); socioeconomic status; spousal and social support; housing; number of children in the home; current life crises; parental and child health and well-being; child behavior; and access and effectiveness of needed services. These contextual variables have been shown to impact parenting and child outcomes in the general parenting literature (Wade, Llewellyn, & Matthews, 2011) and evidence is accumulating that these factors also influence parenting abilities of parents with ID, response to intervention, and child and family outcomes (Aunos, Feldman, & Goupil, 2008; Emerson & Brigham, 2013, 2014; Feldman, McConnell, & Aunos, 2012; Feldman, Varghese, Ramsay, & Rajska, 2002; Feldman & Walton-Allen, 1997/2002; Granqvist et al., 2014; McConnell, Aunos, et al., 2011; Mildon, Wade, & Matthews, 2008; Wade et al., 2011). The contextual model should inform the parent education assessment process so that it includes examining records, conducting interviews and administering questionnaires to identify possible factors that may impede or support successful parenting, response to intervention and child outcomes in a given family (Feldman & Aunos, 2010). For instance, if it is found that a parent has depression, it may be necessary to treat the depression first, before starting parent training.

Objective Evaluation of Parenting Skills

Gathering contextual information to identify variables influencing parenting behaviors is only part of a comprehensive parenting assessment as exemplified in the Step-by-Step model (Feldman & Aunos, 2010). As a behavior analytic approach emphasizes, it is crucial to objectively measure current parenting behavior through direct, naturalistic observations to identify risk to the child, select intervention targets and evaluate intervention results. It is all too commonplace to see child welfare parenting assessment reports in which the assessor did not operationally define and observe specific parenting behaviors that are putting the child at risk (Budd, Pointdexter, Felix, & Naik-Polan, 2001; Feldman & Aunos, 2010). Failure to specify and measure objective intervention targets makes it difficult to evaluate if the parent's behaviors actually improved with intervention; subjective impressions and biases may lead to permanent removal of the child in the absence of objective measurement of response to intervention (Booth et al., 2005; Llewellyn, McConnell, & Ferronato, 2003). Therefore, evidence-based parent training for parent with ID should include direct observation of parenting skills through the use of task analysis and other observational checklists (e.g., Feldman & Case, 1993; McGaw & Sturmey, 1994).

Parenting Skills Checklists

Objective observation of parenting skills is facilitated with the use of task analysis checklists that operationally define the whole skill through clear descriptions of its components (Feldman & Case, 1993; available from the first author). For instance, the Step-by-Step checklists were developed over many years and cover basic child-care (e.g., handling a newborn, diapering, feeding, bathing); health (e.g., treating diaper rash, providing nutritious meals; emergency first aid; when to call the doctor); home safety (e.g., identifying and removing hazards that can cause a child to choke, fall, be poisoned, electrocuted); and parent–child interactions (e.g., talking to, playing with, cuddling and praising the child; imitating and expanding child vocalizations) appropriate for newborn to 3 years. The checklists were reviewed by pediatric health care professionals and revisions were made based on their feedback. Through many published single case replications, the checklists have been shown to have good test-retest reliability (i.e., baseline stability) and acceptable interobserver agreement with trained observers (e.g., Feldman, Case, Garrick, et al., 1992; Feldman et al., 1986; Feldman, Case, Rincover, Towns, & Betel, 1989). The checklists differentiate parents for whom there are concerns about parenting from those for whom there are no concerns (Feldman, 1998) and are sensitive to treatment effects (e.g., Feldman, Case, Garrick, et al., 1992; Feldman, Case, & Sparks, 1992; Feldman, Ducharme, & Case, 1999; Feldman et al., 1993). See Table 23.1 for an example of a Step-by-Step task analysis checklist.

Table 23.1 Example of a Step-by-Step task analysis checklist (adapted from Feldman & Case, 1993)

Bottle feeding
1. Gets a full bottle and a towel.
2. Tests the temperature of the formula on her wrist.
3. If the formula is cold, puts the bottle in a pan of hot water for 2 min. Tests again.
4. If the formula is too warm, puts the bottle in a pan of cold water for 2 min. Tests again.
5. Tests the nipple flow by tilting the bottle down on her hand.
6. Replaces nipple if it flows too fast or too slow.
7. Goes to a comfortable, quiet place for feeding.
8. Sits down and cradles the baby so that her head is higher than her tummy. Does not prop the bottle.
9. Gently puts the nipple into the baby's mouth.
10. Tilts the bottle so that the nipple is always filled with formula.
11. If the baby coughs or chokes, immediately stops feeding and sits her up.
12. Pulls the nipple out a little sometimes to help the formula flow.
13. When the bottle is half empty, stops feeding and burps the baby.
14. Holds the baby and begins feeding again.
15. Stops feeding when the baby turns away, spits out milk, and refuses to take the nipple when trying a few more times.
16. Does not force the baby to drink any more.
17. Burps the baby again.
18. Throws out leftover formula.
19. Talks, sings, and cuddles the baby during and after the feeding.

Observing Skills

Prior to starting the skills assessment, it is important to consider contextual factors as described above. Then the parent educator should focus on developing trust and rapport with the parent.

The parent educator should be clear as to the purpose and nature of the observations and training, as many parents with ID are suspicious of all workers being "spies" for child protection services. The parent educator should work on establishing rapport by being empathic and nonjudgmental, showing interest in supporting the family and focusing on success.

To obtain as natural observations as possible, it is recommended to initially spend a "day in the life" of the family to observe a wide range of skills to determine parenting strengths and skills in need of training. This more extensive observation should be followed up with several shorter home visits to obtain more baseline observations on specific skills likely in need of training. The observer explains to the parent that he/she will be passively observing as the parent goes about caring for the child. The observer avoids telling the parent what to do unless there is a skill that the observer needs to see that the parent may not do during the observation. The observer does not interfere unless the child is in potential danger—e.g., the parent has not checked the temperature of the bath water; the parent walks away leaving the baby on an elevated change table. The observer tells the parent that it is understandable that the parent may be nervous being observed. However, we have found that many parents with ID see the observations in a positive light: as an opportunity to show others (especially child protection workers) how capable they actually are as parents.

Making Sense of the Scores

The checklist scores are summarized as percentage steps performed correctly (or percentage intervals for parent–child interaction observations using partial interval recording). The checklists often represent ideal performance because they were created based on input from healthcare professionals. To come up with realistic criteria to determine if a parent was in need of training on a particular skill and set training objectives, it was necessary to collect data on the performance of parents without ID for whom there were no parenting concerns. Feldman (1998) presents some of these results, as do specific research studies (e.g., Feldman et al., 1989, 1993). Based on Feldman's (1998) findings, the Step-by-Step program generally sets training criterion at 80 % for the task analysis checklists and 30 % of intervals for the parent–child interaction checklists.

Reviews of Parent Training Research Studies

Before describing the specifics of evidence-based parent education for parents with ID, it is worthwhile to summarize the state of knowledge in the field by providing an overview of literature reviews on this topic. In the first such review, Feldman (1994) reviewed 20 parent education studies using group and single-case designs that included direct behavioral measures of parenting behaviors of parents with ID. In total, there were 190 parents (188 mothers, 2 fathers) with IQs ranging from 50 to 79; the majority of studies were with preschool or younger children. Across the studies, several skills were targeted for increase, including basic child-care tasks, nutrition, home safety and emergency training, behavior management for child problem behaviors and positive parent–child interactions. Using visual inspection of graphed data with acceptable interobserver agreement, Feldman (1994) found that parent training generally led to positive changes in parenting skills that were maintained over varying follow-up periods. Feldman (1994) concluded that skill-focused, home-based and individualized parent education programs seem to be the most effective in teaching parents with ID new skills. Feldman (1994) recommended that future intervention research study parenting skill generalization and child outcomes.

Wade et al. (2008) updated Feldman (1994) with eight new studies. Wade et al. (2008) confirmed Feldman's (1994) conclusions that skill-focused, home-based programs using behavioral skills training were the most effective in teaching skills to parents with ID. Some new research developments reviewed by Wade et al. (2008)

include self-directed training for teaching parents basic child-care skills (Feldman & Case, 1997, 1999; Feldman et al., 1999) as well as a new randomized controlled trial (RCT) on effective home safety training (Llewellyn, McConnell, Honey, Mayes, & Russo, 2003). Wade et al. (2008) echoed Feldman's (1994) call for more research on generalization and child outcomes. Wade et al. (2008) highlighted the importance of assessing each family's specific context to inform intervention decisions (Mildon et al., 2008).

Coren, Hutchfield, Thomae, and Gustafsson (2010) narrowly reviewed only randomized and quasi-randomized studies. They arbitrarily excluded RCTs focused on improving parent–child interaction (Feldman et al., 1993; Slater, 1986) and single-case experimental designs (e.g., Feldman, Case, Garrick, et al., 1992). They only found three RCTs that meet their overly strict inclusion criteria and concluded that intervention effects were moderate at best. They ignored the majority of training studies that used single-case experimental designs as they admitted not being aware of how to synthesize single-case experimental studies. Such methods are well established and used frequently in meta-analyses of single-case experimental studies (Ma, 2006; Scruggs & Mastropieri, 2001). By ignoring the bulk of training research in this field, the Coren et al. (2010) conclusions should be seriously questioned. Knowles, Machalicek, and Van Norman (2013) reviewed 14 published studies between 1994 and 2012, and included new research such as contextually informed intervention for parents with ID (Mildon et al., 2008), social support programs for parents (McConnell, Dalziel, Llewellyn, Laidlaw, & Hindmarsh, 2008), and modification of the "Triple P" training program for parents with intellectual disabilities (Glazemakers & Deboutte, 2012). Knowles et al. (2013) discussed the findings of the reviewed studies in behavior analytic terms. They recommended that future studies include more finely tuned operational definitions of parent behavior and program for generalization by transferring stimulus control of verbal/pictorial cues to environmental cues (such as the smell of a dirty diaper) and train parents to meet the dynamic needs of growing children and adolescents. Wilson, McKenzie, Quayle, and Murray (2014) reviewed seven studies since 1999. They, like Coren et al. (2010), showed a bias against "less controlled" (p. 9) single-case experimental designs, although these designs are recognized in defining empirically supported interventions (Chambless & Hollon, 1998). Despite the flaws and narrowness of this review, Wilson et al. (2014) generally agreed with previous reviews that behavioral approaches are the interventions of choice, but more research is needed.

Although intervention research on parents with ID has slowed in the past few years, the literature published to date builds a strong case for the evidence base of skill-focused programs framed within applied behavior analysis. Looking at all the research since 1986 that used some kind of experimental design (between-group or single-case), we conclude that behavioral interventions for teaching parenting skills for persons with ID meet the Chambless and Hollon's (1998) criteria for empirically supported interventions and the American Psychological Association's (2005) guidelines on evidence-based practice. That is, the current literature on training parenting skills to parents with ID includes five randomized clinical trials across four independent research teams (Feldman, Case, & Sparks, 1992; Feldman et al., 1993; Keltner, Finn, & Shearer, 1995; Llewellyn, McConnell, Honey, et al., 2003; Slater, 1986) and numerous independent replications using single-case experimental designs (e.g., Bakken, Miltenberger, & Schauss, 1993; Feldman et al., 1986; Tymchuk, Andron, & Rahbar, 1988) using similar behavioral skills training methods.

In summary, available evidence suggests that effective parent training for parents with ID should be done in the natural setting where the parents actually must use the skills (as opposed to a classroom), be individualized (as different parents have different skill training needs), skill rather than knowledge focused (saying does not equal doing, Bakken et al., 1993), gradually increase demands (initially focus on one clearly defined skill and then gradually add training on additional skills) and offer concrete behavioral skills training rather than didactic instruction

(Feldman, 1994; Wade et al., 2008). Behavioral skills training for parents with ID consists of, task analysis (checklists), simple instructions, audiovisual materials, modeling, prompting, roleplaying, performance feedback, positive reinforcement, and maintenance and generalization strategies (Feldman, 1994; Knowles et al., 2013; Wade et al., 2008). The section below and Table 23.2 describe specific intervention strategies, followed by an illustrative case study and practice recommendations.

Specific Parent Training Components

Task Analysis. Parents with ID appear to learn better when complex skills are broken down into smaller steps. The Step-by-Step task analysis checklists were described above. Not only are they useful in conducting baseline assessments of current skill levels, but also the checklist observations allow the trainer to focus on specific skill components in need of training.

Instructions. Instructions should be simple and concrete. Verbal instructions should include basic rationales for why it is important for the parent to perform the skill—e.g., "It is important to copy your child's words because that is how she will learn to talk." However, even if the parent seems to understand the reason and importance to perform the skill, this knowledge will not necessarily translate to improved and sustained skill performance (Bakken et al., 1993; Feldman et al., 1989). Direct verbal instructions to perform a skill are not likely to be successful (Feldman et al., 1989). Workers may interpret a failure to follow instructions as the parent being uncooperative and be more likely to remove the child (McConnell, Feldman, Aunos, & Prasad, 2011).

Audiovisual materials. To supplement verbal instructions, posters and self-monitoring charts can be used that the parent can put on the wall or fridge—e.g., pictures of nutritious foods that the parent could check off when provided to the child (Feldman, Garrick, & Case, 1997). To improve the parent's ability to recognize, and appropriately prevent and respond to childhood ailments and dangers, they could be given drawings of children suffering from common illnesses (e.g., fever) and accidents (e.g., cuts, burns), as well as household hazards (e.g., no gate on stairs, medicines within reach of child). Feldman and Case (1993) created picture books with drawings of each step of the task analysis alongside simple text (<6th grade level) describing the picture (an example of one page of a Step-by-Step picture book is found in Fig. 23.1). Through pilot testing, parents preferred and better understood simple line drawings (tracings of photographs) as opposed to color photographs (Feldman, 2004a). In this manner, irrelevant stimuli were removed so that the parent could focus on the pertinent items in the picture. Initially, the parent would read the book, describe the pictures, and answer comprehension questions. The parent would receive correction of oral reading and comprehension errors. Parents who had difficulty following the book were provided an audiotape or file that had a voice describing each step/picture that the parent could listen to on a portable tape or mp3 player while reviewing the hard copy picture book. The picture books were originally designed as memory aides to supplement full training, but many parents learned and maintained skills simply through using the audio visual materials as self-directed learning tools (Feldman, 2004a).

Modeling. Prior to the parents practicing the skill, the parent watches a trainer demonstrating the skill, either with the child or through roleplaying. During modeling there is a focus on specific steps that the parent missed in the checklist baseline assessment. Sometimes a brief model of a particular step is given in the midst of the parent practice if the parent performed the step incorrectly or did not do it. To capture the parent's attention, modeling may be exaggerated (e.g., over the top enthusiastic praise to the child). A video can be made of the demonstration to leave with the parents to review at their leisure (Glazemakers & Deboutte, 2013; Mildon et al., 2008).

Prompting. Least-to-most prompting is used as necessary while the parent is practicing. Brief verbal prompts and gestures/points are tried first.

Table 23.2 Task analysis of instructions for how to provide full behavioral skills training to teach parenting skills to parents with ID

1. Call in advance of leaving for the scheduled home visit to make sure parent is home.
2. Be prepared—bring checklists, materials, props needed.
3. Build rapport—start with positive (but short) comment or conversation (“Is that a new outfit? She looks adorable in it.”).
4. Give simple rationale for why the skill needs to be trained (e.g., “It is important to sterilize the baby bottles because it kills the germs that could make your baby sick”); Try to relate to parent’s life experience (e.g., “Don’t you feel good when someone tells you that you are doing a good job? Your child likes to hear your praise, too.”).
5. Use checklists that break down the skill and directions into specific and concrete steps/components.
6. Conduct at least one baseline observation by recording skill performance before starting training to determine overall percentage correct and which steps need training.
7. Only train one skill at a time to start. Gradually add more skills training in a session, if the parent can handle it.
8. When starting training on a skill, give simple and clear instructions.
9. Question the parent to ensure comprehension of instructions or explanations.
10. Initially focus on and praise what the parent is doing correctly (e.g., “I really like how you are serving your child some peas; that’s a healthy choice.”)
11. Gradually intersperse non-judgmental, but specific corrections (e.g., “Don’t forget to clear in the creases when wiping the baby’s bottom.”).
12. Try to give at least three positive feedback statements to every one corrective statement.
13. Provide correction within 5 s of an incorrect or missed step.
14. Give accurate and consistent feedback in a constructive manner.
15. Use one or more of the following prompting techniques in training as needed: (a) verbal instructions, (b) modeling, (c) roleplaying, (d) physical guidance, and (e) permanent prompts—e.g., Step-By-Step picture books and audio (Feldman & Case, 1993), posters, daytimers.
16. Record which prompt was needed for which step on the checklist.
17. Model missed steps, and explain while modeling, as needed (e.g., “Watch me copy him when he says a word; that will help him learn to talk.”).
18. Then allow parent to try again as soon as possible after the model.
19. Ask parent to practice several times.
20. Debrief parent within 1 min of task completion.
21. During debriefing, point out what the parent did correctly (“I really like the way you remember to praise him.”), and then focus on what the parent should be practicing, rather than dwelling on errors (“Remember to repeat his words.”).
22. Program for generalization—remind parent to use skills whenever and wherever needed (e.g., “Don’t forget to praise your child for good behavior wherever you are.”).
23. Program for generalization—conduct training in different rooms and outside, as appropriate.
24. Check maintenance of previously learned skills using the observational checklists. Gradually fade observations of mastered skills, if maintaining at mastery criterion.
25. End visit on a positive note about the parent’s performance (e.g., “You got more steps correct today on the home safety checklist. I see you remembered to put all medications in a locked cabinet—bravo!”).
26. Call between visits to remind parent to practice skill, if necessary, and the schedule for the next visit.

GIVING YOUR BABY A BOTTLE

1. Get a full baby bottle and a towel.

   The towel is for spills and burping.

2. Test the formula on your wrist.

   It should feel like your skin, not too warm or cold.

Fig. 23.1 An example of one page of a picture book from Feldman and Case (1993)

If these do not work, then modeling is added. Hand-over-hand prompting rarely is needed. The Step-by-Step checklist form allows for indicating level of prompting required for each step so that the prompt fading can commence at the next training session. For instance, if in a diapering training session, the trainer advised the parent, “Don’t forget to clean in the creases,” (a step many parents forget to do) while also pointing, the next time if the parent still does not clean in the creases, the trainer may say “creases,” or just point.

Roleplaying. Sometimes, roleplaying is used before the parent actually practices the skill with the child. This is particularly the case when working on behavior support strategies with parents who have older children who may be quite reactive to seeing their parents being trained (Tahir, Sword, & Feldman, 2015). We also roleplay when it is not feasible to involve the child—e.g., how to respond when the child has ingested poison. To promote generalization to the child, roleplaying could make use of life-like dolls, fake blood and vomit to make the roleplays as real as possible. The parents roleplay calling the emergency response number with the trainer playing the role of the operator (after having acquired the operators’ script).

Performance feedback. The parents receive immediate verbal feedback for correct and incorrect responses. Initially, a high ratio of positive to corrective feedback is provided. As parents with ID typically achieve about 60–70 % of steps correct in baseline (Feldman, 1998), it is usually not difficult to find parenting behaviors to praise even at the start of training. Given their lifelong history of being belittled and failure, many parents with ID are very sensitive to corrective feedback and tend to avoid the person providing it. As the parents develop a trusting relationship with the trainer, they are more receptive to corrective feedback, but the trainer should still provide more positive to corrective feedback even when parents are open to correction. As the parent masters the skills, the amount of feedback is reduced, until it is just provided upon completion of the task. Although much of the published research has evaluated verbal feedback, a recent RCT examined video feedback intervention to teach parents with ID how to provide "sensitive discipline" to their children (Hodes, Meppelder, Schuengel, & Kef, 2014). Although no overall group differences were found for the video intervention versus usual care based on observational rating scales, there were significant decreases in the parents' stress and some observable changes in parenting skills in the training group.

Positive Reinforcement. In addition to positive feedback (usually in the form of specific praise), trainers should help parents identify natural contingencies of reinforcement, e.g., "You see how your child is saying words better since you started copying his words?" (Stokes & Baer, 1977). Several Step-by-Step studies have used tangible reinforcers in the form of parenting coupons (e.g., Feldman et al., 1986; Feldman, Case, Garrick, et al., 1992). The coupons are exchangeable for small gift items for the child or the parent (e.g., toys, gift certificates at local shops, transit tickets). The parent could cash them in immediately or save up for a more expensive item (e.g., stroller). Initially the parent earns coupons for being home for the pre-training visits. Then as the parent starts training, he/she is given coupons for improved performance. That is, if the parent's mean baseline score on the feeding the child checklist was 50 % and the parent scored 60 % after the first training session, then he/she would receive a coupon. Once the parent reached the training criterion, the parent earned a coupon for maintaining mastery scores. Another form of positive reinforcement provided by child protection (with knowledge of parental performance) was increasing parental access to the child (or reducing surveillance of the parent if the child was still at home) for accomplishing behavioral objectives (Feldman, Case, Garrick, et al., 1992; Greene, Norman, Searle, Daniels, & Lubeck, 1995).

Maintenance strategies. Several intervention studies with parents with ID show persistent training effects, up to 2 years (Feldman, 1994; Wade et al., 2008). As mentioned above, the trainer alerts the parent to natural contingencies of reinforcement to maintain parenting skills when the training is completed. Many parenting skills may be reinforced by their children's more positive reaction to the different approach the parents is taking as a result of training. For example, after training in feeding techniques, parents reported that mealtimes were much more pleasant. Likewise, parents noticed the improvement in their children's language, mood and behavior after the parents increased their positive and stimulating interactions. Maintenance strategies such as fading observations and thinning reinforcement schedules should also be used. For instance, to fade the coupons, Feldman, Case, Garrick, et al. (1992) instituted a lottery in which the parents who maintained the mastery criterion on a follow-up visit would pick numbers between 1 and 6 and then roll a die. If their number came up they won the coupon. The number of guesses they were allowed gradually decreased over visits until the lottery was stopped and the parent no longer received coupons. Although the parents were receiving fewer and fewer coupons, their behavior maintained and they enjoyed the lottery as it gave them a chance to "gamble."

Generalization strategies. Few training studies with parents who have ID have measured generalization; those studies that do so find generalization difficult to obtain (Feldman, 1994;

Knowles et al., 2013; Wade et al., 2008). Generalization strategies such as sufficient exemplars, common stimuli, recruiting natural contingencies of reinforcement and instructions to generalize should be incorporated into training (Feldman et al., 1989; Stokes & Baer, 1977; Tahir et al., 2015). Feldman et al. (1989) demonstrated that while verbal instructions were not sufficient to improve parental positive interactions before full behavioral skills training, simple instructions to generalize ("e.g., "Remember to praise your child whenever she does something you like no matter where you are") were effective to promote setting generalization. Tahir et al. (2015) used several generalization strategies in their positive behavior support training of parents with older children with behavior problems. Tahir et al. programmed for generalization by including multiple exemplar and common stimuli in their game-based training. Numerous scenarios of common child misbehaviors were role-played with the parents in their homes. While the parents did generalize to untrained scenarios, in situ generalization with their children was inconsistent despite being instructed to generalize to real life interactions ("Don't forget to praise your child when he does what you have asked him to do").

Studies that show child improvements concomitant with parent training suggest that the trainer's presence is not a discriminative stimulus for sustained correct performance. Some examples of improvements in the children whose parents have received training includes increased weight gain when parents are taught how to provide nutritious meals and improve feeding techniques (Feldman et al., 1997); elimination of diaper rash (Feldman, Case, Garrick, et al., 1992); and improvement in child language from delayed to average levels (Feldman et al., 1993). Nonetheless, inconsistent generalization results in some studies indicate that more research is needed to identify effective generalization strategies to use with parents who have ID. Perhaps, using a lottery to reinforce setting and person generalization will work as well as it did for maintenance in Feldman, Case, Garrick, et al. (1992).

Training Variations

Group training for personal well-being and social relationships. As described above, contextual models proposed by Feldman (2002) and others (e.g., Wade et al., 2011) highlight the influence of parental well-being and social support on parenting and child outcomes. While most intervention studies have focused on improving parenting skills and parent–child interactions, two studies examined parent groups to improve personal well-being, social engagement and goal attainment in parents with ID (McConnell et al., 2008; McGaw, Ball, & Clark, 2002). Although McConnell et al.'s (2008) intervention was designed following Freire's (1998) adult learning principles and empowerment while McGaw's et al. (2002) was based on cognitive behavior therapy, both teams used similar teaching methods, including self-reflection, visual representations, task analysis, goal-planning, and problem-solving strategies. Results in both studies were mixed, with parents in the training groups showing some improvement in achieving goals and well-being (McConnell et al.), and self-concept and social relationships (McGaw et al.). As neither study used strong experimental designs and relied exclusively on parent self-report, results should be interpreted cautiously. Nonetheless, the preliminary results are sufficiently promising to warrant further research in this area.

Game formats. Three studies have used game formats to teach parent–child interaction skills to parents with ID (Bakken et al., 1993; Fantuzzo, Wray, Hall, Goins, & Azar, 1986; Tahir et al., 2015). The game sessions involved taking turns to draw cards and roleplay specific parenting scenarios. While Fantuzzo et al. (1986) showed improvement in responses during the game, in a systematic replication, Bakken et al. (1993) did not find increases in parenting skills in the home (in situ generalization) until the parent was trained in the home using behavioral skills training (cf., Feldman et al., 1986). (Tahir et al. 2015) found within game generalization (to untrained scenarios), but mixed effects of in situ generalization of parenting skills and in-home child behavior.

Other Services and Supports

Parent education is not a panacea. Families headed by parents with ID often have complex needs. Many parents with ID are socioeconomically disadvantaged with few social supports (Booth & Booth, 2005; Emerson & Brigham, 2013; Feldman et al., 2002; McConnell, Aunos, et al., 2011). Many parents with ID were abused as children and remain vulnerable to exploitation (Aunos et al., 2008; Emerson & Brigham, 2013). Their children are at risk for behavioral and learning problems (Feldman & Walton-Allen, 1997/2002). Thus, comprehensive and coordinated services are needed for the whole family (Aunos & Feldman, 2007; Booth & Booth, 2005). Services for the parent should include not just parent education, but also support for ancillary and personal issues, as needed. These services could include housekeeping and money management; mental health counselling and therapy; social skills, self-advocacy and assertiveness training; academic upgrading; vocational training; building natural systems of support; accessing financial and community resources; and crisis support (Aunos & Feldman, 2007; Booth & Booth, 2003; Lightfoot & LaLiberte, 2006; Llewellyn, McConnell, & Bye, 1998; McConnell et al., 2008; McGaw et al., 2002; Walton-Allen & Feldman, 1991). Depending on the child's age and needs, services for the child could include child protection, visiting nurse, behavior support, early intervention, specialized preschool and academic tutoring (Aunos & Feldman, 2007; Ramey & Ramey, 1992).

Future Research

While intervention studies with parents with ID started being published in the 1980s, there are still many gaps in identifying components of effective interventions, generalization effects, long-term benefits to the parents and children, applications of technology and wide-spread adoption and implementation of evidence-based programs. Future research is needed on the benefits of video modeling and feedback, identifying effective generalization strategies and the long-term maintenance of parenting skills as the child ages. Large-scale parent education program implementation and dissemination studies that include measures of child and family outcomes are needed to influence increased funding of specialized programs to reduce risk of child neglect and unnecessary out-of-home placement of children (McConnell et al., 2014; Starke, Wade, Feldman, & Mildon, 2013).

Case Study

Anne is a parent who participated in the Family Game training program, which is designed for parents with intellectual disabilities who have preschool and school-age children with behavior problems (Feldman, 2004b; Tahir et al. 2015). Anne was a 42-year-old single mother receiving government financial support for having an intellectual disability at the time of training. She lived with her 20-year-old daughter who also had an intellectual disability and her 10-year-old son who was diagnosed with ADHD and Oppositional Defiant Disorder. Anne participated in the Family Game program due to behavioral challenges she was facing with her son, specifically noncooperation with instructions during home routines.

Some other variables that affected Anne's parenting success included a history of marital problems and ongoing negative contact with her former spouse, lack of experience with positive parenting practices and her own upbringing (i.e., she often mentioned, “this is how my mother taught me”). Due to her complex family situation, Anne was involved with several other services, including adult community support for herself (e.g., help with financial planning, housing), behavioral intervention for her daughter and mental health services for her son. Some of the parenting practices Anne was using prior to involvement in the Family Game included incorrect use of response cost (e.g., removing several privileges for many days), arguing or shouting in an effort to get her son to cooperate with an instruction or using physical restraint as a last resort (e.g., holding her son down if he was engaging in aggressive behaviors such as hitting, kicking or throwing objects).

The program began with pretest ratings of child problem behaviors, parenting stress and parental self-efficacy, in addition to informal interviews to obtain further information about parenting situations that Anne commonly struggled with at home with her son. Based on assessment results, various individualized parenting scenarios were formulated for an objective baseline assessment of how Anne would deal with each situation (e.g., “You ask your son to put his backpack away after school and he yells ‘no.’ What do you say or do?”). The parent training was delivered in a game format in which a variety of parenting scenarios written on game cards were practiced via roleplays. The game cards incorporated multiple exemplars and new cards were constantly added based on new parenting challenges as they arose. Generalization cards that never received training were probed at various points in training. The curriculum consisted of three parental skill areas: delivering clear instructions, providing praise for cooperation, and correcting non-cooperation with parental instructions.

During Anne’s participation in the parenting program, her son’s mental health problems and school truancy created crisis situations at home. The parent trainer helped her navigate the service system to access mental health services for her son in addition to providing parenting training in the home. This is an example of the complex circumstances that parents with intellectual disabilities may find themselves in that may affect parent training implementation and outcomes. After completing the Family Game training, Anne’s scores on both the trained and untrained (generalization) game cards increased considerably compared to baseline (Tahir et al., 2015). Moreover, during naturalistic observations, Anne demonstrated in situ generalization of delivering clear instructions to her son during home routines; however, in situ generalization of praise and corrections for noncooperation was not observed. Nonetheless, the observations revealed her son’s cooperation to his mother’s instructions at home increased after parent training. At posttest, Anne reported increased parental self-efficacy and use of proactive behavior support strategies with her son, as well as decreased child problem behaviors. She was highly satisfied with the Family Game intervention.

Practice Recommendations

Thirty years of research has identified empirically supported assessment and intervention approaches for improving parenting skills in parents with ID. As described in this chapter, these strategies are based on behavior analytic principles that emphasize individualized skill-based assessments and behavioral skills training. Given the current state of knowledge, this section summarizes best practice in supporting parents with intellectual disabilities.

1. **Establish Rapport**. Before starting assessment and training, the trainer should build rapport with, and gain the trust of, the family. Among other things, a positive relationship may increase the value and effectiveness of the trainer’s advice and feedback to the parent.
2. **Parenting Skills Assessment**. Conduct a comprehensive parenting assessment based on an objective evaluation of specific parenting skills (Feldman & Aunos, 2010). Assessments should include direct observations of parenting behavior to determine the exact skills in which parents need further training.
3. **Contextual Assessment**. In addition to the skills assessment, contextual, ecological factors (e.g., parental history, health and social support; family structure, accommodations and economic status; child health, development and behavior) that may impede or support successful parenting and response to intervention should be examined. The contextual assessment can be used to identify other supports and services besides parent training that will increase likelihood of positive outcomes.
4. **Behavioral Skills Training**. Formulate parent training interventions using evidence-based behavior analytic teaching methods. Skill-based

teaching methods provided in the home (and other settings where parents are expected to display the skills) are most effective in teaching parenting skills. These methods are summarized below:

(a) *Task Analysis*. Break down each skill that needs to be taught into smaller steps and specific components to make it easier to assess parenting skill level as well as to pinpoint which steps of each task need further training—e.g., steps of changing a diaper or preparing a baby bottle (Feldman, Sparks, & Case, 1993).

(b) *Observational Checklists*. Training progress should be monitored as objectively as possible using observational checklists (Feldman & Case, 1993). Observers should be trained to reliably identify specific parenting behaviors being observed.

(c) *Modeling*. Demonstrate how to perform a skill or part of a skill before asking parents to practice the skill. Skills modeled should be those that the parent did not perform correctly in the skills assessment and during training.

(d) *Prompting*. Use a least-to-most prompting hierarchy to guide parents through each step of a parenting skill or task. Start by using simple instructions and gestural prompts and then provide additional modeling and verbal or physical prompts as needed.

(e) *Audiovisual Aids*. Use picture books or videos to supplement verbal instructions on how to perform a certain skill. Similar to modeling and roleplaying, parents learn better from seeing each specific step of a skill, rather than simply being told verbally how each step is performed. Also, such materials can be beneficial in prompting self-learning and maintenance of parenting skills when the trainer is not present (Feldman, 2004a).

(f) *Roleplaying*. Practice the skill without the child present, before performing the skill in the natural setting, for some specific parenting skills. Parents with ID like to roleplay, particularly in a game format (Tahir et al., 2015). For example, when teaching positive behavior management strategies, the trainer may act as the child, while the parent practices what they would do (e.g., when the child does not cooperate with an instruction). Moreover, roleplaying is also a useful strategy for teaching parents how to handle emergency situations.

(g) *Practice*. The parent must practice the skill until performing at a mastery level seen in parents for whom there are no concerns about their parenting abilities.

(h) *Performance Feedback*. In real-life and roleplay practice, the parent receives immediate positive and corrective performance feedback. There should be higher ratio of positive to corrective feedback, especially in the beginning of training, and the feedback should be as specific as possible (e.g., "Wonderful! You checked the bath water before putting the baby in the tub").

(i) *Positive Reinforcement*. In addition to praise statements that are part of positive performance feedback, trainers should alert parents to natural contingencies of reinforcement (e.g., "your child is smiling more since you starting praising him;" "you put the diaper on nice and snug so no poo will come out like the last time and make a mess"). Parenting programs may include tangible reinforcement contingencies (e.g., coupons or money) to increase response to intervention (Feldman, Case, Garrick, et al., 1992).

(j) *Generalization Strategies*. Do not assume that parents will be able to generalize trained skills to other settings. Ensure that generalization strategies are incorporated from the beginning of training, in order to maximize the effects of training, so that parents are able to demonstrate the skills in various settings and situations. Some effective generalization strategies used in the past include multiple exemplars (e.g., roleplay a variety of parenting scenarios; train in different locations), program common stimuli (e.g., train in the parent's home; use the child's picture during role-plays), mediating generalization (e.g., provide pictorial task analyses of skills or reminder posters to praise children at home) as well as instructing to generalize (e.g., the trainer says "remember to praise your child when they follow your instruction right away") (Feldman et al., 1989; Tahir et al., 2015).

(k) *Maintenance*. Similar to generalization strategies, ensure that the skills parents have learned during training will endure over long periods of time. This can be accomplished by gradually decreasing home visits and thinning reinforcement schedules (reduce frequency of praise and tangible reinforcement during follow-up [Feldman, Case, Garrick, et al., 1992]).

5. **Ongoing Support**. Identify new skills the parents will have to learn as the child gets older. Help the parent establish natural systems of support or find services to provide ongoing training as needed. Conducting follow-up visits to assess maintenance of skills.

Conclusion

This chapter presents the current evidence base showing that parents with intellectual disabilities can be taught to improve a multitude of parenting skills. We present an objective method of comprehensive assessment to identify intervention targets as well as outline well-documented training components that make parent education programs successful. Practice recommendations for parent educators are also provided in order to improve future service delivery. However, further research is still needed in regard to remaining intervention gaps such as best generalization strategies, long-term benefits of parent training for children of parents with intellectual disabilities, and large-scale evaluations of parenting programs to influence more progressive policies, practices, and funding of programs.

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Part III

Evidence-Based Interventions

Self-Injury

24

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Introduction

Self-injurious behavior (SIB) is a problem that seriously affects the lives of those who exhibit this behavior, as well as family members and staff who care for them. This behavior can lead to hospitalization for injuries incurred by it, injuries incurred by others who are intervening in management of this behavior, or hospitalization for assessment and treatment of the behavior. Indeed, SIB has been cited as the primary reason for hospitalization of children diagnosed with autism (Mandell, 2008). Additionally, SIB can impede educational and vocational progress of those exhibiting it, and can impede acquisition of leisure skills and curtail one's involvement in community activities. If untreated, SIB is likely to persist over the lifetime of the individual (Furniss and Biswas, 2012; Taylor, Oliver, & Murphy, 2011). Self-injurious behavior most often affects individuals diagnosed with severe or profound intellectual disabilities (McClintock, Hall, & Oliver, 2003), and has often been reported in individuals diagnosed with autism (Lance, York, Lee, & Zimmerman, 2014; Minshawi et al., 2014) and in persons diagnosed with a variety of genetic disorders, such as Fragile X syndrome, Prader–Willi syndrome, Lesch–Nyhan syndrome, and others (Arron, Oliver, Moss, Berg, & Burbidge, 2011; Wolff et al., 2012).

Considerations of etiology of self-injury in individuals with intellectual or other disabilities have progressed from those based on psychodynamic theory to more contemporary conceptualizations based on operant or biological mechanisms. Early on, SIB was considered an extreme form of anger, which itself was said to be an expression of egoism and vanity (Hall, 1899). Later, SIB was considered to be the product of a faulty or underdeveloped superego. According to Nurnberg (1934), in those whose superegos have not yet developed sufficiently, aggression toward others that is evoked by a feared loss of affection is turned inward, toward oneself, given a need for self-punishment. Nurnberg goes on to explain that when the superego evolves sufficiently and one is able to manage this feared loss of love differently, then the self-injury remits. More contemporary views of self-injury consider it to be operant in nature, learned within the lifetime

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experiences of the individual, and the product of both nature and nurture. Given this view, one's unique genetic endowment and current medical status are at play along with other environmental events, which, over time and in relation to the movements of the person, result for some in evolutions of topographies that are self-injurious in nature. These behaviors are then influenced and maintained by the environmental events that surround them, and so can likely be altered by altering either those events, or the physiology that engages in those movements.

Functional analysis of self-injurious behavior had its start when Lovaas, Freitag, Gold, and Kassorla (1965) reported on environmental manipulations from which they determined that the self-injury exhibited by a 9-year-old child diagnosed with schizophrenia occurred more frequently in low stimulation conditions than it did when music was provided and alternative behavior was reinforced. Later, Carr (1977) contrasted a psychodynamic account of self-injury, which was essentially tautological, with a conceptualization of self-injury as an operant behavior maintained by positive, negative, or nonsocially mediated reinforcement, or etiologically related to physiological function. Carr then laid out the framework for functional analysis of problem behavior, which was formalized by Iwata, Dorsey, Slifer, Bauman, and Richman (1982).

Functional analyses of self-injury in individuals with autism, intellectual disability, or genetic syndromes have indicated that, for some, this behavior is maintained by socially mediated positive reinforcement (Carr, 1977; LaRue, Lenard, Weiss, Bamond, Palmieri, & Kelley, 2010; Lerman & Iwata, 1993; Mace & Mauk, 1995), socially mediated negative reinforcement in the form of social attention or demand termination (Bergen, Holborn, & Scott-Huyghebaert, 2002; Carr, 1977; Iwata et al., 1982; Lerman & Iwata, 1993; Mace & Mauk, 1995; Schroeder, Richman, Abby, Courtemanche, & Omaya-Ganiko, 2014; Smith, Iwata, Goh, & Shore, 1995), nonsocially mediated reinforcement (Carr, 1977; Iwata et al., 1982; Lerman & Iwata, 1993; Mace & Mauk, 1995; McKerchar, Kahng, Casioppo, & Wilson, 2001; Shore, Iwata, DeLeon, Kahng, & Smith, 1997), and multiple contingencies (Carr, 1977; Iwata et al., 1982; LaRue et al., 2010; Mace & Mauk, 1995; Schroeder et al., 2014). Carr and Smith (1995), Mace and Mauk (1995), and Bosch, Van Dyke, Smith, and Poulton (1997) described evocative functions of physiological events, such as illness, menses, or other events with regard to SIB, and O'Reilly (1997) and O'Reilly and Lancioni (2000) demonstrated self-injury to be functionally related to otitis media and to sleep disturbance, respectively.

History

One's assessment and conceptualization of a problem determines one's approach to treating it. In an article published in *American Journal of Psychology* in 1899, G. S. Hall reported on a child who would cause lacerations to her face through scratching. He further describes lip and hand biting, head banging, and self-choking as being emitted by those with severe intellectual disability. Hall reported that this type of behavior occurred most commonly in children between 2 and 9 years of age, and that the behavior generally would remit by 14 years of age. Considering this behavior to be a product of anger turned inward, which, itself, was a product of self-importance or selfishness. Similarly, Nurnberg (1934) considered self-injury to be the product of an underdeveloped superego.

Functional analysis of self-injurious behavior had its start in 1965, when Lovaas, Freitag, Gold, and Kassorla reported on environmental manipulations from which they determined that the self-injury exhibited by a 9-year-old child diagnosed with schizophrenia occurred more frequently in low stimulation conditions than it did when music was provided and alternative behavior was reinforced. Later, Carr (1977) contrasted a psychodynamic account of self-injury, which was essentially tautological, with a conceptualization of self-injury as an operant behavior maintained by positive, negative, or nonsocially mediated reinforcement, or etiologically related to physiological function. Carr then laid out the framework for functional analysis of problem behavior, which was formalized by Iwata et al. (1982).

Identification of functional relations of which self-injury is a part permits, in many cases, implementation of procedures that address those functional relations. As functional analysis and related procedures (e.g., descriptive analysis, conditional probability analysis, and contingency interviews) have become more prevalent, range of interventions has expanded beyond extinction and punishment procedures to include a variety of reinforcement procedures and antecedent interventions (Table 24.1). Additionally, identification of multiple maintaining relations has often resulted in multicomponent treatment packages.

Definition

SIB has been defined in a number of different, but similar ways over the years. Tate and Baroff (1966) defined SIB as "repetitive acts by individuals directed toward themselves which result in physical harm or tissue damage." Schroeder, Mulick, and Rojahn (1980) defined self-injury as behaviors directed toward oneself that cause or have potential to cause tissue damage. Baghdadli, Pascal, Grisi, and Aussilloux (2003) defined SIB as "aggressive behaviors directed toward one's self…." Rojahn, Schroeder, and Hoch (2008) described SIB as self-directed behavior that causes or has the potential to cause physical damage, and which occurs repeatedly, in idiosyncratic form. Glasser and Perkins (2013) define SIB as "a nonsuicidal, repetitive, and deliberate condition whereby an individual causes injury, tissue damage, or both to his or her body." Minshawi et al. (2014) define SIB as "a class of behaviors which the individual inflicts upon his/herself that have potential to result in injury, more specifically tissue damage." While various authors may approach this problem from differing epistemological vantage points, what the definitions have in common is that the behavior is emitted by the person whose body is also the object of that behavior, and that the behavior causes or has potential to cause physical harm to the body. Glasser and Perkins' (2013) consideration of SIB as nonsuicidal is important, as acts that constitute suicide or parasuicide typically have a very different nature from the self-injurious topographies exhibited by people with intellectual disabilities and autism.

A variety of topographies have been reported in the self-injury literature. These have included head banging (Favell et al., 1978; Fisher et al., 1998; Goh & Iwata, 1994; Grace et al., 1996; Horner et al., 1997; Iwata et al., 1990; Kahng et al., 2001; Kurtz et al., 2003; Lovaas et al., 1965, Lovaas & Simmons, 1969; Linscheid et al., 1990; Luiselli, 1986; Mace et al., 1998; Mazaleski et al., 1993; Morrison (1972); O'Reilly & Lancioni, 2000; Salvy et al., 2004; Tate & Baroff, 1966; Vollmer et al., 1993; Vollmer et al., 1995; Vollmer & Vorndran, 1998; Wachtel et al., 2009; Williams et al., 1994; Zarcone et al., 1994), striking one's own body with one's hands, with objects, or against other objects (Azrin et al., 1975, 1982; Bailey & Meyerson, 1969; Carr & Durand, 1985; Corte et al., 1971; Cunningham & Peltz, 1982; Dorsey et al., 1982; Durand & Carr, 1987; Favell et al., 1978; Goh & Iwata, 1994; Harris & Romanczyk, 1976; Healy et al., 2001; Horner et al., 1997; Johnson et al., 1982; Kahng et al., 2001; Kerth et al., 2009; Kurtz et al., 2003; Linscheid & Reichenbach, 2002; Lovaas et al., 1965; Lovaas & Simmons, 1969; Linscheid et al., 1990; Luiselli, 1986; Mace et al., 1998; Mazaleski et al., 1993; Merbaum, 1973; O'Reilly & Lancioni, 2000; Oliver et al., 1998; Roberts et al., 1995; Tanner & Zeiler, 1975; Tate & Baroff, 1973; Van Houten, 1993; Vollmer et al., 1993, 1995; Vollmer & Vorndran, 1998; Wachtel et al., 2009; Wachtel, Jaffe, & Kellner, 2011; Wachtel, Reti, & Ying, 2014; Williams et al., 1993), self-biting (Azrin et al., 1975, 1982; Bailey et al., 1983; Carr & Durand, 1985; Cautela & Baron, 1973; Dorsey et al., 1980, 1982; Horner et al., 1997; Jenson et al., 1985; Johnson et al., 1982; Kerth et al., 2009; Kurtz et al., 2003; Linscheid et al., 1990; Luiselli et al., 1981; Myers, 1975; Neufeld & Fantuzzo, 1984; Singh, 1980; Steege et al., 1990; Wacker et al., 1990; Wachtel et al., 2011; Williams et al., 1993; Zarcone et al., 1994), eye gouging, eye poking, or eye punching or hitting (Azrin

Table 24.1 Assessment and intervention type by study

Authors	Pre-intervention assessment	Antecedent based intervention	Consequence based intervention	Post-experimental follow-up
Lovaas et al. (1965)	Functional analysis	Environmental modification	Extinction	Not reported
Bailey and Meyerson (1969)	Not reported		DRA	Not reported
Lovaas and Simmons (1969)	Functional analysis		Contingent electric shock + Extinction	Not reported
Corte, Wolf, and Locke (1971)	Not reported		Contingent electric shock + DRO + DRA	Not reported
Myers and Deibert (1971)	Not reported		DRO	Not reported
Morrison (1972)	Not reported		Positive punishment	Not reported
Cautela and Baron (1973)	Not reported	Thought stopping, desensitization, relaxation training		Reported up to 2 years
Foxx and Azrin (1973)	Pre-intervention treatment evaluation		Verbal warning + Overcorrection	Reported at 125 and 150 days
Tate and Baroff (1973)	Not reported		Negative punishment	Reported at 6 months
Merbaum (1974)	Not reported		Contingent electric shock	Reported at 1 year
Repp and Deitz (1974)	Not reported		DRO + Verbal reprimand	Not reported
Azrin, Gottlieb, Hughart, Wesolowski, and Rahn (1975)	Not reported		DRO + Contingent Relaxation + Contingent exercise	Not reported
Myers (1975)	Not reported		Extinction, DRO	Reported at 12 weeks
Tanner and Zeiler (1975)	Not reported		Contingent aeromatic ammonia	Reported at 21 days
Harris and Romanczyk (1976)	Functional analysis		Overcorrection by contingent exercise	Not reported
Kelly and Drabman (1977)	Observational analysis		Overcorrection	Not reported
Favell, McGimsey, and Jones (1978)	Observation and staff interview	"Distraction"	Restraint access contingent on absence of SIB	Not reported
Coleman, Whitman, and Johnson (1979)	Not reported		Overcorrection + DRA	Not reported

Conley and Wolery (1980)	Not reported		Overcorrection + Spoken reprimand	Not reported
Dorsey, Iwata, Ong, and McSween (1980)	Not reported		Positive punishment + DRO	Not reported
Singh (1980)	Not reported		Facial screen + Verbal reprimand	Reported up to 12 months
Fleming and Nolley (1981)	Not reported	Stimulus control	DRI	Reported up to 18 months
Luiselli, Suskin, and McPhee (1981)	Not reported		Overcorrection	Reported up to 6 months
Azrin, Besalel, and Wisotzek (1982)	Not reported		DRI + Response interruption	Interval not reported
Cunningham and Peltz (1982)	Not reported	In vivo desensitization across situations		Reported up to 15 months
Dorsey, Iwata, Reid, and Davis (1982)	Not reported	Restraint fading	Contingent restraint + DRA	Reported up to 104 days
Favell, McGimsey, and Schell (1982)	Not reported	Environmental enrichment	DRA	Not reported
Johnson, Baumeister, Penland, and Inwald (1982)	Not reported		Overcorrection + DRA	Not reported
Wesolowski and Zawlocki (1982)	Not reported		Time out + DRO	Reported at 1 year
Bailey, Pokrzywinski, and Bryant (1983)	Not reported		Contingent water mist	Not reported
Neufeld and Fantuzzo (1984)	Not reported		Helmet barrier	Reported at 14 days
Slifer, Iwata, and Dorsey (1984)	Functional analysis		Response interruption, DRO, DRI	Reported up to 5 months
Carr and Durand (1985)	Functional analysis	FCT		Not reported
Jenson, Rovner, Cameron, Petersen, and Kesler (1985)	Not reported		Contingent water mist	Reported at 6 months

(continued)

Table 24.1 (continued) Assessment and intervention type by study

Luiselli (1986)	None reported		DRO+Contingent protective equipment	Reported up to 6 months
Durand and Carr (1987)	Functional analysis	FCT		Not reported
Iwata, Pace, Kalsher, Cowdery, and Cataldo (1990)	Functional analysis		Extinction, physical Guidance, response blocking, DRO	Interval not reported
Linscheid, Iwata, Ricketts, Williams, and Griffin (1990)	Functional analysis		Contingent electric shock	Reported up to 17 months
Steege et al. (1990)	Functional analysis		Negative reinforcement	Reported at 6 months
Wacker et al. (1990)	Functional analysis		Negative reinforcement, guided compliance	Not reported
Mazaleski, Iwata, Vollmer, Zarcone, and Smith (1993)	Functional analysis		DRO	Interval not reported
Van Houten (1993)	Functional analysis	Wrist weights (e.g., increasing response effort)		Reported at 5 months
Vollmer, Iwata, Zarcone, Smith, and Mazaleski (1993)	Functional analysis	NCR	DRO	Not reported
Williams, Kirkpatrick-Sanchez, and Iwata (1993)	Not reported		Contingent electric shock	Not reported
Goh and Iwata (1994)	Functional analysis		Escape extinction	Not reported
Linscheid, Pejeau, Cohen, and Footo-Lenz (1994)	Observation and interview		Contingent electric shock	Reported at 1 year
Williams, Kirkpatrick-Sanchez, and Crocker (1994)	Functional analysis		Contingent electric shock+DRO+DRA	Reported up to 6 years
Zarcone, Iwata, Mazaleski, and Smith (1994)	Functional analysis	High-p sequence	Extinction	Not reported

Kennedy and Souza (1995)	Functional analysis		Negative punishment	Not reported
Mudford, Boundy, and Murray (1995)	Hypotheses developed on basis of observations and attempted Functional analysis		Contingent electric shock	Not reported
Roberts, Mace, and Daggett (1995)	Functional analysis		DRNA, DRNO	Not reported
Vollmer, Marcus, and Ringdahl (1995)	Functional analysis	noncontingent escape		Not reported
Grace, Thompson, and Fisher (1996)	Interview		Positive reinforcement and response cost within a level system	Not reported
Lalli, Livezey, and Kates (1996)	Functional analysis	Response blocking with glasses		Not reported
Fischer, Iwata, and Mazaleski (1997)	Functional analysis	NCR		Interval not reported
Horner, Day, and Day (1997)	Functional analysis	Neutralizing routine (MO modification)		Not reported
Fisher et al. (1998)	Functional analysis		Contingent TENS stimulation	Not reported
Mace, Shapiro, and Mace (1998)	Functional analysis	NCR, warning stimulus	Extinction	Reported at 10 months
Oliver, Hall, Hales, Murphy, and Watts (1998)	Observation		Systematic fading of mechanical restraints	Reported at 17 months
Roscoe, Iwata, and Goh (1998)	Functional analysis		NCR	Not reported
Vollmer and Vorndran (1998)	Functional analysis		DRA (Functional Communication Training)	Not reported
O'Reilly and Lancioni (2000)	Functional analysis	Neutralizing routine (MO modification)		Not reported
Healy et al. (2001)	Functional analysis	FT delivery of preferred stimuli with a COD, scheduled instructions	DRA	Not reported

(continued)

Table 24.1 (continued) Assessment and intervention type by study

Kahng, Abt, and Wilder (2001)	Functional analysis	Restraint fading, environmental enrichment	Contingent exercise	Not reported
Linscheid and Reichenbach (2002)	Observation		Contingent electric shock	Reported at 5 years
MacDonald, Wilder, and Dempsey (2002)	Functional analysis	Response blocking	Positive reinforcement	Interval not specified
Kurtz et al. (2003)	Functional analysis	Mand training (FCT)	Positive reinforcement extinction (FCT), punishment, DRO	Not reported
Salvy, Mulick, Butter, Bartlett, and Linscheid (2004)	Interview		Contingent electric shock	Reported at 7 months
Kerth, Progar, and Morales (2009)	Functional analysis	Noncontingent access to self-restraint material		Not reported
Tiger, Fisher, and Bouxsein (2009)	Functional analysis		DRO	Interval not specified
Toussaint et al. (2012)	Functional analysis		Variable momentary DRO	Not reported

et al., 1975; Conley & Wolery, 1980; Corte et al., 1971; Dorsey et al., 1982; Favell et al., 1978, 1982; Fisher et al., 1998; Kelly & Drabman, 1977; Kennedy & Souza, 1995; MacDonald et al., 2002; Slifer et al., 1984; Wesolowski & Zawlocki, 1982; Williams et al., 1993), hand mouthing, sucking, or chewing (Bailey & Meyerson, 1969; Corte et al., 1971; Favell et al., 1982; Foxx & Azrin, 1973; Johnson et al., 1982; Vollmer et al., 1993), hair pulling (Corte et al., 1971; Favell et al., 1978; Linscheid et al., 1990; Mace et al., 1998), skin and nail picking (Corte et al., 1971; Dorsey et al., 1980; Fisher et al., 1998; Grace et al., 1996; Kurtz et al., 2003; Linscheid & Reichenbach, 2002; Roscoe et al., 1998; Tiger et al., 2009; Toussaint & Tiger, 2012), and others. It is not unusual for a person who exhibits SIB to exhibit more than one SIB topography (Table 24.2). Indeed, of 42 intervention studies surveyed for this chapter that included a single participant, the range of number of SIB topographies exhibited by participants was 1–8 topographies, with a mean of 1.9 different SIB topographies per participant (Table 24.2). As reported by Derby et al. (2000), differing topographies exhibited by the same person may be parts of differing functional relations, and so multiple SIB topographies exhibited by the same person would mean that each would need to be assessed separately, and, depending on assessment outcome, treated with separate procedures.

Epidemiology of the Behavior

Earlier examinations of prevalence of SIB relied on institutional populations, but more recently, community populations have been sampled. Green (1967) found that 40 % of children diagnosed with schizophrenia who lived in a residential program engaged in SIB, while Baumester and Ronnlings (1976) reported that 10–17 % of children with intellectual disabilities who resided in an institution engaged in SIB. Schroeder, Schroeder, Smith, and Dalldorf (1978) found that SIB was exhibited by 10 % of the population of a large state residential facility for people with intellectual disabilities, and Fovell, Lash, Barron, and Roberts (1989) found that SIB was exhibited by 28 % of individuals with intellectual disabilities residing in a large state facility.

More recently, community-based samples have shown differing prevalence numbers. Berkson, Tupa, and Sherman (2001) report 4.6 % of 457 children enrolled in an early intervention program engaged in SIB, while MacLean and Dornbush (2012) reported 19 % of children receiving home-based early intervention services engaged in this behavior. Emerson et al., (2001) found that 4 % of people with intellectual disabilities living in two Health Authorities districts of the United Kingdom engaged in SIB, and Holden and Gitlesen (2006) report a similar finding of 4.4 % of a community sample of individuals with intellectual disabilities living in Norway engaging in this behavior. In a perhaps more clinical sample, MacLean, Tervo, Hoch, Tervo, and Symons (2010) found that 32 % of children receiving outpatient services from a neurodevelopmental clinic engaged in SIB.

Self-injury has been reported in 25 % (Minshawi et al., 2014) to 50 % (Baghdadli et al., 2003) of people diagnosed with Autism. Individuals with autism who experienced a regression in skills prior to diagnosis are said to be at no greater risk for SIB than are individuals with autism who did not experience such a regression (Lance et al., 2014). Individuals who are diagnosed with both Down Syndrome and Autism are reported to be more likely to exhibit SIB than are individuals diagnosed only with Down Syndrome (Moss, Richards, Nelson, & Oliver, 2013). Clarke, Boer, Chung, Sturmey, and Webb (1996) report that SIB can occur during adulthood for people diagnosed with Prader–Willi Syndrome. Arron et al. (2011) report prevalence rates of 45 % of their sample of participants with Angelman Syndrome, 77 % of participants diagnosed with Cri du Chat Syndrome, 70 % of participants with Cornelia de Lange syndrome, 51.3 % of participants diagnosed with Fragile X Syndrome, 52 % of participants with Prader–Willi Syndrome, 64 % of participants with Lowe

Table 24.2 Participants and topographies by study

Authors	Participants	Topography
Lovaas et al. (1965)	9-year-old girl with schizophrenia	Head banging, arm banging, self-pinching, self-slapping, setting own hair on fire
Bailey and Meyerson (1969)	7-year-old boy with profound ID, blindness, and deafness	Facial slapping; hitting own chin, ears, and side of head; jabbing his teeth; finger and hand sucking; banging head, teeth, and feet against side of crib
Lovaas and Simmons (1969)	8-year-old boy with ID 8-year-old girl with ID and blindness 11-year-old boy with severe ID	Punching own head, banging head with knee, banging head on side of bed
Corte et al. (1971)	17- to 20-year-old participants with profound ID	Slapping self, eye poking, tongue gouging, striking face against surfaces, plucking out own hair, skin picking, hand mouthing and chewing
Myers and Deibert (1971)	11-year-old boy with visual impairment and ID	Punching head
Morrison (1972)	8-year-old girl with ID	Striking head against hard surfaces
Cautela and Baron (1973)	20-year-old man with schizophrenia	Lip and tongue biting
Foxx and Azrin (1973)	7- and 8-year-old girls with severe ID	Handmouthing
Tate and Baroff (1973)	9-year-old boy with autism and blindness	Facial slapping, head banging
Merbaum (1974)	12-year-old boy with autism, schizophrenia, and ID	Facial slapping
Repp and Deitz (1974)	10-year-old girl with severe ID	Facial scratching
Azrin et al. (1975)	11 participants ranging from 10- to 46-year-old; nine diagnosed with profound and one with severe ID; one diagnosed with schizophrenia	Face hitting, self-choking, self-biting, self-kicking, self-scratching, eye gouging, self-slapping, finger biting, ear punching
Myers (1975)	12-year-old boy with ID	Biting fingertips and nails
Tanner and Zeiler (1975)	20-year-old woman with autism	Self-slapping
Harris and Romanczyk (1976)	8-year-old boy with Rubella Syndrome	Contact of head or jaw with other objects (including own body)
Kelly and Drabman (1977)	3-year-old boy with blindness	Inserting fingers into eyes
Favell et al. (1978)	8-year-old boy, 15-year-old girl, and 27-year-old woman with profound ID	Eye poking, scratching, head banging, head slapping, hair pulling
Coleman et al. (1979)	17-year-old boy with profound ID	Hand mouthing
Conley and Wolery (1980)	5-year-old boy with blindness; 7-year-old girl with blindness and ID	Eye gouging

Dorsey et al. (1980)	Seven participants with profound ID, from 5 to 37 years old	Hand mouthing, hand biting, skin tearing, head banging
Singh (1980)	11-month boy with severe ID	Thumb biting
Fleming and Nolley (1981)	47-year-old woman with mild ID	Scratching, skin picking
Luiselli et al. (1981)	10-year-old boy with autism	Hand biting
Azrin et al. (1982)	35-year-old woman with severe ID; 20-year-old man with profound ID	Face slapping, arm biting
Cunningham and Peltz (1982)	10-year-old boy with moderate ID	Face slapping
Dorsey et al. (1982)	16-year-old boy with profound ID; 16-year-old girl and 14-year-old boy with severe ID	Head hitting, hand biting, eye gouging
Favell et al. (1982)	Six participants, mean age 17 years old, profound ID	Hand mouthing, eye poking
Johnson et al. (1982)	20-year-old woman and 44-year-old man with profound ID; 13-year-old boy with severe ID	Hitting head, face and other body parts; hand-mouthing; foot stomping, self-pinching, self-biting, self-punching, self-slapping
Wesolowski and Zawlocki (1982)	6-year-old monozygous twin girls with blindness and profound ID	Eye gouging
Bailey et al. (1983)	7-year-old boy with autism and severe ID	Hand and finger mouthing and biting
Neufeld and Fantuzzo (1984)	9-year-old boy with moderate ID	Self-biting
Slifer et al. (1984)	6-year-old boy with profound ID	Eye gouging
Carr and Durand (1985)	13-year-old boy, 13 and 14-year-old girl, autism, brain injury	Head hitting, hand biting
Jenson et al. (1985)	6-year-old girl with autism and severe ID	Arm and hand biting
Luiselli (1986)	16-year-old boy with Rubella syndrome	Head, face, and body hitting; head banging
Durand and Carr (1987)	11-year-old boy, autism	Head and face slapping
Iwata et al. (1990)	Seven participants ranging from 4 to 16 years old; one with mild, three with moderate, and three profound ID	Arm biting, hand biting, face hitting, head banging
Linscheid et al. (1990)	16-year-old girl with profound ID; 11-year-old boy with severe ID and autism; 17-year-old girl with profound ID; 24-year-old man with profound ID; 22-year-old woman with severe ID, autism	Head hitting, head banging, self-biting, hair pulling, pinching self
Steege et al. (1990)	5-year-old girl and 6-year-old boy with profound ID	Hand, wrist, arm, and shoulder biting
Wacker et al. (1990)	6-year-old boy and 4-year-old girl with profound ID	Hand, wrist, and arm biting

(continued)

Table 24.2 (continued)

Mazaleski et al. (1993)	32-, 40-, and 42-year-old women with severe and profound ID	Body and head hitting, head banging
Van Houten (1993)	10-year-old boy with severe ID, autism	Facial slapping
Vollmer et al. (1993)	32- and 42-year-old women with profound ID, 40-year-old woman with severe intellectual ID	Head and body hitting, head banging, hand mouthing
Williams et al. (1993)	24-year-old woman with profound ID and blindness	Self-biting, ear and eye gouging, thigh hitting
Goh and Iwata (1994)	40-year-old man with profound ID	Head banging, head hitting
Linscheid et al. (1994)	8-year-old boy with severe/profound ID	Head hitting
Williams et al. (1994)	22-year-old woman with severe ID and autism	Head banging, head hitting
Zarcone et al. (1994)	38- and 45-year-old men with profound ID	Head banging Finger biting, face slapping
Kennedy and Souza (1995)	19-year-old man with profound ID	Eye poking
Mudford et al. (1995)	36-year-old man with profound ID	Hand to ear hitting
Roberts et al. (1995)	4-year-old girl with severe ID	Head hitting, buttocks slamming, face slapping
Vollmer et al. (1995)	18-year-old man with profound ID 4-year-old girl with autism	Head punching, face hitting Hand biting, head banging
Derby et al. (1996)	12-year-old girl with profound ID	Hand to head and knee to head blows
Duker and Seys (1996)	Six males and six females, age 3- to 43-year-old, with severe or profound ID	Topographies not specified
Grace et al. (1996)	21-year-old man with mild ID	Skin and nail picking, head banging, self-biting inserting objects into own orifices, eyelid pulling
Lalli et al. (1996)	4-year-old girl with severe DD	Eye poking
Saunders et al. (1996)	13-year-old boy and 18-year-old man with profound ID	Facial hitting, hand biting
Fischer et al. (1997)	24-year-old man and 44-year-old woman with profound ID	Facial slapping, hand mouthing
Horner et al. (1997)	12-year-old boy with severe and 14-year-old boy with profound ID	Head banging, head hitting, self-biting
O'Reilly (1997)	26 months girl with moderate DD	Head banging and ear poking
Fisher et al. (1998)	25-year-old man with profound ID	Eye poking, head punching, skin picking, head banging
Mace et al. (1998)	7-year-old girl with moderate ID and autism	Head banging, head hitting, hair pulling
Oliver et al. (1998)	25-year-old woman with profound ID	Head and body punching

Roscoe et al. (1998)	29-year-old man and 35-year-old woman with profound ID; 20-year-old woman with moderate ID	Arm rubbing, arm banging, hand mouthing, skin picking
Vollmer and Vorndran (1998)	29-year-old woman with severe and 37-year-old man with profound ID	Self-punching, face slapping, head banging
O'Reilly and Lancioni (2000)	4-year-old girl with moderate ID	Head hitting and head banging
Healy et al. (2001)	21-year-old man with autism and profound ID	Self-hitting
Kahng et al. (2001)	16-year-old girl with severe ID	Head banging, head hitting, body hitting
Linscheid and Reichenbach (2002)	15-year-old boy with ID	Head hitting, self-pinching, skin picking
MacDonald et al. (2002)	5-year-old boy with visual impairment	Eye poking
Kurtz et al. (2003)	30 participants from 10 month to 4 years old, with average intellectual functioning to profound ID	Head banging, head hitting, self-biting, body slapping, body slamming, self-kicking, self-scratching, skin picking, hair pulling
Salvy et al. (2004)	3-year-old girl with ID	Head banging
Kerth et al. (2009)	16-year-old boy with autism, intermittent explosive disorder, and moderate to severe ID	Striking self, striking surfaces, biting self, kicking self
Tiger et al. (2009)	19-year-old man with Asperger's Syndrome	Skin picking
Toussaint et al. (2012)	12-year-old boy with autism, cerebral palsy, traumatic brain injury, and deletion of chromosomes 3 and 6	Skin picking

Syndrome, and 93 % of participants diagnosed with Smith–Magenis Syndrome. Indeed, SIB has been cited as part of a behavioral phenotype of individuals diagnosed with a variety of genetic syndromes (Arron et al., 2011; Wolff et al., 2012). Despite this, however, Dawson, Matson, and Cherry (1998) point out that environmental evocative and maintaining variables appear more related to SIB than does a diagnosis.

Self-injury has been associated with greater degrees of intellectual disability (Richards, Oliver, Nelson, & Moss, 2012), lesser conventional verbal behavior abilities (Baghdadli et al., 2003; Richards et al., 2012), lesser social skills (Duerden, Oatley, et al., 2012), and presence of ritualistic behaviors (Duerden, Oatley, et al., 2012; Duerden, Szatmari, and Roberts 2012). Buono, Palmigiano, and Elia (2012) found similar incidence of SIB in people with intellectual disabilities who did and did not have a comorbid diagnosis of a seizure disorder. Findings by Davies and Oliver (2014) suggest that individuals with intellectual disabilities who are also diagnosed with depression may be more likely to engage in SIB. Davies and Oliver (2013) describe a curvilinear relationship between age and SIB for people with intellectual disabilities, with probably of this behavior occurring increasing across childhood, adolescence, and adulthood, but decreasing with age over the course of adulthood. Despite this, Glaesser and Perkins (2013) report that live events occurring in aging individuals with intellectual disabilities may give rise to SIB in this population.

Various life events have been reported to be related to SIB in individuals with intellectual disabilities. Owen, Hastings, Noone, Chinn, Harman, Roberts, and Taylor (2004) found that problem behaviors, including SIB, were associated with events such as a change of staff serving the person, physical illness, new roommate, assault by another resident, death of a close friend or family member, move to another residence, and separation from a significant person. Harper and Wadsworth (1993) reported that newly emergent self-injury occurred in 10–15 % of participants who'd lost a close family member or other to death within the last year. Burke and Bedard (1994) report that self-injury may be an iatrogenic problem that occurs in the context of treatment of sexual trauma of people with intellectual disability. Self-injury related to grieving and survival of sexual trauma are both fertile grounds for additional research and service, given the paucity of research in these areas as they relate to service of people with intellectual disabilities (Burke & Bedard, 1994; Morse, Hoch, and Freeman, in press).

Measurement and reliability of measurement. An operational definition (either structural or functional) is required in order to determine the frequency of a behavior within a person or within a population. Studies reviewed generally defined self-injury in terms of topographies exhibited, and 99 % of these studies provided an operational definition of self-injury (Table 24.2). Interestingly, although these intervention studies defined self-injury topographically, general definitions for the class of behavior called self-injury are generally functional in nature, specifying that this behavior is one that causes or can cause injury to oneself (Schroeder et al., 1980; Tate & Baroff, 1966).

Of the 72 studies reviewed, 40 % reported partial interval sampling data. The most frequently occurring interval was 10 s, which was reported in 28 % of articles, percentage of 15 min intervals occurrence of SIB reported in 6 % of studies, 3 % of studies reporting 6 s partial interval sampling data, and 1 % of studies reporting each of 1 min partial interval sampling data, 1 h partial interval sampling data, and not specifying interval for which partial interval sampling data were reported. Eighteen percent of studies reported rate data, with 15 % of studies measuring and reporting SIB responses per minute, and 3 % reporting SIB responses per hour. Count of instances of self-injurious behavior was reported by 17 % of studies surveyed, and cumulative count by 3 %. Total duration of SIB was reported by 3 % of studies, and percentage of observation time allocated to SIB was reported by 4 %. One study, or 1 % of studies, each reported count of days with self-injury per month, count of products of SIB, percentage of task trials during which SIB occurred, count of situations in which protective equipment was used, percentage reduction of self-injurious behavior relative to baseline, and an ordinal ranking of response products. Only 3 % of studies did not report numerical data.

Once a behavior has been defined, and while data collection is underway, it is essential to collect interobserver agreement or other reliability data, and to use those data to ensure that data are recorded as specified in the data collection procedures. Seventy-six percent of studies surveyed reported interobserver agreement data, and 54 % reported interobserver agreement for at least 20 % of sessions or observations (Table 24.3). Twenty-four percent of studies did not report interobserver agreement or other reliability data.

Criteria for Evidence-Based Treatments

The SIB literature contains numerous reports and case studies detailing assessment and treatment with varying degrees of specificity with regard to descriptions of independent and dependent variables. Most studies have been conducted in the context of a single-subject research design, and some (e.g., Kurtz et al., 2003) report summary of numerous data sets which were individually obtained in the context of a single subject design. In reviewing the literature, we used guidelines provided by Kratochwill, Hitchcock, Horner, Levin, Odom, and Rindskopf (2010) to determine which studies met evidence for demonstrating treatment efficacy. These were:

1. The independent variable was controlled by the experimenter.
2. Interobserver agreement data (or other reliability data) were gathered for at least 20 % of sessions within each phase of the experiment.
3. The experimental design used permits demonstration of functional control by the independent variable of the dependent variable, through demonstration of prediction, verification, and replication, for all participants (Cooper, Heron, & Heward, 2007).

Studies meeting all three of these criteria were found to *Meet Evidence Standards*. Studies meeting the first two criteria, but failing to meet the third criterion for at least one participant, were found to *Meet Evidence Standards with Reservations*. We deviated from these procedures by finding a study to *Meet Evidence Standards with Reservations* if both criteria 1 and 3 were met, and interobserver agreement or other data were gathered for less than 20 % of sessions across all phases, or was not reported. Of 72 studies surveyed, 45 (63 %) were given a rating of *Evidence Standards Met*; nine (13 %) were given a rating of *Evidence Standards Met with Reservations*; and the remaining 18 studies (25 %) were rated as *Evidence Standards Not Met* (Table 24.3). Studies found to have met evidence standards with reservations with reservation employed independent variables controlled by the experimenter, and were conducted in the context of single subject experimental designs which permitted demonstration of functional control of the dependent variable by the independent variable, but reported interobserver agreement or other reliability measurement procedures and data for fewer than 20 % of observations across all phases for all subjects. Nineteen studies (26 %) did not employ designs that permitted demonstration of functional relations between independent and dependent variables, and 15 (21 %) did not report interobserver agreement or other data reliability measurement.

Procedures reported in studies rated as *Evidence Standards Met* or *Evidence Standards Met with Reservation* were reexamined to determine extent to which they were supported by strong evidence, moderate evidence, or limited or no evidence of efficacy. We again based these determinations on the procedures of Kratchowill et al. (2010). Procedures were said to be strongly supported by the literature (or rated as having Strong Evidence for efficacy for self-injury) when:

1. They were reported in at least five single subject experimental design studies that met evidence standards (with or without reservation).
2. Those five or more studies were published by at least three geographically distinct research teams.
3. The five or more single subject design studies contained a minimum of 20 data-based determinations of efficacy for participants.

Table 24.3 Degree to which Evidence Standards and criteria met by study

Authors	Degree to which Evidence Standards are met	Experimenter controlled IV	IOA reliability	Demonstrates functional control
Lovaas et al. (1965)	Evidence Standards Not Met	Yes	No	No
Bailey and Meyerson (1969)	Evidence Standards Not Met	Yes	No	No
Lovaas and Simmons (1969)	Evidence Standards Not Met	Yes	Yes (# sessions not reported)	No
Corte et al. (1971)	Evidence Standards Met with Reservations	Yes	Yes (>20 % of sessions)	Yes
Myers and Deibert (1971)	Evidence Standards Not Met	Yes	No	No
Morrison (1972)	Evidence Standards Not Met	Yes	No	No
Cautela and Baron (1973)	Evidence Standards Not Met	No	No	No
Foxx and Azrin (1973)	Evidence Standards Met with Reservations	Yes	Yes (% sessions not reported)	Yes
Tate and Baroff (1973)	Evidence Standards Not Met	Yes	No	Yes
Merbaum (1974)	Evidence Standards Not Met	No	No	No
Repp and Deitz (1974)	Evidence Standards Not Met	Yes	Yes (<20 % of sessions)	No
Azrin et al. (1975)	Evidence Standards Not Met	Yes	No	No
Myers (1975)	Evidence Standards Not Met	Yes	No	No
Tanner and Zeiler (1975)	Evidence Standards Met	Yes	Yes	Yes
Harris and Romanczyk (1976)	Evidence Standards Not Met	Yes	No	Yes
Kelly and Drabman (1977)	Evidence Standards Met	Yes	Yes	Yes
Favell et al. (1978)	Evidence Standards Met	Yes	Yes	Yes
Coleman et al. (1979)	Evidence Standards Met with Reservation	Yes	Yes (% sessions not reported)	Yes
Conley and Wolery (1980)	Evidence Standards Not Met	Yes	Yes (<20 % of sessions)	No
Dorsey et al. (1980)	Evidence Standards Met	Yes	Yes	Yes
Singh (1980)	Evidence Standards Met with Reservation	Yes	Yes (<20 % of sessions)	Yes
Fleming and Nolley (1981)	Evidence Standards Not Met	Yes	No	Yes
Luiselli et al. (1981)	Evidence Standards Met	Yes	Yes	Yes
Azrin et al. (1982)	Evidence Standards Met	Yes	Yes	Yes
Cunningham and Peltz (1982)	Evidence Standards Not Met	No	Yes (% sessions not reported)	No

Dorsey et al. (1982)	Evidence Standards Met	Yes	Yes	Yes
Favell et al. (1982)	Evidence Standards Met	Yes	Yes	Yes
Johnson et al. (1982)	Evidence Standards Met	Yes	Yes	Yes
Wesolowski and Zawlocki (1982)	Evidence Standards Met with Reservations	Yes	Yes (% sessions not reported)	Yes
Bailey et al. (1983)	Evidence Standards Met with Reservation	Yes	Yes (<20 % of sessions)	Yes
Neufeld and Fantuzzo (1984)	Evidence Standards Not Met	Yes	Yes	No
Slifer et al. (1984)	Evidence Standards Met	Yes	Yes	Yes
Carr and Durand (1985)	Evidence Standards Met	Yes	Yes	Yes
Jenson et al. (1985)	Evidence Standards Not Met	Yes	Yes (<20 % of sessions)	No
Luiselli (1986)	Evidence Standards Met with Reservations	Yes	Yes (<20 % of sessions)	Yes
Durand and Carr (1987)	Evidence Standards Met	Yes	Yes	Yes
Iwata et al. (1990)	Evidence Standards Met	Yes	Yes	Yes
Linscheid et al. (1990)	Evidence Standards Met	Yes	Yes	Yes
Steege et al. (1990)	Evidence Standards Met	Yes	Yes	Yes
Wacker et al. (1990)	Evidence Standards Met	Yes	Yes	Yes
Mazaleski et al. (1993)	Evidence Standards Met	Yes	Yes	Yes
Van Houten (1993)	Evidence Standards Met with Reservation	Yes	Yes (<20 % of sessions)	Yes
Williams et al. (1993)	Evidence Standards Met	Yes	Yes	Yes
Vollmer et al. (1993)	Evidence Standards Met	Yes	Yes	Yes
Goh and Iwata (1994)	Evidence Standards Met	Yes	Yes	Yes
Linscheid et al. (1994)	Evidence Standards Met with Reservation	Yes	Yes (<20 % of sessions)	Yes
Williams et al. (1994)	Evidence Standards Not Met	Yes	Yes	No
Zarcone et al. (1994)	Evidence Standards Met	Yes	Yes	Yes
Kennedy and Souza (1995)	Evidence Standards Met	Yes	Yes	Yes
Mudford et al. (1995)	Evidence Standards Met	Yes	Yes	Yes
Roberts et al. (1995)	Evidence Standards Met	Yes	Yes	Yes
Vollmer et al. (1995)	Evidence Standards Met	Yes	Yes	Yes

(continued)

Table 24.3 (continued) Degree to which Evidence Standards and criteria met by study

Grace et al. (1996)	Evidence Standards Met	Yes	Yes	Yes
Lalli et al. (1996)	Evidence Standards Met	Yes	Yes	Yes
Saunders et al. (1996)	Evidence Standards Met	Yes	Yes	Yes
Fischer et al. (1997)	Evidence Standards Met	Yes	Yes	Yes
Horner et al. (1997)	Evidence Standards Met	Yes	Yes	Yes
Fisher et al. (1998)	Evidence Standards Met	Yes	Yes	Yes
Mace et al. (1998)	Evidence Standards Met	Yes	Yes	Yes
Oliver et al. (1998)	Evidence Standards Met	Yes	Yes	Yes
Roscoe et al. (1998)	Evidence Standards Met	Yes	Yes	Yes
Vollmer and Vorndran (1998)	Evidence Standards Met	Yes	Yes	Yes
O'Reilly and Lancioni (2000)	Evidence Standards Met	Yes	Yes	Yes
Healy et al. (2001)	Evidence Standards Met	Yes	Yes	Yes
Kahng et al. (2001)	Evidence Standards Met	Yes	Yes	Yes
Linscheid and Reichenbach (2002)	Evidence Standards Met	Yes	Yes	Yes
MacDonald et al. (2002)	Evidence Standards Met	Yes	Yes	Yes
Kurtz et al. (2003)	Evidence Standards Met	Yes	Yes	Yes
Salvy et al. (2004)	Evidence Standards Met	Yes	Yes (<20 % of observations)	Yes
Kerth et al. (2009)	Evidence Standards Met	Yes	Yes	Yes
Tiger et al. (2009)	Evidence Standards Met	Yes	Yes	Yes
Toussaint et al. (2012)	Evidence Standards Met	Yes	Yes	Yes

Procedures meeting only two of these three criteria were determined to be supported by Moderate Evidence. Those meeting fewer than two of these criteria were categorized as having Limited Evidence-based support in the literature. Twenty-six procedures or combinations of procedures that were rated among the 72 studies surveyed as *Evidence Standards Met* or *Evidence Standards Met with Reservation* were examined (Table 24.4). Most procedures considered were multicomponent procedures, consisting of at least two different procedures for which efficacy in reducing or eliminating self-injury was demonstrated when they were implemented together. We report data regarding degree to which evidence standards are met in two ways. First, we consider each intervention or multicomponent intervention published separately. When we do this, no interventions met the criteria for a rating of supported by *Strong Evidence*; two multicomponent procedures (8 % of those considered) were found to be supported by *Moderate Evidence*; the remaining 92 % of procedures considered (24 of the 26) were found to be supported by *Limited Evidence*.

We then regrouped the procedures, and categorized them according to the first component listed by the authors in the multicomponent intervention. For example, a study examining efficacy of Positive Punishment + Differential Reinforcement in reducing SIB would be classified with studies examining positive punishment. Classified this way, there were twelve categories of interventions, and two were found to be supported by Strong Evidence, one by Moderate Evidence, and the remaining nine by Limited Evidence (Table 24.4).

Antecedent Interventions

Antecedent-based interventions involve managing discriminative stimuli, motivating operations, and setting events found to be functionally related to the self-injury. Such interventions can include providing noncontingent access to stimuli that function as reinforcers (Healy et al., 2001; Mace et al., 1998; Vollmer et al., 1993); altering motivation operations that affect the reinforcers maintaining the self-injury and so altering evocative effect of discriminative stimuli that occasion that self-injury (Horner et al., 1997; O'Reilly & Lancioni, 2000, Van Houten, 1993), delivery of task instructions such that instructions less likely to occasion compliance are preceded by a number of instructions for which compliance is more likely (Zarcone et al., 1994); or environmental enrichment (Favell et al., 1982; Kahng et al., 2001). In other instances, protective equipment was applied which prevented occurrence of self-injury, and which was systematically faded and eliminated in conjunction with other procedures (Dorsey et al., 1982; Kahng et al., 2001) or was provided noncontingently (Kerth et al., 2009). In all, 18 of 72 studies examined (25 %) involved antecedent interventions.

Strong evidence. Although 25 % of studies examined involved included demonstration of efficacy of antecedent interventions or multicomponent procedures involving at least one antecedent intervention, no antecedent intervention was reported in the self-injurious behavior literature in a sufficient number of studies, conducted by a sufficient number of geographically distinct research teams, with a sufficient number of participants to be rated as supported by *Strong Evidence*.

Moderate evidence. Noncontingent or fixed-time delivery of stimulus changes that have reinforcer function when occurring contingently, also known as noncontingent reinforcement or noncontingent negative reinforcement, was found efficacious either by itself (Kerth et al., 2009; Roscoe et al., 1998; Vollmer et al., 1995) or in conjunction with other procedures (Healy et al., 2001; Mace et al., 1998; Vollmer et al., 1993). When taken together as a group, procedures incorporating noncontingent reinforcement or noncontingent negative reinforcement have been reported in at least six studies, conducted by at least five geographically distinct research teams, and have been shown efficacious with at least ten participants (Table 24.4). These data suggest that procedures involving noncontingent reinforcement or noncontingent negative reinforcement as a main component are supported by *Moderate Evidence*.

Table 24.4 Degree to which procedures Meet Evidence Standards

Procedure	Authors	Degree of evidence	Number of studies	Number of independent research teams	Total number of participants
Positive punishment	Tanner and Zeiler (1975), Kelly and Drabman (1977), Singh (1980), Luiselli et al. (1981), Bailey et al. (1983), Linscheid et al. (1990), Williams et al. (1993), Linscheid et al. (1994), Mudford et al. (1995), Fisher et al. (1998), Linscheid and Reichenbach (2002), Salvy et al. (2004)	Moderate evidence	12	10	16
Positive punishment + Differential reinforcement	Corte et al. (1971), Colemand et al. (1979), Dorsey et al. (1980), Johnson et al. (1982), Wesolowski and Zawlocki (1982)	Moderate evidence	5	5	17
Positive punishment + Warning stimulus	Foxx and Azrin (1973)	Limited evidence	1	1	1
Positive punishment + Protective equipment fading + Environmental enrichment	Kahng et al. (2001)	Limited evidence	1	1	1
Negative punishment	Kennedy and Souza (1995)		1	1	1
Differential reinforcement	Mazaleski et al. (1993), Roberts et al. (1995), Saunders et al. (1996), Vollmer and Vorndran (1998), Tiger et al. (2009), Toussaint and Tiger (2012)	Moderate evidence	6	5	9
Differential reinforcement + Response interruption	Azrin et al. (1982), Slifer et al. (1984)	Limited evidence	2	2	3
Differential reinforcement + Environmental enrichment	Favell et al. (1978), Favell et al. (1982)	Limited evidence	2	2	9
Differential reinforcement + Guided compliance + Time out	Wacker et al. (1990)	Limited evidence	1	1	2
Response blocking	MacDonald et al. (2002)	Limited evidence	1	1	1
Positive reinforcement + Negative punishment within a level system	Grace et al. (1996)	Limited evidence	1	1	1
Negative reinforcement	Steege et al. (1990)	Limited evidence	1	1	1
Extinction	Goh and Iwata (1994)	Limited evidence	1	1	1

Extinction + Physical guidance + Response blocking + Differential reinforcement	Iwata et al. (1990)	Limited evidence	1	1	7
Noncontingent reinforcement	Vollmer et al. (1995), Derby et al. (1996), Fischer et al. (1997), Roscoe et al. (1998), Kerth et al. (2009)	Moderate evidence	5	5	8
Noncontingent reinforcement + Warning stimulus + Extinction	Mace et al. (1998)	Limited evidence	1	1	1
Noncontingent reinforcement + Schedule instructions	Healy et al. (2001)	Limited evidence	1	1	1
Noncontingent reinforcement + Differential reinforcement	Vollmer et al. (1993)	Limited evidence	1	1	2
Motivating operation manipulation	Van Houten (1993), Horner et al. (1997), Lalli et al. (1996), O'Reilly and Lancioni (2000)	Limited evidence	4	4	5
High probability instructional sequence + Extinction	Zarcone et al. (1994)	Limited evidence	1	1	2
Functional communication training	Carr and Durand (1985), Durand and Carr (1987)	Limited evidence	2	1	4
Functional communication training + Punishment + Differential reinforcement	Kurtz et al. (2003)	Limited evidence	1	1	30
Functional communication training + Delay in access to preferred event	Kern et al. (1997)	Limited evidence	1	1	1
Contingent application of protective equipment	Dorsey et al. (1982), Luiselli (1986)	Limited evidence	2	2	4
Systematic protective equipment fading	Oliver et al. (1998)	Limited evidence	1	1	1
Contingent application of protective equipment + Differential reinforcement	Luiselli (1986)	Limited evidence	1	1	1

Noncontingent delivery of reinforcers has been found to decrease the frequency of behaviors on which those reinforcers were previously contingent by virtue of providing an alternative source of reinforcement, thereby decreasing the value of reinforcement that occurs contingent on the targeted behavior (Hagopian, Crockett, Stone, Deleon, & Bowman, 2000). Given this, the mechanism underlying effective noncontingent reinforcement procedures is an abolishing operation. Vollmer et al. (1995) determined on functional analysis that self-injury for an 18-year-old man diagnosed with profound intellectual disability was maintained by contingent escape from task demands. These researchers provided escape from task demands on a fixed time schedule, irrespective of occurrence of the self-injury, and found a reduction in self-injury to zero frequency. Mace et al. (1998) combined noncontingent escape from task demands with a visual schedule indicating when the noncontingent escape would occur, and found a reduction to near zero rate of self-injury for their 7-year-old participant with autism and moderate intellectual disability. Roscoe et al. (1998) provided noncontingent access to leisure items for three participants with profound intellectual disabilities whose self-injury was found on functional analysis to be maintained by nonsocially mediated reinforcement. In all three instances, rate of self-injury was reduced to near zero. Kerth et al. (2009) provided noncontingent access to clothing that permitted self-restraint for a 16-year-old boy diagnosed with autism and severe intellectual disability, whose self-injury was found to be maintained by access to attention and materials and by demand termination. Doing so resulted in reductions in self-injury by 54 % relative to baseline rates. Healy et al. (2001) provided access to sensory materials on a fixed-time schedule for a 21-year-old man with autism and profound intellectual disability whose self-injury was found to be maintained by nonsocially mediated reinforcement. Doing so produced reductions in rate of self-injury by more than 50 % relative to baseline. In each of these instances, a stimulus change found to be functionally related to the participant's self-injury was delivered on a response irrelevant basis, and the result was a reduction in the self-injury. Fischer et al. (1997) identified a stimulus that functioned as a reinforcer (e.g., food) for behaviors reinforced by stimuli other than food, and found that when this stimulus was delivered on a response irrelevant schedule, a reduction in self-injury was found for both adult participants diagnosed with profound intellectual disability. This latter result is interesting in that response irrelevant access to an arbitrary reinforcer, rather than one determined to be functionally related to the self-injury, was found to decrease frequency of self-injury.

Limited evidence. While procedures involving noncontingent reinforcement may be found to have support by *Moderate Evidence* when grouped together, when these unique combinations of procedures are considered separately, each is supported by *Limited Evidence*, given insufficient numbers of reports, geographically independent research teams, and/or participants (Table 24.4).

Motivating operation based interventions. A number of studies have reported manipulation of motivating operations which resulted in reductions in self-injury. Van Houten (1993) provided wrist weights to a 10-year-old boy diagnosed with severe intellectual disabilities whose self-injury was maintained by nonsocially mediated reinforcement. As a result of increasing response effort required to engage in self-injury, SIB was reduced to zero frequency when wrist weights were worn. Horner et al. (1997) identified naturally occurring abolishing operations (e.g., unplanned delay in planned preferred event, sleep deprivation), which were functionally related to increases in problem behaviors, including self-injury, for their participants. Next, they provided alternative activities (e.g., formally rescheduling the delayed event and spending time engaging in a highly preferred activity, nap) and examined the extent to which these events might counteract the evocative effect of the abolishing operation. In all instances, providing the alternative activities (termed "neutralizing routines") resulted in a decrease in problem behaviors to near zero. O'Reilly and Lancioni (2000) also identified sleep deprivation as a motivating operation related to their participant's self-injury. They found that providing their participant with an opportunity to nap decreased self-injury to fewer than 10 % of 10 s intervals, from baseline measures of 10–50 % of intervals with self-injury. Each of these studies provides clear demonstrations of efficacy of these motivating operation based interventions in reducing self-injury for the participants involved, but none of the procedures involved were replicated across sufficient studies, research teams, or participants to permit stating that each is supported by more than *Limited Evidence* in the literature.

High probability instructional sequence. Zarcone et al. (1994) combined a high-probability instructional sequence with extinction to treat problem behavior which included head-banging for a 38-year-old man diagnosed with profound intellectual disability. High probability instructional sequence interventions involve delivering 3–5 instructions to which compliance is very likely prior to giving an instruction to which compliance is unlikely. Such an instructional sequence gives opportunity for the participant to experience a momentarily high rate of reinforcement for following instructions, which may increase probability that the low probability instruction will be followed. Functional analysis found that the participant's head-banging was maintained by contingent demand termination. Implementing the high probability instructional sequence plus extinction following self-injury resulted in near zero rates of self-injury. Their data, however, suggest that the extinction component was very critical to the success of this intervention, as rates of self-injury were much higher when the high probability instructional sequence was implemented alone, without extinction. Despite the strong demonstration of efficacy of this combined intervention for this participant, there have been insufficient reports of this combination of interventions across insufficient numbers of research teams with an insufficient number of participants to permit determination of more than support by *Limited Evidence*.

Response blocking. MacDonald et al. (2002) determined that the eye poking exhibited by their 5-year-old participant diagnosed with language delays was maintained by nonsocially mediated reinforcement. They found that providing their participant with goggles resulted in near zero rates of eye poking when goggles were worn, but at slightly higher than baseline rates of eye poking when goggles were not worn, and that these findings occurred across settings.

Fading use of protective equipment. Protective equipment, or restraining devices, are sometimes used to prevent injury when self-injury has been resistant to intervention. Often, this equipment is applied contingent on an instance of self-injury or a behavior that is reliably precurrent to self-injury. Kahng et al. (2001) combined environmental enrichment and exercise contingent on self-injury with reductions in rigidity of arm restraints worn by a 16-year-old girl with severe intellectual disability, and found reductions to near zero rates of both hand to head self-injury and other types of self-injury when the three component package was implemented. Again, despite the strong demonstration of efficacy of this treatment package within this study, insufficient reports of this intervention have been published to permit more than a determination of support by *Limited Evidence*.

Consequence Interventions

Consequence based interventions have been a fixture in treatment of problem behavior since at least the 1960s. These interventions involve delivery of punishers, delivery of reinforcers, removal of reinforcers, removal of punishers, or prevention of consequences that theretofore followed the targeted behavior; as well as interventions such as response interruption, contingent prompting, and contingent use of protective equipment. Of the 60 studies involving consequence based interventions reviewed, 32 (or 53 %) involved punishment procedures, 30 (or 50 %) involved reinforcement-based procedures, seven (or 12 %) involved extinction-based procedures, and six (or 10 %) involved either response interruption, contingent prompting, or contingent application of protective equipment (Table 24.1). Although frequency of articles reporting punishment procedures decreased over the 40 year period between 1965 and 2014, frequency of reinforcement- and extinction-based procedures remained relatively stable during this same time (Table 24.1).

As with our consideration of antecedent interventions, consideration of studies involving consequence-based interventions to determine extent to which the procedures contained there in are supported in the literature by *Strong Evidence*, *Moderate Evidence*, or *Little Evidence* is complicated by reporting of numerous multicomponent interventions involving consequence-based interventions. Below, we will report extent to which individual interventions are supported by the three degree categories of evidence, as well as the extent to which groupings of interventions are supported by these varying degrees of evidence.

Strong evidence. Only procedures reported in at least five single subject design studies, conducted by at least three geographically distinct research teams, with a total of at least 20 participants are said to be supported in the literature by *Strong Evidence*. Given these requirements, no procedures reported in the studies reviewed met the criteria for *Strong Evidence*. However, if one groups interventions by primary component, several groupings of interventions do meet this variation on support by *Strong Evidence*. These are described as follows.

Positive punishment-based procedures. Positive punishment involves contingent application of a stimulus, following occurrence of a target behavior, resulting in a decrease in that behavior over time. Seventeen studies were published between 1965 and 2014 in which positive punishment was a main feature, and these studies were conducted by 15 geographically independent research teams, and a total of 32 participants were involved (Table 24.4). Electric shock delivered contingent on self-injurious responses was found to decrease self-injury by Corte et al. (1971), Luiselli et al. (1981), Williams et al. (1993), Linscheid et al. (1994), Linscheid & Reichenbach (2002), and Salvy et al. (2004). Fisher et al. (1998) reported a variation on contingent delivery of electric shock, by substituting contingent transcutaneous electrical nerve stimulation (TENS), and found that this milder form of electrical stimulation, often used medically for pain relief, was also efficacious in reducing self-injury. Duker and Seys (1996) examined long term effectiveness of contingent electric shock in suppressing self-injury for twelve individuals. They report that observations made up to 47 months after initial suppression of SIB was achieved by this procedure indicated that self-injury remained at zero rates for seven of the 12 individuals; that moderate reductions in self-injury were maintained for three individuals; and that suppression of SIB by contingent electric shock was not maintained over this time for two individuals.

As an alternative to contingent electric shock, Tanner and Zeiler (1975) delivered contingent aeromatic ammonia following instances of self-slapping exhibited by a 20-year-old woman diagnosed with autism. These authors report rapid reduction in rate of self-injury to zero, however they do not report any measurement of self-injury outside of their 5 min observation/intervention sessions, and so conclusions that can be drawn from this study are severely limited.

Bailey et al. (1983) delivered water mist to the face contingent on hand mouthing and hand-biting exhibited by a 7-year-old boy with severe intellectual disability. These authors report rapid suppression of self-injury with no ill effects. Dorsey et al. (1980) found contingent water mist efficacious in eliminating self-injury for all seven of their participants, and demonstrated that a combination of contingent water mist plus verbal reprimand plus differential reinforcement of other behavior facilitated generalization of the reduction in self-injury from one environment to another for both participants for whom this combined intervention was implemented.

Overcorrection in the form of contingent exercise involves requiring (either through instruction or through prompting) repeated movements contingent on emission of the targeted response. These repeated movements are often correct execution of a particular task, but are sometimes other effortful movements, such as arm exercises. Such interventions were demonstrated efficacious by Kelly and Drabman (1977), and when combined with differential reinforcement was found efficacious by Coleman et al. (1979) and Johnson et al. (1982). Foxx and Azrin (1973) combined overcorrection with a verbal warning to enhance generalization of the punishment effect brought about through the overcorrection, such that behaviors precurrent to self-injury were followed by a verbal warning, and if the precurrent did not stop, or if self-injury followed, overcorrection was implemented. When the verbal warning was added, frequency of self-injury remained near zero, and overcorrection was only infrequently administered. Kahng et al. (2001) found that application of protective equipment contingent on hand to head self-injury resulted in collateral increases in other self-injurious responses, but that these collateral responses decreased when contingent exercise was added.

Differential reinforcement based procedures. Differential reinforcement involves a combination of reinforcement and extinction procedures. Differential reinforcement of other behavior (DRO) involves identification of and extinction for a targeted behavior, and delivery of reinforcement following passing of intervals in which any behavior occurred but that behavior. Differential reinforcement of alternative behavior (DRA) involves identification and extinction for a targeted behavior, and delivery of reinforcement contingent on a specified alternative topography. Differential reinforcement of incompatible behavior (DRI) is essentially similar to DRA, but that the particular alternative topography on which reinforcement is contingent is one that is physically impossible to emit simultaneously with the behavior targeted for extinction. Several variations on these basic differential reinforcement arrangements include differential negative reinforcement for other behavior (DNRO), differential negative reinforcement for alternative behavior (DNRA), and differential negative reinforcement for incompatible behavior (DNRI). Each of these procedures is identical to the respective basic differential reinforcement procedures, but for substitution of termination of a stimulus or event—often escape from a situation—rather than delivery of a reinforcer, contingent on occurrence of other topographies.

Mazaleski et al. (1993), Tiger et al. (2009), and Toussaint and Tiger (2012) implemented DRO procedures, whereby delivery of empirically determined reinforcing consequences was delivered contingent on passage of intervals during which behaviors exclusive of targeted self-injury responses occurred. Mazaleski et al. found that DRO implemented in this manner was insufficient to reduce self-injury, but that adding an extinction component did produce reduction in self-injury to near zero rates. In contrast, Tiger et al. found DRO sufficient to eliminate self-injury for their participant who was diagnosed with Asperger's Disorder, and taught their participant to self-monitor, which may have added additional feedback which could help maintain reductions in self-injury. Given the covert nature of the self-injury exhibited by their participant, Toussaint and Tiger (2012) implemented a variable momentary differential reinforcement of other behavior contingency, by which engagement in behavior exclusive of self-injury at the moment of direct observations made on a variable time schedule resulted in reinforcement. These researchers were able to bring about near zero rates of self-injury, with intervals expanding to 5 min duration.

Functional communication training is a differential reinforcement of alternative behavior procedure implemented when it is determined that the behavior to be reduced functions as a mand. This intervention includes reinforcement for manding combined with extinction for the behavior targeted for reduction. Carr and Durrand (1985) reinforced manding assistance and extinguished a set of problem behaviors which included self-injury for four participants with intellectual disabilities whose problem behavior was evoked by increased task difficulty, and found increases in manding and near zero frequency of problem behaviors for their participants. These findings were replicated by Durrand and Carr (1987).

Functional analysis conducted by Vollmer and Vorndran (1998) found that their participant's self-injury was maintained by contingent access to protective equipment. These researchers provided access to the equipment contingent on manding a sweater that functioned similarly to the protective equipment, and no access to restraint materials following self-injury, and the result was zero rates of self-injury while this intervention was in place.

Roberts et al. (1995) implemented DNRA, providing breaks for task demands contingent on following instructions during self-care tasks, and physical guidance was provided following noncompliance with these instructions. These authors found reduction in rate of self-injury to 0–5 instances per minute (from baseline rates three to five times that amount), and found DNRA to be superior to DNRO in reducing their 4-year-old participant's self-injury.

A number of authors have combined differential reinforcement with other procedures. Azrin et al. (1982) combined DRI with response interruption, and found this combination of procedures superior to either of these procedures alone, and to DRO, in reducing self-injury of their adult participant with severe intellectual disability. Slifer et al. (1984) found DRO plus environmental enrichment had no effect on frequency of eye gouging emitted by their 6-year-old participant with Rubella Syndrome, but found that adding a response interruption component greatly reduced frequency of this behavior, with treatment gains maintained over 9 months. Favell et al. (1978) combined a DRO procedure, whereby access to restraint materials was made contingent on passage of durations in which behaviors exclusive of SIB occurred, with environmental enrichment, and found percentage of intervals with self-injury approaching zero. Favell et al. (1982) combined DRA, in which toy play was reinforced and SIB was not, with environmental enrichment, and likewise found reductions in self-injury for their participants.

Moderate evidence. Procedures meeting at least two of three evidence support criteria (e.g., publication in at least five studies that met evidence standards, conducted by at least three geographically independent research teams, and involving at least 20 participants) are determined to be supported in the literature by *Moderate Evidence*.

Positive punishment. Described previously in a grouping of all procedures involving positive punishment, positive punishment implemented exclusive of other procedures, meets criteria for *Moderate Support*. Our review found 11 published reports conducted by nine geographically independent research teams involving 15 participants detailing efficacy of this intervention (Table 24.4).

Differential reinforcement. Also described previously in a grouping of all procedures involving differential reinforcement, differential reinforcement implemented exclusive of other procedures meets criteria for *Moderate Support*. Our review found five articles published by five geographically distinct research teams involving eight participants whose self-injury was reduced or eliminated by differential reinforcement alone (Table 24.4).

Limited evidence. There have been many studies published that detail efficacy of various procedures in reducing or eliminating self-injurious behavior in people with disabilities. Many of these studies additionally shape or accelerate other behaviors to serve the functions previously served by the self-injury. However, in many instances, the procedures contained in these studies have been reported in an insufficient number of studies, and/or in studies conducted by an insufficient number of geographically independent research teams, and/or involved an insufficient combined number of participants to permit determination of support in the literature by more than *Limited Evidence*. We describe these procedures below.

Positive punishment + differential reinforcement. Although this procedure was previously described in the positive punishment grouping, when considered independent of other procedures involving positive punishment, this intervention meets criteria for *Limited Evidence*. Corte et al. (1971) combined contingent electric shock with differential reinforcement and eliminated self-injury in all four of their participants. Coleman et al. (1979) and Johnson et al. (1982)

combined contingent physical exercise (overcorrection) with differential reinforcement and report substantial reductions in self-injury for all participants across two settings (Coleman et al., 1979), and that positive punishment combined with differential reinforcement was more effective than differential reinforcement alone (Johnson et al., 1982). Finally, Wesolowski and Zawlocki (1982) report that contingent exercise plus differential reinforcement of other behavior was superior to auditory time out plus DRO, auditory time out alone, and response blocking in reducing eye poking in their two participants, and that the reductions were maintained 1 year later.

Positive punishment + a warning stimulus. Foxx and Azrin (1973) applied contingent exercise (overcorrection) to hand mouthing exhibited by four children with intellectual disability, and found substantial reductions in each case. In preparation for generalization of this reduction to non-experimental environments, these researchers delivered a warning stimulus (e.g., a stern, "No") contingent on a topography precurrent to hand mouthing. If the precurrent response terminated at that point, and hand mouthing did not follow, then no overcorrection was applied. If, however, the precurrent behavior continued, or handmouthing occurred, overcorrection was applied. Foxx and Azrin (1973) report the warning stimulus acquired inhibitory stimulus control, and was effective in other environments in preventing occurrence of the hand mouthing.

Positive punishment + protective equipment fading + environmental enrichment. Kahng et al. (2001) reduced a targeted self-injury topography through contingent application of protective equipment. They observed, however, collateral increases in other self-injurious responses. Environmental enrichment in the form of provision of leisure materials did little to reduce this collateral SIB, but substantial reductions were observed when contingent exercise (overcorrection) was added.

Negative punishment. Kennedy and Souza (1995) report that providing enhanced visual stimulation (e.g., video game) reduced rate of eye poking slightly, but that removal of the video game contingent on eye poking produced reductions in eye poking that approached zero instances per hour.

Differential reinforcement + response interruption. Azrin et al. (1982) combined a response interruption procedure (e.g., instruction to stop and gentle prompting of hands down) with differential reinforcement of incompatible behavior in treatment of facial striking and arm biting exhibited by a lady and a gentleman diagnosed with profound intellectual disability, and found this combined procedure superior to differential reinforcement of other behavior, DRI alone, and response interruption alone for both participants. Slifer et al. (1984) combined differential reinforcement of alternative behavior with response interruption (a stern "No" combined with manual prompting of hands to toys), and found substantial reduction in eye gouging for their 6-year-old participant with profound intellectual disability.

Positive reinforcement + negative punishment within a level system. Grace et al. (1996) report on assessment and treatment of self-injury exhibited by their 21-year-old participant when no one else was present. Since they could not directly measure this covert self-injury, they instead measured response products, through physical examinations conducted by medical personnel thrice daily. Reinforcer assessment determined that social and tangible reinforcers were most potent for this gentleman. Grace and colleagues then implemented a level system in which their participant could earn or lose tokens, exchangeable for items and social events, contingent on findings of the thrice daily medical examinations. They report 100 % examinations with no new injuries within approximately 9 weeks.

Negative reinforcement based procedures. Steege et al. (1990) found that self-injury that occurred in the context of self-care activities for their two participants was maintained by negative reinforcement. They then provided brief breaks from self-care activities contingent on completing steps in the self-care routine, and report elimination of self-injury for both participants across self-care activities, maintained over 6 months.

Extinction based procedures. Goh and Iwata (1994) determined that the head banging and head hitting exhibited by their 40-year-old participant with profound intellectual disability was maintained by escape from task demands, despite ongoing contingent social attention delivered for compliance with these task demands. They exhibited an escape extinction procedure whereby the social attention continued to follow compliance with task demands, but noncompliance with task demands was followed by physical guidance through completion of the instructed task. These authors report achieving zero rates of self-injury in the context of tasks when this procedure was implemented. Iwata et al. (1990) similarly found that extinction plus physical guidance was sufficient to produce near zero rates of self-injury and increases in compliance for five of their six participants, and that addition of a response blocking procedure achieved this result for their sixth participant.

Noncontingent reinforcement based procedures. When combined, treatment packages including a noncontingent reinforcement component have been found to meet criteria for support in the literature by *Moderate Evidence*. However, considered as independent groupings of procedures, despite their common component, these interventions each meet the criteria for support by *Little Evidence*. Described earlier in this chapter, these treatment packages include noncontingent reinforcement combined with a warning stimulus and extinction (Mace et al., 1998), noncontingent reinforcement combined with differential reinforcement (Vollmer et al., 1993). Considered by itself, noncontingent reinforcement also meets the criterion for limited evidence, despite demonstrations of efficacy by Fischer et al. (1997), Kerth et al. (2009), Roscoe et al. (1998) and Vollmer et al. (1995), due to consideration in an insufficient number of publications and involvement of an insufficient number of participants.

Combining Antecedent and Consequent Interventions

A number of researchers have examined combinations of antecedent and consequence interventions in treatment of self-injurious behavior. This makes sense, given occurrence of this behavior in a temporal sequence that includes both antecedent and consequent events. When both types of events are determined to be important in evoking and maintaining the behavior, both may require intervention.

Limited evidence. Despite this state of affairs, relatively few procedures have been published that demonstrate efficacy of these combined interventions, and so those combinations that have been published meet the criteria for support in the literature by *Limited Evidence*. These are described below.

Differential reinforcement plus environmental enrichment. Favell et al. (1978) determined that restraint functioned as a positive reinforcer for the self-injury that produced access to the restraint for the 15-year-old girl with profound intellectual disability. They made access to physical restraint contingent on periods of absence of self-injury (e.g., differential reinforcement of other behavior), and provided access to preferred leisure materials during periods during which the child was not restrained. They found rapid reduction to near zero rate of self-injury with this combined procedure, and found it superior to positive punishment by contingent lemon juice presentation. Similarly, Favell et al. (1982) found that environmental enrichment produced a reduction in self-injury for their three participants whose behavior was maintained by nonsocially mediated reinforcement, but that reinforcing toy play further reduced frequency of self-injury to near 0 % of observation intervals.

High probability instructional sequence plus extinction. As described previously, the high probability instructional sequence involves delivering 3–5 instructions to which a person is likely to comply prior to delivering an instruction to which the person is less likely to comply. As a result of compliance with and reinforcement for complying with the prior 3–5 instructions, the probability of complying with the typically lower probability instruction is much greater. Zarcone et al. (1994) combined this antecedent intervention with escape extinction for two gentlemen diagnosed with profound intellectual disability, and found this combined intervention produced greater reduction in self-injury than the high probability instructional sequence implemented alone.

Other Interventions

Although a wide range of alternative interventions appear in the literature, only one is considered here. Given the number of intervention studies published examining efficacy of this intervention in treating self-injury, this intervention found to be supported by *Limited Evidence*.

Contingent or noncontingent use of protective equipment. For many who engage in self-injury, this behavior has resulted and has great potential to result in severe injury or even death. Given this, protection from these dire sequelae is of paramount importance. This protection sometimes involves use of protective equipment, such as arm splints, helmets, masks, or other devices. Luiselli (1986) applied a football helmet with a face guard and padded mittens contingent on their 16-year-old participant's striking his body or head, or his head and face banging, and maintained the differential reinforcement of other behavior procedure that was already in place. It is noted that numerous prior interventions were reported to have been implemented, to include contingent water mist and contingent exercise, to no avail. Luiselli (1986) reports that this intervention resulted in a nearly 80 % reduction in self-injury relative to implementation of the DRO procedure by itself.

Oliver et al. (1998) worked with three individuals for whom arm splints were worn noncontingently to prevent self-injury, but which also precluded fuller participation in daily life. They report systematically increasing the degree of arm flexion permitted by the splints (from 0 % flexion to 100 % flexion in 25 % increments) resulted in zero rates of self-injury and increases in positive vocalizations for one participant; and that increases in flexion from 25 % to 50 % to 75 % similarly decreased self-injury and produced variable increases in positive vocalizations for a second participant. Systematically reducing head coverage for a helmet worn by a third participant was followed by reductions in self-injury to zero with increases in positive vocalizations. Oliver et al. (1998) report no other interventions implemented in the course of restraint reduction.

Translation of Research to Practice

The evolution of pre-treatment assessment, treatment selection, and treatment evaluation for self-injurious behavior appears to largely parallel the evolution of pre-treatment assessment, treatment selection, and treatment evaluation for other behavioral difficulties. Conceptualizations were generally psychodynamic in nature (Hall, 1899; Nurnberg, 1934), and these conceptualizations drove treatment selection. Consideration of the operant nature of self-injury was sometimes accompanied by various forms of functional analysis (see Lovaas et al., 1965; Lovaas and Simmons, 1969) to identify contingencies evoking and maintaining the behavior, although some authors (i.e., Corte et al., 1971; Myers & Deibert, 1971, and others) implemented operant procedures without prior functional assessment and analysis. By the late 1980s, functional analysis or functional assessment became a standard feature in assessment of self-injury and as a tool for determining intervention procedures (Table 24.1).

Pre-treatment assessment. Pre-treatment assessment can be conceptualized as three general types of procedures. These are Indirect Assessment, which can include conducting interviews (including checklists) to collect verbal reports regarding possible controlling contingencies and other important information regarding self-injury; Descriptive Analysis, which can include data collection in the form of Antecedent–Behavior–Consequence (ABC) Event recording and use of Stimulus Control Scatterplots; and Functional Analysis, which involves systematic manipulation of antecedent and postcedent events within the context of a single subject experimental design, to determine whether any of these events is functionally related to the behavior of concern. Although Indirect Assessment produces only verbal reports regarding contingencies, which may or may not be accurate; and Descriptive Analysis produces correlational information regarding potentially controlling contingencies; Functional Analysis can result in empirical demonstration of controlling contingencies. Each of these three types of pre-treatment assessment methods is considered next.

Indirect assessment. Most pre-treatment assessments involve some type of interview. Interviews often precede functional analysis, and may inform selection of conditions (Harding, Wacker, Berg, Barretto, & Ringdahl, 2005). Post-analysis interviews are sometimes conducted when functional analyses are undifferentiated, and can inform condition selection for reanalysis. The Functional Assessment Interview (FAI) (O'Neill et al., 1997) is a comprehensive interview that can be used to generate hypotheses regarding environmental variables that may influence self-injury or other problem behavior. This interview considers both molecular variables, such as immediate antecedents and consequences, and more molar variables, such as medical conditions and medication effects, daily routines, communication capabilities, and sleep patterns. The authors recommend conducting the interview with more than one informant who has daily contact with the participant, and suggest conducting the interview with the participant, her or himself.

Several studies report pre-treatment assessment using the FAI. Sprague, Holland, and Thomas (1997) conducted FAIs to assess self-injury for two participants with intellectual disabilities. FAI-generated hypotheses were subsequently assessed and confirmed in functional analysis, and the resulting treatment substantially reduced self-injury for both participants. In contrast, English and Anderson (2004) compared hypotheses generated by the FAI with outcomes of experimental functional analyses for self-injury, and found that hypotheses developed on the basis of informants' reports (FAI) overestimated weak functional relations and underestimated strong ones.

Checklists can potentially be the quickest method of functional assessment. We will consider two: the Questions About Behavioral Function (QABF) (Matson & Vollmer, 1995) and the Motivational Assessment Scale (MAS) (Durand & Crimmins, 1988). The QABF is a 25-item questionnaire on which informants rate frequency with which self-injury occurs on a four-point Likert scale (e.g., zero indicating "never," one "rarely," two "some," and three "often") for items pertaining to maintenance by social positive reinforcement via attention (e.g., *Attention* scale), negative social reinforcement (e.g., *Escape* scale), automatic positive or negative reinforcement (e.g., *Nonsocial* scale), pain attenuation or physical discomfort reduction (e.g., *Physical* scale), or social positive reinforcement via access to tangibles (e.g., *Tangible* scale). To interpret the QABF, one examines both the number of items endorsed and sum of endorsements for each subscale. Subscales with the greatest number and sum of endorsements are said to indicate maintenance by the type of contingency for which the subscale is named. Should two or more subscales have the same number of items endorsed, the subscale(s) with higher sum of endorsements are said to reflect contingencies more strongly influencing the behavior than the subscale(s) with the same number of items endorsed but a lesser sum of endorsements. The pattern that emerges from considering number of items endorsed and sum of endorsements indicates relative strength with which each type of contingency is maintaining the behavior. High or low rate behavior occurring across multiple situations may produce patterns of endorsements that are similar across subscales.

The Motivation Assessment Scale (Durand & Crimmins, 1988) (MAS) is a 16 item questionnaire on which informants rate on a seven-point Likert scale (i.e., zero being "never" and six being "always") the frequency with which a behavior is followed by automatic reinforcement (e.g., *Self-Stimulatory* scale), negative reinforcement (e.g., *Escape/Avoidance* scale), social positive reinforcement by attention (e.g., *Attention* scale), or social positive reinforcement by gaining access to tangibles (e.g., *Tangible* scale). One transposes informants' ratings onto the scoring sheet, which categorizes the responses into four sets of four responses, corresponding to the four scales. One sums the scores and calculates means for each scale, and then rank orders the means. When one scale mean is substantially higher than others, the type of reinforcement named by that scale is said to maintain the behavior. If two or more means are high, the interpreter is cautioned to consider the possibility that instrument wasn't properly administered, and to consider readministering the scale (Monaco Associates, 2001). If, however, the interpreter determines that the scale was administered properly, and two or more scale means are equally high, then the behavior is said to be multiply maintained by those types of contingencies.

Interrater agreement for the MAS has been criticized as unacceptably low (Conroy, Fox, Bucklin, & Good, 1996), and intrarater agreement has been criticized as poor (Barton-Arwood, Wehby, Gunter, & Lane, 2003). Behavioral frequency appears to influence reliability, however, with higher frequency behaviors generally producing greater agreement than low and moderate frequency behaviors (Kearney, 1994). Test-retest reliability has been criticized as poor (Conroy et al., 1996; Durand & Crimmins, 1988), as has construct validity (Duker & Sigafoos, 1998), although internal consistency has been reported as good (Newton, 1991). Fewer studies have examined psychometric properties of the QABF. Available research, however, suggests that the QABF has acceptable test-retest reliability, interrater agreement, and internal consistency (Paclawskyj, Matson, Rush, Smalls, & Vollmer, 2000). Although these findings are promising, additional research is needed on this instrument's psychometric properties and utility.

Neither interviews nor checklists demonstrate functional relations, but only suggest them. Still, much valuable information may be learned from a well conducted interview, and an interview and a checklist may guide a more comprehensive assessment or analysis.

Descriptive analysis. Unlike Indirect Assessment methods, which involve questioning a knowledgeable informant, Descriptive Analysis involves recording data based on direct observation of events, and may be conducted by the experimenter, clinician, carer, or by the participant, him or herself. Like Indirect Assessment, however, Descriptive Analysis does not involve changing any of the events occurring in the participant's environment. Instead, information is gathered regarding naturally occurring situations in which the self-injury occurs.

Bijou, Peterson, and Ault (1968) described a method, often called Antecedent-Behavior-Consequence Event recording (or ABC recording), for recording descriptions of behaviors of interest, and events that precede and follow them. ABC recording typically involves constructing a recording form that minimally includes columns for the date, time, and descriptions of antecedent events, behavior observed, and consequent events. Additional columns may include location at which the behavior occurred (i.e., in the living room, at the day program, etc.), names of people present when the behavior occurred, and name or initials of the person making the data entry. One then observes the participant in her or his natural situations, and documents events as required by the form when the targeted behavior occurs. From these data entries, one can calculate the frequency with which the various recorded antecedent and consequent events precede and follow the targeted behavior, and these figures may suggest correlations between the behavior and environmental events, thereby suggesting possible functional relations. Despite this, this method does not inform the user as to frequency with which those events occur irrespective of the behavior, thereby potentially producing inaccurate conclusions regarding contingency.

ABC recording does not yield identification of functional relations. Instead, through analysis of the frequency with which various antecedent and consequent events accompany self-injury, it can suggest that functional relations may exist. Given this, ABC recording could be useful in determining conditions to conduct in a functional analysis. Similarly, ABC data collection has been reported as helpful in subsequent empirical identification of maintaining contingencies when functional analysis outcomes were undifferentiated (Fisher et al., 1998).

Self-injury can sometime occur with temporal regularity. Stimulus control scatterplots, first described by Touchette, MacDonald, and Langer (1985) can greatly aid discerning temporal behavioral patterns. A scatterplot is a grid on which time of day runs along the vertical axis, and day of week along the horizontal axis. Data are recorded using partial interval sampling, whole interval sampling, or momentary interval sampling, depending on nature of the behavior and question to be answered. Alternatively, one can record frequency estimates or tally counts within intervals. To record data on the scatterplot, the observer make a mark indicating occurrence or nonoccurrence (when using interval sampling), frequency estimate, or a tally of the behavior in the cell corresponding to the day and time on which the behavior happened. As such, recording can be relatively simple. Alternatively, data might be recorded in an ABC data collection system, and then the counts, frequency estimates, or records of occurrence can be transferred to the scatterplot at a later time.

Touchette et al. (1985) recorded self-injury frequency estimates for two participants with scatterplots using one hour increments along the vertical axis. When five or more instances of self-injury occurred within an hour, a filled circle was recorded; if one to four instances occurred, an open square was recorded. Hours with no self-injury were left blank. Given patterns that emerged from this data recording, Touchette and colleagues were able to rearrange events and circumstances in the participants' day such that self-injury was eliminated for one gentleman and greatly reduced for another, without imposing any direct contingencies on their behavior.

Despite reports of scatterplots included in several published studies on assessment and treatment of self-injury (Lalli, Browder, Mace, & Brown, 1993; Repp, Felce, & Barton, 1988), scatterplots themselves have rarely been published (Kahng et al., 1998). Scatterplots can become very lengthy when data are recorded across weeks or months, and recording in half-hour (or even hour) increments across the clock can possibly render a scatterplot illegible when reduced in size for publication. A scatterplot may provide valuable data regarding temporal distribution of self-injury, but additional information and data from other sources may be needed for effective action toward behavioral improvement (Hoch, 2008). Kahng et al. (1998) report that poor interobserver agreement in scatterplot documentation for self-injury and other problem behavior for 20 residents of a large residential facility rendered the scatterplots unusable without additional statistical analysis, and recommend that additional procedures may be needed to enhance utility of scatterplots.

Functional analysis. Systematic manipulation of environmental variables in the context of a single subject experimental design in an effort to identify functional relations between a behavior and those events, from which intervention can then be derived, is termed *functional analysis*. Two general types of functional analysis described in the literature are analogue functional analysis and trial based functional analysis.

Analogue functional analysis involves arranging and systematically varying antecedent and consequent conditions while measuring effects on the behavior of interest, to empirically identify contingencies maintaining that behavior. An early analysis of self-injury may be attributed to Lovaas et al. (1965), who identified social attention as a maintaining variable for the self-injury exhibited by a 9-year-old girl diagnosed with schizophrenia by alternating conditions in which attention was and was not delivered contingent on self-injurious behavior. Lovaas et al. (1965) reported greater frequency of self-injury when the behavior was followed by attention. Lovaas et al. (1969) presented data indicating that a social extinction procedure produced declines to near zero frequency of self-injury for two participants, suggesting socially mediated reinforcement (either positive or negative) may have maintained their self-injury. Carr (1977) published a conceptual paper outlining possibility that self-injury is maintained either by positive social reinforcement, negative social reinforcement, nonsocially mediated reinforcement, or that it is evoked by physiological mechanisms or is a product of faulty ego boundaries. In this argument, Carr cites evidence supporting the first four hypotheses and dismisses the fifth.

A tremendous leap forward was made in assessment and treatment of self-injury with publication of *Toward a Functional Analysis of Self-Injury* by Iwata et al. (1982). In this study, Iwata et al. demonstrated and detailed a more standardized method for assessing extent to which self-injury is maintained by social positive reinforcement, social negative reinforcement, or non-socially mediated reinforcement. Their analysis identified environmental determinants of self-injury for six of nine participants.

Subsequent functional analysis research by Iwata, Pace, et al. (1994) examined 152 analyses conducted across an 11 year period. Researchers found 26 % of instances of self-injury maintained by social positive reinforcement, with 23 % by attention, 2 % by socially mediated access to materials, and 1 % by access to food. Thirty-eight percent of cases were maintained by social negative reinforcement, with 35 % by termination of instructional demands, 1 % social interactions, 1 % physical exam termination, and 1 % ambient noise termination. These researchers suspected automatic or sensory reinforcement in 26 % of instances, with sensory positive reinforcement accounting for 20 %, sensory negative reinforcement in 1 % of cases, and unclear non-socially mediated reinforcement in 5 % of cases. Only 5 % of cases had multiple maintaining contingencies.

Analogue functional analysis has since become somewhat commonplace in assessment and treatment of self-injury, and research has continued, focusing on extent to which enriched or impoverished environments affect responding in a control condition (Kahng & Iwata, 1998), influence of including features of the participant's natural environments in the analysis (Shirley, Iwata, & Kahng, 1999); effects of differing session durations on functional analysis outcome (Wallace & Iwata, 1999); examination of possible discriminative stimulus control (Bergen et al., 2002); effects of novel versus familiar therapists on functional analysis outcome (Huete & Kurtz, 2010); extent to which spoken attention accompanies delivery of tangibles when assessing for social positive reinforcement by contingent tangible delivery (Moore, Mueller, Dubard, Roberts, & Sterling-Turner, 2002); refinement of condition procedures when functional analysis outcome is unclear (McKerchar et al., 2001); and identification of motivating operations (Smith et al., 1995). O'Reilly (1997) described a procedure through which functional analysis can be conducted with episodic self-injury that occurs with long periods between bouts. Finally, Sturmey (1994) reported on seven functional analyses through which maintaining variables were unable to be determined, and concluded that in such instances, it may be worth assessing the extent to which environmental enrichment, or provision of preferred stimuli contingent on durations in which behavior occurred exclusive of self-injury occurred may produce reductions in self-injury, before conducting further, prolonged analysis.

Analogue functional analysis has most often been conducted in the context of an alternating treatments design (e.g., Iwata et al., 1982), although some have conducted analyses using a pairwise comparison design (Iwata, Duncan, et al., 1994; Iwata, Pace, et al., 1994). Some have followed inconclusive functional analyses conducted with an alternating treatments design with continued analysis conducted in the context of a withdrawal design (Carr, Smith, Giacin, Whelan, & Pancari, 2003).

Several alternatives have been posed to analogue functional analysis conducted in the context of one of these experimental designs. As conducted by MacDonald et al. (2002), brief functional analysis involved conducting only two 5 min sessions of each of four functional analysis conditions in the context of an alternating treatments design, and were able to identify the type of reinforcement maintaining their participant's eye-poking as nonsocially mediated reinforcement. Tincani et al. (1999) compared outcome of brief functional analysis, consisting of a single session of each assessment condition, versus a traditional functional analysis conducted within an alternating treatments design, and found that both analyses produced the same outcomes, with the brief assessment requiring approximately

20 % of the time to conduct as the longer assessment.

Another alternative method of conducting functional analysis is a trial based functional analysis. Such an analysis involves conducting a series of single-trial sessions that are often one or two minutes in duration (LaRue et al., 2010). In the attention condition, the therapist stands near the participant and withholds attention unless and until the self-injury occurs, at which point attention is delivered for 20 s and the trial is terminated. The tangible condition replicates the attention condition, but for substitution of deprivation of the particular tangible and its delivery in place of the attention. In the demand condition, nonpreferred tasks are presented, and escape from task demands is contingent on occurrence of the self-injury, at which point the session is terminated. In the ignore condition, a therapist stands nearby the participant but otherwise does not interact with him or her, and the session terminates on elapsing of total session time or on the occasion of the self-injury. Finally, in the toy play (control) condition, the participant is provided with an enriched environment full of preferred leisure materials, and there is no interaction with the therapist, with the session terminating either on the occasion of session time elapsing or occurrence of a self-injurious response. LaRue et al. (2010) compared outcomes of trial based functional analyses and traditional functional analyses, and found exact agreement regarding function of behavior for four out of five participants, and close correspondence between the outcomes of the two assessments for the fifth participant.

Verbal behavior assessment. Drs. Mark Sundberg and James Partington published the *Assessment of Basic Language and Learning Skills* (*ABLLS*) in 1998. Dr. Sundberg published the *Verbal Behavior Milestones Assessment and Placement Program* (*VB-MAPP)* in 2008. Dr. Partington published a revised *Assessment of Basic Language and Learning Skills (Revised) (ABLLS-R)* in 2006, and Dr. Sundberg published the *Verbal Behavior Milestones Assessment and Placement Program (Second Edition)* in 2014. These excellent verbal behavior assessments are widely used in assessing verbal and related repertoires for children and adults with autism and intellectual disabilities, and are very helpful in developing effective instruction for these individuals. Among the repertoires assessed at the most basic level in each of these instruments is the mand repertoire. This is the repertoire that is addressed in functional communication training procedures (Carr & Durand, 1985; Durand & Carr, 1987; Kurtz et al., 2003). It is very likely that in individuals for whom mand repertoires are deficient, and with whom functional communication training is applied, that additional verbal and related repertoires would benefit from instruction. Were this done, the individuals who benefit from functional communication training may benefit from gaining further appropriate control of their worlds and additional development of relationships that can come with development of conventional verbal repertoires.

Treatment selection. A good number of studies published in the 1960s through the mid-1980s examining efficacy of interventions in reduction and elimination of self-injury did not involve pre-intervention indirect or descriptive assessment or functional analysis (Table 24.1). For these studies, choice of intervention appeared to be made on the basis of logical extensions of prior research (Azrin et al., 1975, 1982; Coleman et al., 1979; Conley & Wolery, 1980; Corte et al., 1971; Favell et al., 1982; Fleming & Nolley, 1981; Johnson et al., 1982; Luiselli, 1986; Luiselli et al., 1981; Merbaum, 1973; Repp & Deitz, 1974; Tanner & Zeiler, 1975; Wesolowski & Zawlocki, 1982), social ramifications of previously published interventions (Bailey et al., 1983; Dorsey et al., 1980; Jenson et al., 1985; Myers, 1975; Myers & Deibert, 1971; Neufeld & Fantuzzo, 1984; Singh, 1980), or need for a rapid reduction in the self-injurious behavior (Cunningham & Peltz, 1982; Dorsey et al., 1982; Morrison, 1972; Tate & Baroff, 1973).

Several studies conducted in the 1960s and 1970s, and an increasing number of studies beginning in the mid-1980s, have involved pre-treatment indirect assessment or functional analysis (Table 24.1). Given identification or strong suggestion of functional relations between environmental events and self-injury, some authors selected intervention procedures that were logically related to the demonstrated or hypothesized controlling variables (Favell et al., 1978; Grace et al., 1996; Kelly & Drabman, 1977; Linscheid et al., 1994; Linscheid & Reichenbach, 2002; Lovaas et al., 1965; Lovaas & Simmons, 1969; Oliver et al., 1998). Others conducted pre-intervention treatment evaluations, through which they compared several different interventions to determine which would have greatest effect prior to implementing that intervention (i.e., Foxx & Azrin, 1973; Lalli et al., 1996; Roberts et al., 1995; Vollmer et al., 1995).

A second method for identifying functional relevant interventions is through contingency reversal, as described by Northup, Wacker, Sasso, Steege, Cigrand, Cook, and DeRaad (1991). Briefly, this procedure begins with a functional analysis and identification of the contingency or contingencies currently maintaining the to-be-reduced behavior. Next, those contingencies are applied to an alternative behavior, while the to-be reduced behavior is met with extinction. Should one see an increase in the alternative behavior coupled with a decrease in the to-be-reduced behavior under this circumstance, then one has identified a potentially effective intervention.

Alternatively, one may use the Competing Behavior Model, described by O'Neill et al., 1997. Although presented as part of their overall functional assessment and program development package, this treatment selection format can guide selection of interventions after functional analyses or other functional assessments, as well. When using the competing behavior model, one first lists the motivating operations or setting events, immediate antecedents, and consequences for the self-injury or other problem behavior. Next, one lists an alternative behavior that already occurs under those circumstances, should one exist; and then a second replacement behavior that one could potentially teach instead of the problem behavior, and the reinforcement that might follow that behavior. Under setting event / motivating operation, immediate antecedent, behavior, and consequence categories, then, one lists, with others involved in service of the participant, as many relevant interventions that may be implemented which address those variables. The team then selects from among those variables the intervention or interventions that could feasibly be implemented, and develops an intervention around those. The goal of using this format is to identify interventions that will render the problem behavior ineffective (meaning it produces no reinforcement), inefficient (meaning alternative behaviors require less response effort than the problem behavior), and irrelevant (meaning reinforcement is more readily available for alternative behaviors) (O'Neill et al., 1997).

Treatment evaluation. All but two studies (Corte et al., 1971; Merbaum, 1973) reviewed in preparation of this chapter reported numerical data depicting either effectiveness or efficacy of interventions implemented. We consider a demonstration of a reduction or elimination of self-injury relative to baseline measures to be a demonstration of effectiveness, but such a demonstration in the context of a single subject experimental design in which a functional relation is demonstrated between the intervention and the behavior change to be a demonstration of efficacy. Of the 71 studies reviewed that presented numerical data, 53 (or 75 %) demonstrated efficacy of interventions, while 18 (or 25 %) demonstrated effectiveness.

An intervention that produces durable behavior change would be greatly preferable to one that produces behavior change limited to the experimental context. To demonstrate durability of behavior change requires measurement of follow-up data, taken after completion of the experimental study. Of the 73 studies reviewed, 56 (or 77 %) did not report follow up data, either graphically or anecdotally. Of the 23 % of studies reporting follow-up data, follow-up measurement intervals ranged from 14 days (Neufeld & Fantuzzo, 1984) to 2 years (Cautela & Baron, 1973). Several studies, themselves, were long term follow-up reports with Williams et al. (1994)

reporting reductions of self-injury remaining low 6 years after (and during continued) treatment with contingent electric shock, and McGlynn and Locke (1997) reporting a 25 year record review follow-up indicating zero instances of self-injury despite nonintervention in the interim for a gentleman whose self-injury was treated through punishment procedures at age 15 years.

Conclusions

Self-injurious behavior is a vexing problem that produces serious medical sequelae and limits life options for those who exhibit it, and creates hardship for those who care for them. Initial conceptualizations of this behavior considered it to be attributable to intrapsychic variables. More recently, self-injury is considered an operant behavior that is related to temporally antecedent and consequent variables, as well as physiological and medical variables. A number of researchers have provided very elegant demonstrations of functional relations between molecular antecedent and consequent events and self-injury (i.e., Bergen et al., 2002; Iwata et al., 1982; McKerchar et al., 2001; Moore et al., 2002; Smith et al., 1995) and others have discussed potential relationships between more molar events, such as grieving the loss of a loved one (Harper & Wadsworth, 1993), survival of a sexual assault (Burke & Bedard, 1994), or other life events (Owen et al., 2004) and self-injury.

Current assessment and intervention methods permit identification of molar and molecular variables, and so permit interventionists to select or develop treatments that address the factors that evoke and maintain the self-injury. Many of these interventions are multicomponent interventions (Table 24.1), comprised of several different interventions, given identified functions of the self-injury. While assessment has progressed greatly, one area for growth appears to be incorporation of verbal behavior assessments into functional assessment and analysis, particularly when the self-injury is found to function as a verbal response. Many impressive reductions in self-injury have been demonstrated, which have undoubtedly improved the lives of those who have previously exhibited this behavior, and those around them. Greater attention, however, must be given to measuring and reporting durability of these treatment gains.

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Rumination

25

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Introduction

Rumination (sometimes called *merycism*) is the chronic regurgitation of previously ingested food and drink, followed by reswallowing (Bryant-Waugh, Markham, Kriepe, & Walsh, 2010). For many who exhibit this behavior, rumination occurs often after eating (Lang et al., 2011) and can have severe medical and behavioral sequelae (Dunn, Lockwood, Williams, & Peacock, 1997; Gal, Hardal-Nasser, & Engel-Yeger, 2011; Gravestock, 2000). Rumination most often affects three documented populations: (1) typically developing infants (Gaddini & Gaddini, 1959; Menking, Wagnitz, Burton, Coddington, & Sotos, 1969); (2) individuals with special needs (primarily profound intellectual disabilities) (Davis & Cuvo, 1980; Sisson, Egan, & Van Hasselt, 1988); and (3) individuals with eating disorders (Schroedl, Alioto, & DiLorenzo, 2013; Weakley, Petti, & Karwisch, 1997; Williamson, Lawson, Bennett, & Hinz, 1989).

Etiology may differ across populations. In typically developing infants, rumination has been called a neurosis (Allen, 1944), and has been attributed to inadequate maternal stimulation (Gaddini & Gaddini, 1959; Hopper & Pineau, 1957; Lang & Melamed, 1969; Menking et al., 1969) or other inadequate stimulation in the immediate environment (Richmond & Eddy, 1957). Infant rumination typically occurs after 3 months of development (Anderson & Lock, 1997). In people with intellectual disabilities, rumination may evolve over time, with etiology of initial instances of rumination unknown and unreported (Starin & Fuqua, 1987). Initial instances sometimes occur in the context of a medical difficulty such as hiatal hernia (Canilleri & Malagelada, 1984). Some have reported that rumination is most likely to occur when the person engaging in the behavior has recently eaten or drunk (Vollmer & Roane, 1998). Functional analyses of rumination with this population indicate that the behavior is often maintained nonsocially mediated reinforcement (Kliebert & Tiger, 2011; Lyons, Rue, Luiselli, & DiGennaro, 2007; Matson et al., 2005; Sharp, Phillips, & Mudford, 2012; Wilder, Register, Register, Bajagic, & Neidert, 2009; Wrigley, Kahn, Winder, Vollmer, & Sy, 2010), by contingent removal of task demands (Lockwood, Maenpaa, & Williams, 1997); or by contingent social positive reinforcement (Matson et al., 2005).

In individuals with eating disorders, rumination may be a collaterally developed behavior that

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is maintained by both nonsocial and social consequences (i.e., body image, weight, social attention). Williamson et al. (1989) reported rumination occurring in the context of binging and purging, with rumination originating as a method of evoking further vomiting. Weakley et al. (1997) likewise reported evolution of rumination in the context of anorexia nervosa. Schroedl et al. (2013) reported rumination first appearing in a 17-year-old girl with typical development in the course of a severe case of influenza.

History

An article published in *Science* in 1889 summarized accounts of rumination in humans that appeared in the medical literature up until that date. The author reported that rumination was first identified and documented in 1618 by Italian anatomist Fabricious ab Aquapendente. The author went on to describe rumination occurring in three more contemporary patients. Rumination exhibited by a 27-year-old woman was described as beginning between 5 and 30 min after a meal, and involving her bringing up and chewing previously ingested food before swallowing it again, and continuing this behavior for up to 2 h, with no signs of distress. A 60-year-old gentleman's rumination was similarly described, as was that of a 35-year-old woman, who was described as coming from a "highly neurotic family." The author then described rumination in six patients with intellectual disabilities and three with dementia. In each of these cases, rumination commenced after eating, consisted of chewing and reswallowing previously ingested food, continued for up to 2 h after eating, and caused no distress for those engaging in this behavior (Anonymous, 1889, p. 418).

More contemporary descriptions of rumination, regardless of population in which the behavior occurs, are similar to the one just described (see Table 25.1). Topographies exhibited by infants have included stimulating the oral tract with fingers or hands, extension of the head or neck, bringing up previously swallowed stomach contents, sucking movements of the mouth, and reswallowing (Gaddini & Gaddini, 1959; Lang & Melamed, 1969; Libet, Sajwaj, & Argas, 1973; Menking et al., 1969; Mestre, Resnick, Wallace, & Berman, 1983; Sajwaj, Libet, & Agras, 1974; Toister, Condron, Worley, & Arthur, 1975). Topographies reported among children, adolescents, and adults with intellectual disabilities have included movements of the face or throat such as sucking motions, movements of the Adam's apple, mouth opening, and tongue extension, followed by presence of previously ingested stomach contents entering the mouth such that cheeks puff outward, then rotary mouth movements, followed by reswallowing contents of the mouth (Carroll, Rapp, Rieck, & Siewert, 2011; Clauser & Scibak, 1990; Daniel, 1982; Foxx, Snyder, & Schroeder, 1979; Heering, Wilder, & Ladd, 2003; Lobato, Carlson, & Barrera, 1986; McKeegan, Estill, & Campbell, 1987; Rast, Johnston, Allen, & Drum, 1985; Sharp et al., 2012; Sisson et al., 1988; White & Taylor, 1967; Woods, Luiselli, & Tomassone, 2013; Yang, 1988). There have been occasional reports of a child, adult, or adolescent with an intellectual disability orienting toward an empty bowl prior to ruminating (Smeets, 1970), belching (Foxx et al., 1979), manually stimulating the oral tract (Carroll et al., 2011; Glasscock, Friman, O'Brien, & Christophersen, 1986; Marholin, Luiselli, Robinson, & Lott, 1980; Singh, Manning, & Angell, 1982), and expelling previously ingested stomach contents after they reenter the mouth (Dunn et al., 1997; Lockwood et al., 1997). Reports of rumination topographies exhibited by adolescents or adults with eating disorders (e.g., anorexia nervosa or bulimia nervosa) have included binging, self-induced vomiting, rechewing, and reswallowing previously digested food (Weakley et al., 1997), or simply regurgitating and reswallowing previously ingested foods (Williamson et al., 1989).

Intervention to suppress, manage, or treat the behavior have included psychodynamic, consequence, antecedent, and combined interventions. Interventions from a psychodynamic perspective have been reported in insufficient detail to permit replication (Gaddini & Gaddini, 1959; Menking et al., 1969). These interventions

Table 25.1 Participants, onset and duration of rumination, topographical descriptions, behavioral measures, and experimental designs

Authors	Participant	Onset	Topography	Duration	Measures	Design
Gaddini and Gaddini (1959)	6 mothers (23–35 years old), 6 infants (3 months, 15 days–8 months, 14 days)	Within 1–2 h after eating	Placing one or more fingers in mouth (2 Ss); bringing up previously swallowed food (6 Ss); rotating and sucking movements of the tongue (2 Ss); reswallowing some or all of previously swallowed food (6 Ss)	Not reported	Count of ruminations	Not reported
White and Taylor (1967)	23-year-old woman (severe ID) 14-year-old boy (profound ID)	During meal; shortly after meal	Facial, throat, or eye movements followed by vomiting and rumination	Not reported	Rate of ruminations	Not reported
Luckey et al. (1968)	6-year-old boy (severe ID)	After eating	Vomiting with rumination	Not reported	Count of ruminations	Not reported
Lang and Melamed (1969)	9 months boy	10–15 min after each meal	Fingers in mouth, thumb sucking, blotchiness of face, followed by vomiting and rumination	Not reported	Duration of vomiting	AB
Menking et al. (1969)	6.5 months boy	Immediately after onset of gastrostomy tube feedings	Thumb sucking, thumb removed from mouth, head slightly extended, tongue stretched forward and curved in spoon like fashion, contractions of abdominal wall, followed by stomach contents filling child's mouth chewing movements, and reswallowing	Not reported	Not reported	Not reported
Galbraith et al. (1970)	13-year-old boy (severe ID)	Not reported	Not topography	Not reported	Weight, count of vomiting	AB
Smeets (1970)	18-year-old man (profound ID)	Almost immediately after completing meal	At end of meal, orienting face toward empty food bowl or drink bottle, followed by ruminating and vomiting	Not reported	Percentage intervals with vomiting and with rumination	AB
Libet et al. (1973)	6 months girl	Immediately after feeding	Child would gag herself, change her position, and roll her tongue, followed by vomiting and rumination	Not reported	Duration of vomiting; weight	AB
Sajwaj et al. (1974)	6 months girl (cleft lip and palate)	Immediately after feeding	Opening mouth, elevating and folding tongue, vigorously thrusting tongue forward and backward, followed by formula entering child's mouth, with some reswallowed and some exiting her mouth	20–40 min	Percentage intervals with rumination	AB

(continued)

Table 25.1 (continued)

Authors	Participant	Onset	Topography	Duration	Measures	Design
Toister et al. (1975)	7.5 months boy	After feeding, once placed in crib	Assume sitting or crawling position, rock back and forth, thrust thumb into mouth, vomit, ruminate	Not reported	Rate of rumination; weight	AB
Foxx et al. (1979)	25-year-old man 22-year-old woman (profound ID)	Following meals	Sucking motion, cheeks moving inward, Adam's apple moving up and down; opening mouth, sticking out tongue, belching, cheeks filling with vomitus, mouth closing and catching vomitus	30 min	Percentage intervals with rumination	Multiple baseline across participants
O'Neil et al. (1979)	26 months girl	5–10 min after feeding	Stomach muscle contractions, tongue thrusting, placement of hands or one or more fingers in mouth, ejection of vomitus from mouth	1 h	Percentage intervals with rumination	Multiple treatment withdrawal design
Marholin et al. (1980)	16-year-old boy (profound ID)	Following meals	Placing thumb of right hand in mouth, thrusting tongue toward posterior oral cavity, followed by vomiting and rumination	30–60 min	Weight	Treatment only
Davis et al. (1980)	26-year-old man (profound ID)	Not reported	Not reported	Not reported	Count of ruminations	Multiple baseline across meals
Daniel (1982)	10-year-old boy (profound ID)	Throughout waking hours (when not walking)	Visual or auditory perception of gagging which may or may not have been accompanied by a surge of vomit into through or mouth, expansion of cheeks, followed by expansion of cheeks	Not reported	Rate of rumination	AB
Conrin et al. (1982)	23-year-old and 19-year-old men (profound ID)	Immediately after meals	Bobbing of head and upper body; observable swelling of cheeks and chewing movements; movement of the Adam's apple and subsiding of swelling of cheeks	2 h	Rate and duration of rumination	ABAB
Singh et al. (1982)	Two 17-year-old boys (profound ID)	Throughout waking hours, more frequently after meals	Placing fingers in the mouth, extending tongue, followed by upward movement of throat accompanied by cheeks puffing out, then chewing motions with mouth closed	Not reported	Percentage intervals with rumination	Multiple baseline design across participants and meals
Mestre et al. (1983)	16 week old boy	After feeding	Tongue smacking movement, extension of the head, regurgitation of previously ingested material, followed by reswallowing	Not reported	Count of vomiting by day; weight	Treatment only

Beukelman and Rogers (1984)	8-year-old boy (severe ID) 20-year-old man (profound ID)	Not reported	Not reported	Not reported	Rate of rumination	ABC
Rast, Johnston, and Drum (1984)	23-year-old woman 24- and 34-year-old men (profound ID)	Not reported	Production of previously swallowed food into mouth that returns to esophagus and stomach	Not reported	Rate of rumination	ABCDEFGA
Rast et al. (1985)	34-year-old man 18, 22, and 23-year-old women (profound ID)	Following all meals	Previously swallowed food entering mouth and then returning to esophagus and stomach	30–60 min	Rate of rumination	ABCA
Lobato et al. (1986)	28-year-old woman (profound ID) 25-year-old man (severe ID)	30 min after breakfast	Regurgitation, holding regurgitated food in mouth, chewing and swishing food, reswallowing food	Not reported	Percentage intervals with rumination and with self-stimulatory behavior	Withdrawal design in context of multiple baseline design across participants
Glasscock et al. (1986)	13-year-old girl (Batten's disease and ID)	Not reported	Manual stimulation of mouth or exaggerated coughing, followed by vomiting and rumination	Not reported	Rate of rumination	ABAB
McKeegan et al. (1987)	25-year-old man (autism and severe ID)	Immediately after each meal	Outward thrusting of the neck, followed by swelling of cheeks, then chewing and reswallowing	20 min	Mean count of rumination per interval	Multiple treatment withdrawal design
Sisson et al. (1988)	10-year-old girl (profound ID)	Throughout waking hours	Regurgitation, shewing, swishing, and reswallowing or expelling previously swallowed food.	Continuous	Percentage intervals with rumination	Multiple baseline design across time of day
Yang (1988)	17-year-old boy (profound ID)	Not reported	Expulsion of food or drink from mouth	Not reported	Count of ruminations; weight	Multiple treatment withdrawal design
Williamson et al. (1989)	24-year-old woman (bulimia nervosa)	Approximately every other day, following binging in the evening	Regurgitating and reswallowing ingested foods	A few minutes to more than 20 min	Self-reported count of nights without eating	Multiple treatment withdrawal design

(continued)

Table 25.1 (continued)

Authors	Participant	Onset	Topography	Duration	Measures	Design
Clauser and Scibak (1990)	22, 33, and 40-year-old men (profound ID)	Following every meal	Bringing up food into the mouth; chewing when nothing had been eaten, the appearance of food in the mouth or coming out of the mouth, observable movements of the mouth, tongue, and/or throat	1–2 h	Rate of rumination	Multiple treatment withdrawal design
Greene et al. (1991)	Two 37-year-old men, 45 and 53-year-old men, 31-year-old woman (severe and profound ID)	Within 20 min of completing meal	Bringing previously ingested food into mouth and reswallowing	Not reported	Count of ruminations	AB
Fullerton et al. (1992)	13-year-old girl (typical) 16-year-old boy (typical)	Not reported	Not reported	Not reported	Not reported	Not reported
Franco et al. (1993)	6-month-old boy 16-month-old boy	Not reported	Not reported	Not reported	Count of ruminations per feeding	Not reported
Tamburrino et al. (1995)	23-year-old man (typical) mid-30s-year-old woman (typical)	Not reported	Not reported	Not reported	Not reported	Not reported
Dunn et al. (1997)	24-year-old man (profound ID)	Following meals	Bringing stomach contents into the mouth as evidenced by upward movement of the Adam's apple, puffed cheeks, or vomitus emerging from mouth or nostrils.	20 min	Percentage intervals with rumination; weight	AB
Lockwood et al. (1997)	34-year-old woman (severe ID)	Following requests from staff	Vomiting into hands and rubbing vomitus into hair and clothing, rolling in vomitus on floor, or directing flow of vomitus toward staff	Not reported	Mean count of vomiting incidents per day; weight	ABC
Weakley et al. (1997)	15-year-old girl (typical)	Following meals	Binging, self-induced vomiting, rechewing, and reswallowing previously digested food	30–60 min	Self-reported count of rumination; weight	Not reported
Wilder et al. (1997)	46-year-old man (profound ID)	Not reported	Subtle motions of the jaw	Not reported	Percentage intervals with rumination	Alternating treatments design within ABAB design
Thibadeau et al. (1999)	18-year-old man (autism and ID)	Throughout the day; most often after meals	Bringing food back into mouth, puffing cheeks, visible food in mouth, strong odor emanating from mouth, reconsumption of previously digested food	Not reported	Count of ruminations	ABAB

Dudley et al. (2002)	9-year-old girl (autism)	After meals	Closing mouth and pursing lips, ending with lips opening	Not reported	Percentage intervals with rumination	ABAB
Heering et al. (2003)	19-year-old man (autism, profound ID)	Following ingestion of liquids (with neither bread nor peanut butter) or yogurt and liquids	Any movement of the throat muscles, any swirling of the mouth motion, or any swallowing movements	60 min	Rate of rumination	Alternating treatments design and ABAB
Sanders-Dewey and Larson (2006)	20-year-old man (severe ID)	Not reported	Opening the mouth, moving the Adam's apple, stomach contents entering mouth, stomach contents being swished around inside mouth	Not reported	Count of ruminations	ABCD
Kenzer and Wallace (2007)	59-year-old man (profound ID)	After meals	Puffing out cheeks as previously swallowed food is brought into mouth and subsequently re-swallowed	Not reported	Rate of rumination	Alternating treatments design
Lyons et al. (2007)	11 and 14-year-old boys (ID)	Continuous; most often within 30–60 min of meals	Upward movement of the throat, puffing of cheeks, swishing tongue, gurgling sounds	Not reported	Percentage intervals with rumination	Alternating treatments design and ABAB
Wilder et al. (2009)	37-year-old man (autism, profound ID)	After meals	Upward movement of the throat and immediate swishing of the tongue, which produced visible indentation on the cheeks	Not reported	Rate of rumination	Alternating treatments design and multiple treatment withdrawal design
Rhine and Tarbox (2009)	6-year-old boy (autism)	Throughout the day	Presence of food material in mouth at a time other than when eating	Not reported	Rate of rumination	Alternating treatments design
Wrigley et al. (2010)	Adult woman (severe ID)	Given lesser social attention or instructions	Vertical movement of the throat, pursing of lips, retaining product of rumination until both cheeks were fully extended	Not reported	Rate of rumination	Alternating Treatments design and ABABA design

(continued)

Table 25.1 (continued)

Authors	Participant	Onset	Topography	Duration	Measures	Design
Wrigley et al. (2010)	Adult woman (severe ID)	During lesser social attention or when instructions were given	Vertical movement of the throat, pursing of lips, retaining product of rumination until both cheeks were fully extended	Not reported	Rate of rumination	Alternating treatments design and ABABA design
Carroll et al. (2011)	8-year-old boy (autism)	Not reported	Contact of hand or piece of furniture with abdomen while leaning forward, presence of food or liquid in mouth in absence of ingestion of food, or sounds of air originating from mouth, followed by regurgitation, and manipulating food with tongue	Not reported	Duration of rumination (percentage of session)	ABABA
Kliebert and Tiger (2011)	11-year-old boy (autism, severe ID)	After lunch	Rotary chewing motion when not in the context of a meal	Not reported	Rate of rumination	Alternating Treatments Design within AB
Sharp et al. (2012)	31-year-old man (autism and severe ID) 41-year-old woman (autism and severe ID)	Not reported	Prolonged swirling or chewing movements of mouth, previously ingested food entering mouth; puffing out cheeks, chewing, and swallowing	Not reported	Rate of rumination and percentage intervals with rumination	Alternating treatments design and AB
Schroedl et al. (2013)	17-year-old girl (typical)	Following meals	Not reported	Not reported	Physiological monitoring; self-reports; weight	Not reported
Woods et al. (2013)	19-year-old man (ID)	Immediately following meals	Any instance of gurgling, swishing, or gagging with or without puffed cheeks or drooling	Not reported	Percentage intervals with rumination	Alternating treatments design and ABCD

often included surrogate parenting by nurses (Gaddini & Gaddini, 1959; Menking et al., 1969), increasing frequency of maternal attention (Hopper & Pinneau, 1957), and a combination of environmental changes and enhanced mothering (Franco, Campbell, Tamburrino, & Evans, 1993; Tamburrino, Campbell, Franco, & Evans, 1995).

Initial consequence-based interventions included faradic therapy, with electric shock delivered contingent on rumination or a precursor behavior (Galbraith, Byrick, & Rutledge, 1970; Lang & Melamed, 1969; White & Taylor, 1967). Interventions progressed to contingent presentation of aversive tastes following rumination or precursors (Libet et al., 1973; Marholin et al., 1980; Sajwaj et al., 1974), and then contingent oral hygiene (Foxx et al., 1979; Singh et al., 1982). Several authors reported punishment procedures involving contingent exercise (Daniel, 1982), contingent termination of music (Davis, Wieseler, & Hanzel, 1980), and contingent removal of food and social attention (Smeets, 1970). Antecedent interventions have included food satiation (Rast, Johnston, Drum, & Conrin, 1981; Yang, 1988), altering foods or caloric content (Beukelman & Rogers, 1984; Greene et al., 1991; Rast et al., 1985), or rescheduling meal or snack times (Wilder, Draper, Williams, & Higbee, 1997). While many of these interventions were preceded by medical evaluation to rule out or control medical contributory factors (e.g., Galbraith et al., 1970; Lang & Melamed, 1969, Libet et al., 1973; Marholin et al., 1980), only a few involved a pre-intervention functional assessment or functional analysis. More recently, however, interventions are being reported as having been selected on the basis of a functional analysis (Kliebert & Tiger, 2011; Wilder et al., 2009; Woods et al., 2013). Studies that did report pre-intervention functional assessment or analysis were able to match treatments to functional relations evoking and maintaining the rumination.

A number of harmful sequelae of rumination have been reported. Medical effects have included weight loss and underweight (Franco et al., 1993; Fullerton, Neff, & Getto, 1992; Khan, Hymna, Cocjin, & Carlo, 2002); gastrointestinal bleeding (Dunn et al., 1997); dehydration (Conrin, Pennypacker, Johnston, & Rast, 1982), damage to esophagus, mouth, and teeth (Clauser & Scibak, 1990); maceration and chapped lips (Foxx et al., 1979), and death, with a reported mortality rate of 12–20 % (Gaddini & Gaddini, 1959; Kanner, 1957; Sajwaj et al., 1974). Social repercussions, which sometimes are a result of the medical side effects, can include persistent foul odor (Starin & Fuqua, 1987), caretaker avoidance (Sanders-Dewey & Larson, 2006), social stigmatization (Sisson et al., 1988), and decreased social opportunity (Starin & Fuqua, 1987). Rumination has also been reported to occupy one's behavioral repertoire to the extent that one is not available for learning other skills (Beukelman & Rogers, 1984).

Definition

The Diagnostic and Statistical Manual (fifth edition) describes rumination as an eating disorder characterized by regurgitation of previously consumed food, that is not used as a means of controlling weight, and which is not driven by negative feelings about oneself, but which involves using the musculature of one's gastroesophageal tract to propel stomach contents back into one's mouth, where they may be rechewed, reswallowed, or expelled (American Psychiatric Association, 2013). Some researchers have opted to list topographies (e.g., Foxx et al., 1979), or chains of topographies (Conrin et al., 1982), while others have defined behaviors that were precurrent to rumination (see Sajwaj et al., 1974) (Table 25.1). The majority of rumination definitions included reswallowing of the vomitus; however, some studies allowed for the vomitus to exit the mouth and may fall into the category of functional vomiting rather than rumination. A number of studies do not include operational definitions of rumination (Beukelman & Rogers, 1984; Davis et al., 1980; Franco et al., 1993; Fullerton, Neff, & Getto, 1992; Luckey, Watson, & Musick, 1968; Schroedl et al., 2013; Tamburrino et al., 1995).

Rumination is sometimes described as occurring throughout all waking hours (Humphrey, Mayes, & Bixler, 1989), or beginning immediately, or after 30–60 min after a meal (Lyons et al., 2007; Marholin et al., 1980; O'Neil, White, King, & Carek, 1979). Duration of rumination has been more rarely reported. While some authors do report rumination occurring throughout all waking hours (Humphrey et al., 1989) and others report rumination to occur for 20 min (McKeegan et al., 1987) to up to 2 h (Clauser & Scibak, 1990) once it begins, many authors do not include mention of duration of this behavior (Table 25.1).

Epidemiology of the Behavior

Rumination is said to be rare in adults with typical intellectual functioning (O'Brien, Bruce, & Camilleri, 1995) and, when it does occur in such adults, it is typically in conjunction with bulimia nervosa (Tamburrino et al., 1995). In this population, it is estimated that 20 % of affected people exhibit rumination (Fairburn & Cooper, 1984). The typical age of onset for rumination in typically developing infants is 3–12 months (Friedrich & Jaworski, 1995). An estimated 5 % (Kuhn & Matson, 2002) to 10 % (Ball, Hendricksen, & Clayton, 1974) of adults with intellectual disabilities are said to engage in this behavior. Gal, Hardal-Nasser, and Engel-Yeger (2011) report rumination to be more frequent among individuals with severe and profound intellectual disability than among individuals with mild or moderate intellectual disability. Kuhn, Matson, Mayville, and Matson (2001) reported that individuals with intellectual disabilities who ruminate exhibit fewer positive social behaviors than those who do not.

Appropriate diagnosis of rumination requires thorough medical examination to rule out medical disorders that account for the regurgitation component of this behavior (Banez & Cunningham, 2003). In an examination of rumination at a developmental center for adults with intellectual disabilities, Rogers, Stratton, Victor, Kennedy, and Andres (1992) reported that, although 10.4 % of residents were initially diagnosed with rumination, medical evaluation of possible dysphagia and gastroesophageal abnormalities in these people indicated that more than 90 % had physiological or medical conditions that were functionally related to this behavior, or were taking medications that could potentiate this behavior. Knowing this, one would then need to consider either treating or managing the medical issue and potentially thereby eliminating the rumination, or combining medical management of the medical condition with other interventions for the rumination

Measurement and Reliability of Measurement

In order to determine the frequency of a behavior within a person, or its prevalence across a population, it is essential to operationally define the behavior (either structurally or functionally) and to devise and implement a measurement system that includes assessment of reliability. Studies reviewed defined rumination with varying degrees of specificity, and 14.6 % of articles surveyed provided no operational definition at all (Table 25.1). While it is true that a diagnosis of rumination is made on the basis of a recurring pattern of regurgitation and reswallowing occurring over time, other precurrent or co-occurring behaviors have been listed among operational definitions. Despite the common features of regurgitation and reswallowing across reports of rumination, failure to operationally define the particular behavioral display on which counts or other measures were made can result in data collection, reporting, and treatment errors.

Of the studies reviewed that operationally defined rumination, 25 % recorded frequency (or count) of rumination (Table 25.1). Thirty-one percent of studies reviewed measured rate of rumination, reporting ruminations per minute (Daniel, 1982; Dudley, Johnson, & Barnes, 2002; Glasscock et al., 1986; Kenzer & Wallace, 2007; Sharp et al., 2012; Toister et al., 1975; Wilder et al., 2009), ruminations per hour (Clauser & Scibak, 1990), per 2-h session (Wrigley et al., 2010), or ruminations per day (Lockwood et al., 1997). Seventeen percent reported estimating frequency of the behavior through partial interval sampling or momentary time sampling (Carroll et al., 2011; Dunn et al., 1997; Foxx et al., 1979; Lobato et al., 1986; McKeegan et al., 1987; Sajwaj et al., 1974; Sanders-Dewey & Larson, 2006; Singh et al., 1982; Thibadeau, Blew, Reedy, & Luiselli, 1999; Yang, 1988). Several others reported duration measures (Davis et al., 1980; Conrin et al., 1982; Rast et al., 1981). A number of studies reported participant's weight as a dependent variable (Galbraith et al., 1970; Lobato et al., 1986; Mestre et al., 1983; O'Neil et al., 1979; Rast et al., 1985).

Once a behavior is operationally defined and a data collection system implemented, it is important to ensure reliability of measurement and adherence to the operational definition. While 62.5 % of articles surveyed reported gathering interobserver agreement data, 37.5 % neither mentioned nor reported interobserver agreement or other reliability measurement (Table 25.2). Of those studies reporting interobserver agreement, many reported these data for 20 % or more observations (e.g., Rhine & Tarbox, 2009; Wilder et al., 1997; Yang, 1988), although some report their frequency of data collection for interobserver agreement in terms of number of occasions (instead of percentage) without stating the total number of observations made (e.g., Rast et al., 1984).

Table 25.2 Degree to which Evidence Standards and criteria met, by study

Authors	Degree to which Evidence Standards are met	Experimenter controlled IV	IOA reliability	Demonstrates functional control
Gaddini and Gaddini (1959)	Does Not Meet Evidence Standards	Yes	No	No
White and Taylor (1967)	Does Not Meet Evidence Standards	Yes	No	No
Luckey et al. (1968)	Does Not Meet Evidence Standards	Yes	No	No
Lang and Melamed (1969)	Does Not Meet Evidence Standards	Yes	No	No
Menking et al. (1969)	Does Not Meet Evidence Standards	No	No	No
Galbraith et al. (1970)	Does Not Meet Evidence Standards	Yes	No	No
Smeets (1970)	Does Not Meet Evidence Standards	Yes	No	No
Libet et al. (1973)	Does Not Meet Evidence Standards	Yes	No	Yes
Sajwaj et al. (1974)	Meets Evidence Standards with Reservation	Yes	<20 % of data	Yes
Toister et al. (1975)	Does Not Meet Evidence Standards	Yes	No	No
Foxx et al. (1979)	Does Not Meet Evidence Standards	Yes	<20 % of data	Yes
O'Neil et al. (1979)	Meets Evidence Standards with Reservation	Yes	<20 % of data	Yes
Marholin et al. (1980)	Does Not Meet Evidence Standards	Yes	No	No
Davis et al. (1980)	Does Not Meet Evidence Standards	Yes	No	No
Daniel (1982)	Does Not Meet Evidence Standards	Yes	No	No

(continued)

Table 25.2 (continued)

Authors	Degree to which Evidence Standards are met	Experimenter controlled IV	IOA reliability	Demonstrates functional control
Conrin et al. (1982)	Meets Evidence Standards with Reservation	Yes	<20 % of data	Yes
Singh et al. (1982)	Meets Evidence Standards	Yes	Yes	Yes
dMestre et al. (1983)	Does Not Meet Evidence Standards	Yes	No	No
Beukelman and Rogers (1984)	Does Not Meet Evidence Standards	Yes	No	No
Rast et al. (1984)	Does Not Meet Evidence Standards	Yes	Yes	No
Rast et al. (1985)	Does Not Meet Evidence Standards	Yes	Yes	No
Glasscock et al. (1986)	Meets Evidence Standards	Yes	Yes	Yes
Lobato et al. (1986)	Meets Evidence Standards with Reservation	Yes	<20 % of data	Yes
McKeegan et al. (1987)	Meets Evidence Standards	Yes	Yes	Yes
Sisson et al. (1988)	Meets Evidence Standards with Reservation	Yes	<20 % of data	Yes
Yang (1988)	Does Not Meet Evidence Standards	Yes	Yes	No
Williamson et al. (1989)	Does Not Meet Evidence Standards	No	No	No
Clauser and Scibak (1990)	Meets Evidence Standards with Reservation	Yes	<20 % of data	For two of three participants
Greene et al. (1991)	Does Not Meet Evidence Standards	Yes	<20 % of data	No
Fullerton et al. (1992)	Does Not Meet Evidence Standards	No	No	No
Franco et al. (1993)	Does Not Meet Evidence	No	No	No
Tamburrino et al. (1995)	Does Not Meet Evidence Standards	No	No	No
Dunn et al. (1997)	Does Not Meet Evidence Standards	Yes	<20 % of data	No
Lockwood et al. (1997)	Does Not Meet Evidence Standards	Yes	No	No
Weakley et al. (1997)	Does Not Meet Evidence Standards	No	No	No
Wilder et al. (1997)	Meets Evidence Standards	Yes	Yes	Yes
Thibadeau et al. (1999)	Does Not Meet Evidence Standards	Yes	<20 % of data	No

(continued)

Table 25.2 (continued)

Authors	Degree to which Evidence Standards are met	Experimenter controlled IV	IOA reliability	Demonstrates functional control
Dudley et al. (2002)	Meets Evidence Standards	Yes	Yes	Yes
Heering et al. (2003)	Meets Evidence Standards	Yes	Yes	Yes
Sanders-Dewey and Larson (2006)	Does Not Meet Evidence Standards	Yes	<20 % of data	No
Kenzer and Wallace (2007)	Meets Evidence Standards	Yes	Yes	Yes
Lyons et al. (2007)	Meets Evidence Standards	Yes	Yes	Yes
Wilder et al. (2009)	Meets Evidence Standards	Yes	Yes	Yes
Rhine and Tarbox (2009)	Meets Evidence Standards	Yes	Yes	Yes
Wrigley et al. (2010)	Meets Evidence Standards with Reservation	Yes	<20 % of data	Yes
Carroll et al. (2011)	Meets Evidence Standards	Yes	Yes	Yes
Kliebert and Tiger (2011)	Meets Evidence Standards	Yes	Yes	Yes
Sharp et al. (2012)	Meets Evidence Standards with Reservation	Yes	<20 % of data	Yes
Schroedl et al. (2013)	Does Not Meet Evidence Standards	No	No	No
Woods et al. (2013)	Meets Evidence Standards	Yes	Yes	Yes

Criteria for Evidence-Based Treatments

The literature on rumination contains a variety of reports and case studies on assessment and treatment with varying degrees of specificity regarding descriptions of independent and dependent variables and other technological aspects. Most studies were conducted in the context of a single-subject experimental design, or, at least, included data at the level of the individual subject in a graph or table. In reviewing the literature, we used the guidelines provided by Kratchowill et al. (2010) to determine which studies meet evidence standards for demonstrating treatment efficacy. These were:

1. The independent variable is controlled by the experimenter.
2. Interobserver agreement data (or other reliability data) are gathered for at least 20 % of data points within each session of the experiment.
3. The experimental design used permits demonstration of functional control by the independent variable of the dependent variable, through demonstration of prediction, verification, and replication for all participants (Cooper, Heron, & Heward, 2007).

Studies meeting all three of these criteria were found to *Meet Evidence Standards*. Studies meeting the first two criteria, but failing to meet the third criterion for at least one participant, were found to *Meet Evidence Standards with Reservations*. We deviated from these procedures by finding a study to *Meet Evidence Standards with Reservations* if both criteria 1 and 3 were met, and interobserver agreement or other reliability data were reported, but the percentage of data points for which interobserver agreement data were gathered was less than 20 % across all phases, or was not reported. Studies not meeting these three criteria were found to *Not Meet Evidence Standards*. Of 50 articles surveyed, 14 (28 %) were given a rating of *Meets Evidence Standards*; eight (16 %) were given a rating of *Meets Evidence Standards with Reservations*; and the remaining 28 studies were given a rating of *Does Not Meet Evidence Standards* (Table 25.2). Studies found to have met evidence standards with reservation employed independent variables controlled by the experimenter, and included designs which demonstrated functional control of the dependent variable(s) by the independent variable(s), but reported interobserver agreement or other reliability measurement procedures and figures for fewer than 20 % of data points across all phases for all subjects (Table 25.2). Twenty-seven studies (54 %) did not employ an experimental design that permitted demonstration of functional control of the dependent variable by the independent variable, and 21 studies (42 %) failed to either measure or report interobserver agreement (Table 25.2).

Procedures contained in those studies found to *Meet Evidence Standards* or *Meet Evidence Standards with Reservation* were then reexamined to determine the extent to which the literature provides strong evidence, moderate evidence, or limited or no evidence for the efficacy of the procedure. We again based these determinations on the procedures of Kratchowill et al. (2010). Procedures were said to be strongly supported by the literature when:

1. They were reported in at least five single subject experimental design studies that met evidence standards.
2. Those five or more studies were published by at least three geographically distinct research teams.
3. The five or more single subject design studies contained a minimum of 20 data-based determinations of efficacy for the participants.

Procedures meeting only two of these three criteria were determined to be supported by moderate evidence. Interventions meeting fewer than two of these criteria were categorized as having limited evidence-based support by the literature. Nine procedures were identified among the 22 studies that met evidence standards or met evidence standards with reservation, and were examined (Table 25.3). Of these procedures, only one met the criteria for a rating of having *Strong Evidence*. None met criteria for a rating of *Moderate Evidence*. The remaining eight procedures were given a rating of *Limited Evidence*. It is noted that most studies included only a single participant, and several included only two.

Antecedent Interventions

Antecedent-based interventions for rumination involve managing events hypothesized to be related to rumination, before the rumination occurs. Such interventions can include providing noncontingent or scheduled access to additional food or drink, either outside of, or before or after meals (Rast et al., 1984), presenting noncontingent access to other oral stimulation materials (e.g., chewing gum, flavor spray, or chew toys) (Carroll et al., 2011; Weakley et al., 1997; Wilder et al., 2009), or altering the pace (McKeegan et al., 1987) or composition of food presented at meals (Rast et al., 1985).

As time progressed, focus of treatment shifted from aversive, consequence-based interventions to less aversive, antecedent-based interventions (Jackson & Tierney, 1984). Prior to Foxx et al. (1979), consequence based punishment procedures (Galbraith et al., 1970; Luckey et al., 1968; White & Taylor, 1967) and loosely defined nurturing procedures (Gaddini & Gaddini, 1959; Menking et al., 1969) had been reported to address rumination. Foxx et al. implemented an antecedent-based intervention (satiation) and added a consequence component (contingent oral hygiene) to further reduce rumination. Rast et al. (1984) used only an antecedent-based procedure by varying food quantity participants received at mealtime.

One of the 12 studies reviewed that was published in the 1970s used antecedent procedures (Foxx et al., 1979) (Table 25.4). An increasing

Table 25.3 Degree to which procedures meet evidence standards

Procedure	Authors	Degree of evidence	Number of studies	Number of independent research teams	Total number of participants
Contingent aversive taste (punishment)	Sajwaj et al. (1974) Glasscock et al. (1986) Sisson et al. (1988)	Limited evidence	3	3	3
Contingent oral hygiene (punishment)	Foxx et al. (1979) Singh et al. (1982)	Limited evidence	2	2	4
Satiation	Foxx et al. (1979) Lobato, Carlson, and Barrera (1986) Clauser and Scibak (1990) Greene et al. (1991) Wilder et al. (1997) Masalsky and Luiselli (1998) Thibadeau et al. (1999) Dudley et al. (2002) Kenzer and Wallace (2007) Lyons et al. (2007) Kliebert and Tiger (2011) Woods et al. (2013)	Strong evidence	12	12	21
Differential reinforcement of other behavior	O'Neil et al. (1979) Conrin et al. (1982)	Limited evidence	2	2	3
Noncontingent presentation of alum	Beukelman and Rogers (1984)	Limited evidence	1	1	2
Altered rate of food presentation + DRI	McKeegan et al. (1987)	Limited evidence	1	1	1
Liquid rescheduling	Heering et al. (2003) Sharp et al. (2012)	Limited evidence	2	2	3
Noncontingent access to nonnutritive reinforcer	Wilder et al. (2009) Rhine and Tarbox (2009) Carroll et al. (2011)	Limited evidence	3	3	3
Resetting DRO + Response interruption + Alternating task schedule	Wrigley et al. (2010)	Limited evidence	1	1	1

Table 25.4 Assessment and intervention type, by study

Authors	Pre-intervention assessment	Antecedent based intervention	Consequence based intervention	Other intervention
Gaddini and Gaddini (1959)	Direct observation and family interview			Nurturing
White and Taylor (1967)	Not reported		Contingent electric shock	
Luckey et al. (1968)	Not reported		Contingent electric shock	
Lang and Melamed (1969)	Not reported		Contingent electric shock	
Menking et al. (1969)	Family interview			Nurturing
Galbraith et al. (1970)	Not reported		Contingent electric shock	
Smeets (1970)	Baseline observation		Contingent removal of social attention	
Libet et al. (1973)	Systematic observation of topography		Contingent presentation of lemon juice	
Sajwaj et al. (1974)	Baseline observation		Contingent presentation of lemon juice	
Toister et al. (1975)	Not reported		Contingent electric shock	
Foxx et al. (1979)	Baseline observation	Satiation (double portions of meals)	Contingent oral hygiene	
O'Neil et al. (1979)	Baseline observation		Contingent presentation of lemon juice + Differential reinforcement of other behavior	
Marholin et al. (1980)	Not reported		Contingent presentation of lemon juice	
Davis et al. (1980)	Baseline observation		Contingent verbal reprimand + Contingent removal of music	
Daniel (1982)	Baseline observation		Contingent exercise	
Conrin et al. (1982)	Baseline observation		Differential reinforcement of other behavior	
Singh et al. (1982)	Baseline observation		Contingent oral hygiene	
Mestre et al. (1983)	Not reported		Contingent presentation of Tabasco sauce + Vinegar	
Beukelman and Rogers (1984)	Not reported		contingent presentation of alum; Noncontingent presentation of alum	
Rast et al. (1984)	Baseline observation	Systematic variation in food quantity		
Rast et al. (1985)	Baseline data collection	Systematic variation in food quantity and composition		
Glasscock et al. (1986)	Baseline observation		Contingent presentation of lemon juice or Lime Juice	
McKeegan et al. (1987)	Baseline observation	Altered pace of food presentation	Differential reinforcement of other behavior	
Sisson et al. (1988)	Baseline observation		Contingent presentation of lemon juice	

(continued)

Table 25.4 (continued)

Authors	Pre-intervention assessment	Antecedent based intervention	Consequence based intervention	Other intervention
Yang (1988)	Baseline observation	Noncontingent access to white bread following meals		
Williamson et al. (1989)	Interview, self-recorded baseline observations		Contingent access to jewelry	Group therapy
Clauser and Scibak (1990)	Baseline observation	Triple portions of food + Unlimited access to cold cereal with milk at each meal		
Greene et al. (1991)	Staff interview	Variation in caloric value of food through presentation of peanut butter or less caloric dense food		
Fullerton et al. (1992)	Psychiatric evaluation			Millieu therapy
Franco et al. (1993)	Medical and nursing evaluation; family observation			Nurturing
Tamburrino et al. (1995)	Psychiatric evaluation			Millieu therapy
Dunn et al. (1997)	Baseline observation	Increased food quantity		
Lockwood et al. (1997)	Descriptive functional analysis		Differential reinforcement of other behavior + Restitution + Escape extinction + Choice making	
Weakley et al. (1997)	Psychiatric evaluation	Noncontingent access to chewing gum		
Wilder et al. (1997)	Baseline observation	FT 20s delivery of gelatin or pudding and liquid rescheduling assessed in alternating treatments design		
Thibadeau et al. (1999)	Baseline observation	Addition of quantities of white bread to meals	Differential reinforcement of other behavior + Contingent toothbrushing	
Dudley et al. (2002)	Baseline data collection	Satiation		
Heering et al. (2003)	Experimental functional analysis	Liquid rescheduling		
Sanders-Dewey and Larson (2006)	Baseline observation		Contingent presentation of aversive taste + Contingent presentation of pleasant taste and verbal praise	
Kenzer and Wallace (2007)	Experimental functional analysis	Satiation		
Lyons et al. (2007)	Experimental functional analysis	Noncontingent food or liquid presentation		

(continued)

Table 25.4 (continued)

Authors	Pre-intervention assessment	Antecedent based intervention	Consequence based intervention	Other intervention
Wilder et al. (2009)	Experimental functional analysis	Experimenter and participant administered flavor spray		
Rhine and Tarbox (2009)	Caregiver interview	Noncontingent access to chewing gum		
Wrigley et al. (2010)	Experimental functional analysis	Systematic alternation of walking and sedentary activity	Response interruption + Differential reinforcement of other behavior	
Carroll et al. (2011)	Baseline observation	Noncontingent access to chew toy		
Kliebert and Tiger (2011)	Experimental functional analysis	Noncontingent presentation of juice post-meal		
Sharp et al. (2012)	Experimental functional analysis	Liquid rescheduling		
Schroedl et al. (2013)	Psychological evaluation			Self-regulation
Woods et al. (2013)	Experimental functional analysis	Pre-meal and continuous food access		

number of studies reported antecedent-based interventions in the 1980s and 1990s (e.g., Clauser & Scibak 1990; Weakley et al., 1997; Wilder et al., 1997; Yang, 1988). These studies reported either use of antecedent based procedures alone (Clauser & Scibak, 1990; Dunn et al., 1997; Greene et al., 1991; Lobato et al., 1986; Rast et al., 1984, 1985; Wilder et al., 1997; Yang, 1988), or in combination with consequence- based procedures (McKeegan et al., 1987; Thibadeau et al., 1999). This transition toward antecedent-based procedures continued into the 2000s (e.g., Heering et al., 2003; Lyons et al., 2007; Wilder et al., 2009).

Strong evidence. Although a good number of studies documenting the treatment of rumination have been published over the last half-century, only one antecedent procedure (satiation) has been replicated sufficiently to be determined strongly evidence-based on the standards of Kratchowill et al. (2010): (1) at least five studies; (2) conducted by at least three independent research teams; and (3) with 20 or more total participants. Satiation-inducing procedures, such as pre-meal or post-meal noncontingent access to food or liquids, increased portion sizes, and increased caloric value of foods presented at meals have been demonstrated in a number of well-conducted studies to produce meaningful decreases in frequency of rumination.

Satiation procedures. Seeking to decrease rumination behavior and evaluate any collateral effects on self-stimulatory behavior, Clauser and Scibak (1990) used a food satiation procedure with three men with intellectual disabilities. Researchers provided triple portions of meals and unlimited access to cold cereal. Results not only indicated that satiation effectively reduced rumination for all three participants, but that there were collateral decreases in self-stimulatory behavior as well. Clauser and Scibak suggested future research should include analyses of food preference and "careful menu planning".

Wilder et al. (1997) compared three different treatments for rumination with a subject diagnosed with profound intellectual disability and blindness. Differential reinforcement, liquid rescheduling and reduction, and satiation were implemented in an alternating treatments design, with one return to baseline. Results indicated that the satiation procedure with noncontingent reinforcement produced the greatest reduction in rumination. Lyons et al. (2007) and Kliebert and Tiger (2011) delivered sips of juice on a fixed time schedule, and found that this satiation procedure produced reductions in satiation for their participants. However, concerns remain about the lasting effectiveness of juice satiation, so more follow-up research is needed to determine the maintenance of the behavior change.

Moderate evidence. Using the criteria described by Kratchowill et al. (2010), insufficient replications across a sufficient number of participants precluded our rating any procedures reported in reviewed literature as *moderately evidence-based*.

Limited evidence. A number of procedures have been shown efficacious for a small number of participants in the research literature, and insufficient numbers of replications result in these procedures being said to have *limited evidence-based support* based on Kratchowill et al. (2010). This label is not meant to impugn the quality of these studies or their findings; instead, it simply indicates that additional replications of these procedures and findings must be conducted before a rating of *moderately evidence-based* or *strongly evidence-based* can be provided.

Noncontingent access to non-nutritive oral stimulation. Concerned that satiation procedures could lead to health problems related to increased caloric intake, Wilder et al. (2009) delivered flavor spray on a fixed time schedule. Preferred flavors were empirically identified, and the researchers then delivered the flavor spray on a fixed-time schedule. After demonstrating functional control, the researchers increased the schedule to fixed time 20 s to further decrease the rumination to near zero rates. The schedule was then thinned to fixed time 10 s, and after a brief return to baseline, the subject was taught to administer the flavor spray independently on a fixed time 10 s schedule, with meaningful success.

Rhine and Tarbox (2009) used chewing gum as an alternative to food satiation for a 6-year-old boy diagnosed with autism. Using an alternating treatments design, the researchers found a drastic reduction of rumination during the chewing gum conditions, as in contrast with baseline. The results maintained across 3 monthly post-treatment follow-up sessions. Benefits reported with using chewing gum as an antecedent treatment were low cost, low effort, non-aversive procedures, and low caloric ingestion.

Carroll et al. (2011) assessed noncontingent use of a chew toy as an antecedent strategy in an attempt to provide a calorie-free replacement for satiation. Using a withdrawal design, the experimenters found therapeutically valuable decreases during the noncontingent chew toy condition, when compared to the baseline conditions. The experimenters found that the rate of rumination decreased as oral engagement with the chew toy increased, and the effects were sustained over eight months' follow-up.

Liquid rescheduling. Heering et al. (2003) examined effects of altering amount of liquids consumed by a 19-year-old man diagnosed with autism and profound intellectual disability. Experimenters conducted a pre-intervention, multi-element assessment, and found that withholding liquid during meals decreased rumination to a rate of zero during the hour following mealtime. Experimenters then examined effects of withholding liquids for 1.5 h after meals, and reported substantial decreases (near-zero levels) in rumination behavior after introducing the liquid rescheduling procedure.

Sharp et al. (2012) compared the effects of four different interventions on the rumination behavior of a 31-year-old man and a 41-year-old woman, both diagnosed with autism and severe intellectual disabilities. The four interventions were examined in an alternating treatments design, and were: Liquid rescheduling, supplemental post-meal food, supplemental post-meal peanut butter, and increased meal size.. Liquid rescheduling was the only effective method of decreasing rumination for both participants and decreased rumination to sub-baseline levels across all follow-up sessions.

Consequence Interventions

We see across the 1960s through the 1980s a movement away from more harshly appearing consequence-based decelerative procedures to use of less intrusive consequences. Studies published in the 1960s and 1970s reported on use of contingent electric shock to reduce rumination (Galbraith et al., 1970; Lang & Melamed, 1969; Luckey et al., 1968; Toister et al., 1975; White & Taylor, 1967). The 1970s and 1980s saw an increase in reports of punishment of rumination by contingent presentation of aversive tastes (Glasscock et al., 1986; Libet et al., 1973; Marholin et al., 1980; Mestre et al., 1983; Sajwaj et al., 1974; Sisson et al., 1988). A variation on this procedure was the oral hygiene procedure published by Foxx et al. (1979) and Singh et al. (1982). Smeets (1970) reported on a punishment procedure involving contingent removal of social attention, Davis et al. (1980) reported on reduction in rumination brought about by contingent verbal reprimand plus contingent termination of music, and Daniel (1982) reported on reduction of rumination through contingent exercise. Beginning in the 1990s, interventions for rumination were more frequently derived from a descriptive or experimental functional analysis (Lockwood et al., 1997; Wrigley et al., 2010), and these multicomponent interventions included reinforcement-based procedures.

Strong evidence and moderate evidence. Despite the abundant research published between the 1960s and 2010s on consequence-based interventions for rumination, no procedures examined in these articles meet standards of evidence to be considered to be strongly or moderately evidence-based. Of 25 articles surveyed which detailed consequence based interventions to reduce rumination (Table 25.1), 16 (or 64 %) did not employ an experimental design that permitted demonstration of functional control of the change in the ruminative behavior by the procedures employed, and 14 (or 56 %) did not report interobserver agreement or other reliability assessment (Table 25.2). Ten studies met requirements for a rating of either Meets Evidence Standards or Meets Evidence Standards with Reservation. Unfortunately, when one considers the second tier of criteria (Kratchowill et al., 2010) for determining degree to which evidence standards have been met, there were insufficient numbers of studies, insufficient numbers of independent research teams, and insufficient numbers of participants for the consequence-based procedures to permit rating any of the procedures as either strongly or moderately evidence based. Therefore, these procedures are described in the following section.

Limited evidence. Only studies that met the first tier of criteria for meeting evidence standards or meeting evidence standards with reservation (Kratchowill et al., 2010) are described. Given this, each of the studies that are described in this section incorporated independent variables that were controlled by the experimenters, reported interobserver agreement or other reliability measurement, and employed single-subject experimental designs that permitted demonstration of functional control of the procedure over the change in the ruminative behavior.

Punishment by contingent presentation of aversive tastes. Given their reluctance to administer contingent electric shock, Sajwaj et al. (1974) delivered 5–10 cc of lemon juice to the mouth of a 6-month old infant exhibiting life-threatening rumination contingent on vigorous tongue movements that were identified as a reliable precurrent behavior to rumination. If rumination occurred again after 30–60 s of a presentation of lemon juice, an additional 5–10 cc of lemon juice was introduced orally, until rumination ceased. Frequency of rumination was estimated using 10 s partial interval sampling, which commenced as soon as a bottle feeding ended, and continued for 20 min. Baseline data showed a range of 40–70 % of intervals, with a reduction to below 10 % intervals following introduction of the punishment procedure. Withdrawal to the baseline procedure for two feedings resulted in a rebound in rumination to 30–65 % of intervals, followed by a decrease in rumination to near zero frequency once the punishment procedure was reintroduced. Six week follow-up data showed reduction in rumination maintained, and that reduction in rumination was accompanied by an increase in weight by approximately 50 %.

Concerned that continued contingent presentation of the same aversive taste might degrade the potency of that punisher, Glasscock et al. (1986) began their intervention with lemon juice, and demonstrated functional control of contingent presentation of lemon juice on the reduction in their participant's rumination. Following an increase in rumination despite consistent implementation of this procedure, they switched to contingent presentation of lime juice, which was followed by a return to greatly reduced rates of rumination. When rate of rumination again increased after approximately 2 weeks of this intervention, the researchers switched back to contingent presentation of lemon juice, which was followed by a return to reduced rates of rumination. Follow-up data gathered at 1, 3, and 7 months showed maintenance of reduced rates of rumination given this procedure.

Using a multiple baseline design across three empirically identified high-rumination-frequency times, Sisson et al. (1988) combined rumination-contingent presentation of 5 cc of lemon juice and a verbal reprimand with access to positive reinforcers (e.g., stroking, a fan, or water play) in absence of rumination. Baseline showed approximately 93 % of 10-s intervals with rumination at the 9:00 am time, 82 % of intervals with rumination at the 10:00 am observation time, and 96 % of 10 s intervals with rumination at the 12:30 pm observation time. Implementing the contingent punishment plus differential reinforcement of other behavior (DRO) procedure produced a reduction to a mean of 6 % of intervals, withdrawing the intervention and returning to baseline procedures at that time resulted in a rebound to 23 % of intervals and increased variability, and reimplementation of the procedure resulted in a return to near zero rates of rumination at that time. No changes in percentage intervals of occurrence of rumination occurred during the 10:00 am and 12:30 pm observation times during this time. Implementing the procedure next at the 10:00 observation time resulted in a reduction in rumination to near zero rates, and extending it later to the 12:30 observation time replicated this effect. Follow-up at 1 month showed reductions maintained.

Punishment by contingent oral hygiene. Using a multiple baseline design across participants, Foxx et al. (1979) reported that their two participants exhibited rumination in 89.5 % and 49.9 % of 30-s intervals using partial interval sampling, respectively, during lunchtime baseline observations. They first implemented a satiation procedure at lunch, and rate of percentage intervals with rumination dropped to 48.8 % and 7.9 %, respectively. Given inadequacy of these reductions, Foxx et al. added an oral hygiene procedure, which consisted of delivery of a verbal reprimand plus 2 min of swabbing the participant's mouth with an oral antiseptic contingent on rumination. Levels of rumination dropped to 3 % of intervals and 1.4 % of intervals for the two participants, respectively. Foxx et al. noted that despite implementing the satiation and satiation plus oral hygiene procedures only at lunch, their observations at breakfast and dinner indicated similar reductions in rumination at those meals, as well, coinciding with introduction of treatments across the participants. Foxx et al. opined that the oral hygiene procedure had the added benefit (over contingent presentation of other aversive tastes) of cleansing the ruminating participant's mouth and breath, "thereby reducing the odor associated with the behavior" (p. 401).

Singh et al. (1982) examined effects of punishment by contingent oral hygiene on rumination of two adolescent monozygous twins, using a multiple baseline design across participants and meals. Using 10 s partial interval sampling for 60 min after each meal, baseline data were collected and interventions implemented for one brother first and then the other, for lunch first, then for breakfast, and then for dinner. Researchers also collected data on stereotyped behavior (e.g., rocking, waving, rubbing parts of the body, rotating items, and tapping objects/toys), self-injury, and appropriate behavior (e.g., smiling, appropriate speech or laughter, toy play, and interaction with others) during these intervals. They found an inverse relationship between rumination and stereotypy, with rumination decreasing to near zero following introduction of the oral hygiene procedure across participants and across meals, as stereotypy increased simultaneously, approaching 100 % of intervals. Self-injury remained at near zero levels across conditions, and no change was observed in appropriate behaviors. Singh et al. (1982) opined that oral hygiene had beneficial side effects, such as improving teeth, gums, and breath, and preventing tooth decay. They concluded, though, that given collateral increase in stereotypy and irrelevance of this procedure to appropriate behaviors, additional procedures would be necessary to bring about constructive behavioral improvements.

Differential reinforcement of other behavior. Citing concerns for ethical and legal aspects of punishment-based procedures involving faradic or other aversive stimuli, Conrin et al. (1982) examined effects of DRO on rumination exhibited by two men with profound intellectual disabilities. Recording duration of rumination movements for 30 min after meals for one participant and 60 min after meals for the other, Conrin et al. reported rumination occurring for between 5 and 30 min duration after meals for one participant, and 30 min duration for the other. Intervention began as contingent delivery of a small bit of food to the participant's mouth when the interresponse time (IRT) since the last instance of rumination reached 15 s. That is, at 15 s following the end of the last instance of rumination, if no new instance of rumination had begun, a small morsel of food was delivered to the participant's mouth. Rumination durations quickly approached zero for both participants. Stretching the IRT to 30 s and then 60 s resulted in continued zero durations for rumination for one participant. Stretched IRTs of 1, 2, 5, and 10 min were each met with increased variability in durations of rumination, but overall greatly reduced durations (0–2 min) for the other participant. Withdrawal of the intervention and return to baseline procedures resulted in increased durations of rumination for both. Reinstituting DRO with an IRT at 30 s returned rumination duration to near zero seconds for the first participant, and reinstituting DRO with IRTs at 2, 5, and then 10 min resulted in return to near zero durations of rumination for the other. These authors hypothesized that the gustatory stimulation produced by rumination reinforced this behavior, and that by providing alternative access to gustatory stimuli contingent on behaviors incompatible with rumination for gradually increasing durations, they were able to reduce rumination for both participants.

Finally, Thibadeau et al. (1999) compared effects of DRO plus contingent oral hygiene with effects of satiation by noncontingent post-meal access to white bread for rumination exhibited by a young man diagnosed with autism and intellectual disability. They found that whereas the satiation procedure produced near zero frequencies of rumination, DRO produced frequencies comparable to those attained in baseline.

No evidence. Consequence-based interventions to reduce rumination have been reported in a number of case studies and in articles that did not include demonstration of a functional relation between the independent and dependent variable, or which did not report assessment of fidelity of data collection. While procedures described in these case studies and articles have not been shown to *Meet Standards of Evidence*, they are still worthy of consideration in a well-conducted single-subject experimental design. These are described as follows.

Punishment by contingent electric shock. Including punishment by contingent electric shock in this section may be considered by some to be somewhat controversial, or incorrect. Many of the first case studies and reports to approach rumination from a framework other than psychodynamic involved contingent electric shock (Galbraith et al., 1970; Lang & Melamed, 1969; Luckey et al., 1968; Toister et al., 1975; White & Taylor, 1967). However descriptive the text of these articles was regarding reduction or elimination of rumination by virtue of contingent electric shock, none incorporated methodology that permitted demonstration of functional control of the electric shock over the reduction or elimination of rumination, and none reported measures of interobserver agreement or other reliability measurement. Given this, none met the threshold set forth by Kratchowill et al. (2010) for either meeting evidence standards, or meeting evidence standards with reservation.

White and Taylor (1967) reported suppression of rumination in a 23-year-old woman and a 14-year-old man, both with intellectual disabilities, when experimenters applied a 400-V electric shock at milliampere contingent on behaviors correlated with rumination. These authors further reported, however, that shock at this voltage lost effectiveness, and so shocks of 500 and 700 V at 1 mA needed to be applied. These authors reported that other variables, such as irregularity in the participants' bowel regimens, may have contributed to variation in their rumination.

Luckey et al. (1968) delivered a 60-V electric shock through electrodes that were 4 in. apart in a belt worn by a 6-year-old boy contingent on his appearing to engage in any behavior related to vomiting or rumination. The boy first wore the belt for 1 week without shock presentation, and shock presentation contingent on vomiting or rumination began in the second week. The authors reported a rapid reduction in vomiting and rumination to zero, with discontinuation of the shock component (and continuation of the wearing of the belt) at day 6. When rumination reemerged on day 24, the experimenters reinstituted the contingent electric shock procedure, resulting in elimination of rumination and vomiting for at least 15 more days. Galbraith et al. (1970) replicated these procedures, but administered shock only for vomiting (and not for rumination). They reported similar findings, but also reported collateral increases in motor activity, talking, masturbation, and body weight following elimination of rumination.

Lang and Melamed (1969) reported administering contingent electric shock to reduce the life threatening vomiting and rumination of an otherwise typically developing 9-month-old infant. Monitoring his pre-regurgitation responding by electromyography, the researchers applied shock as soon as regurgitation was detected. They reported sharp reduction in vomiting and rumination such that it was eliminated by day 6, with discontinuation of the procedure by day 8. Recurrence of rumination on day 10 was followed by reinstatement of the procedure for three sessions on that day. Experimenters reported that rumination no longer occurred following that point, the infant steadily gained weight, and at 1, 5, and 12 months follow-up, he continued to gain weight and was no longer ruminating. Similarly, Toister et al. (1975) administered electric shock contingent on vomiting exhibited by a 7.5-month-old infant who exhibited life-threatening rumination. These authors reported a near elimination in vomiting (a precurrent to rumination) in 7 days, maintenance at 2 weekly follow-up observations, and an increase in weight to greater than the fiftieth percentile for the child's height at 12 months' follow-up.

Although results from these reports appear encouraging, in no cases were experimental designs employed that would permit demonstration of functional control of the changes in rumination by the electric shock. Others have since commented on concerns regarding acceptability, or ethical or legal issues regarding this procedure (Fredericks, Carr, & Williams, 1998; Sanders-Dewey & Larson, 2006; Starin & Fuqua, 1987; Yang, 1988). As suggested earlier in this chapter, treatment of rumination by punishment by contingent electric shock may be considered an historic component in the evolution of operant assessment and treatment methodologies for this disorder.

Combined positive punishment and positive reinforcement. Given concern with intrusive aspects of procedures incorporating contingent electric shock or solely incorporating contingent aversive tastes, Sanders-Dewey and Larson (2006) examined effects of a delivering an aversive taste contingent on rumination and a preferred taste paired with verbal praise for increasing durations (e.g., 10 s to several minutes) when rumination was not observed. Following a baseline when rumination occurred on the order of 26.9 times per 15 min observation period, instituting the combined procedure saw a reduction to 19 instances per observation period. Removing the preferred taste and maintaining the contingent aversive taste and the contingent verbal praise was followed by a further reduction to 7.1 ruminations per period, and then removing the aversive taste and maintaining only the contingent verbal praise was followed by further reduction to 2.56 ruminations per period. Following discontinuation of the contingent verbal praise component, rumination maintained at 1.24 instances per 15 min period. This procedural sequence suggests that the experimenters transitioned control of the behavior from a combined reinforcement and punishment procedure.

However, absence of demonstration of functional control of rumination by the procedures results in a data pattern that could suggest a continued downward trend occurring across treatment phases, irrespective of the procedures.

Daniel (1982) reported observations indicating that his 10-year-old participant did not ruminate while walking. Given his otherwise near continuous rumination, Daniel implemented a 30 s DRO procedure, in which a small bit of cracker was delivered following absence of rumination for 30 s, combined with requirement that the boy walk around a five foot square contingent on ruminating. Following one day of this combined intervention, the DRO component was discontinued and the contingent exercise component maintained. Daniel reported a decrease to zero instances of rumination when walking was made contingent on this behavior, and report zero instances of rumination at 4 monthly follow-up observations. Again, however, methodology of this study does not permit attribution of this elimination of rumination to this procedure.

Contingent removal of social attention. Smeets (1970) hypothesized that social attention functioned as a strong positive reinforcer for his participant, an 18-year-old man with profound intellectual disability. Smeets implemented a negative punishment procedure, in which social stimulation (e.g., appearance of others nearby, sound of others' voices, others attending to the young man) were removed contingent on vomiting or rumination. He reported substantial reduction, but not elimination, of vomiting and rumination, and hypothesized that additional contingencies may have been at play. No experimental design was reported.

Contingent removal of music and contingent verbal reprimand. Davis et al. (1980) conducted three 12-min post-meal observation sessions daily for a 26-year-old gentleman diagnosed with profound intellectual disability who exhibited rumination. Following baseline, Davis et al. implemented 10 s' withdrawal of ambient music following each instance of rumination occurring after breakfast, and maintained baseline at lunch and dinner. They saw no reduction in rumination. They extended duration of contingent music withdrawal to 30 s after breakfast only, and report a reduction in ruminations from 17.95 per session during baseline to 6.75 ruminations per session. The authors then added a verbal punisher (e.g., strong "No") to the 30-s music withdrawal after breakfast, and saw reduction in rumination to 0.37 ruminations per session. The authors then extended the verbal reprimand contingent on rumination to the lunch meal, and report a reduction from 18.75 to 12.00 ruminations per lunch observation. Although these authors report collecting interobserver agreement data for 33 % of their observations with an overall agreement of 98 %, they did not employ a design that permitted examination of functional control of the rumination by the procedures.

Combining Antecedent and Consequent Interventions

Like any other behavior, rumination occurs in temporal relation to events occurring that may be functionally related to it. When this is the case, it is essential to address both antecedent and consequent events in treatment of the rumination. Early reports of treatment focused mainly on consequent events, not insofar as they contributed to maintenance of rumination prior to treatment, but rather as stimuli to be delivered contingent on rumination to decrease its frequency. In the mid- and late-1970s, antecedent-based procedures began to appear in the literature. Coinciding with this, combinations of antecedent-based and consequence-based procedures were published. This trend continued following advent of pre-intervention functional analysis and functional assessment for rumination.

Strong evidence. Both Foxx et al. (1979) and Thibadeau et al. (1999) reported combinations of satiation with contingent oral hygiene. Using a multiple baseline design across participants, Foxx et al. found that the satiation procedure alone produced a moderate decrease in rumination for one participant, and a more substantial decrease for the other, but that addition of the contingent oral hygiene procedure further reduced frequency of rumination to near zero for both. Conversely, Thibadeau et al. (1999) found moderate levels of rumination when contingent oral hygiene and differential reinforcement for behaviors other than rumination was in place, but a reduction approaching zero occurrences when satiation was added. Both groups of authors hypothesized rumination maintained by nonsocially mediated reinforcement (i.e., reexperiencing and reconsumption of food, following a meal) and, that by providing access to alternative food, the value of the reinforcement produced by rumination was thereby degraded.

Limited evidence. McKeegan et al. (1987) reported that satiation would not be an option for their participant, a 23-year-old gentleman diagnosed with autism and severe intellectual disability who was also obese. They used a procedure that involved paced presentation of a single bite of food or a one ounce drink per 60 s during meals, combined with contingent presentation of a small, low caloric edible on a 2 min DRO schedule for 20 min after meals. They reported partial reduction in rumination with controlled eating by itself, followed by a further reduction to near zero with addition of the differential reinforcement aspect. Component analysis suggested that the differential reinforcement component was necessary to maintain the near zero rates of rumination, and during follow-up rumination continued at near zero rates, despite discontinuation of the controlled-eating and continuation only of the differential reinforcement procedure.

Wrigley et al. (2010) conducted an experimental functional analysis of rumination exhibited by a woman diagnosed with severe intellectual disability and found rumination to occur with similar frequency when followed by contingent social interaction and when occurring when she was alone, but with greatly reduced frequency when task demands were terminated contingent on her rumination. From this, they concluded that her rumination was maintained by nonsocially mediated reinforcement. Their intervention consisted of the following antecedent procedures: (1) interruption of precurrents to rumination, and (2) alternation between 10 min periods of instructional demands and 10 min periods of noncontingent attention delivered on a 5 s variable time schedule; and (3) differential reinforcement of behaviors other than rumination on a 1 min schedule. Data indicates a substantial reduction in rumination, and this effect was replicated following a return to baseline conditions and then a return to this multicomponent intervention. These authors arrived at this multicomponent intervention through component analysis in which they measured rate of rumination under the various combinations of these three procedures and the baseline condition, which indicated that rumination was least frequent when all three procedures were implemented together.

Lockwood et al. (1997) identified potential antecedents and consequences to ruminative vomiting exhibited by a 34-year-old woman diagnosed with severe intellectual disability though a descriptive functional assessment using antecedent-behavior-consequence data collection. They found her vomiting was evoked by requests from staff in general, and requests to wash her hands, move from one programming area to another, or to bathe, in particular. Identified consequences included termination or lessening of task demands, and access to vomitus, which she subsequently rubbed in her hair or on her clothing. Their observation began when a treatment consisting of restitution (i.e., requiring the woman to clean the vomitus from the floor), reinforcement for instruction following, and a DRO 1 h schedule was already in place, and which was producing approximately 1.5 instances of ruminative vomiting per day. Maintaining demands despite vomiting to counteract the apparent negative reinforcement contingency at work during the first condition, along with teaching the woman to escape from demands to enter dining room contingent on signing “please”, incorporating her preferred schedule and her preferred stimuli into transitions reduced frequency of ruminative vomiting to only about 1 instance per day (e.g., 33 % reduction). In the third intervention, the prior contingencies continued, and the woman was permitted to choose her own foods that she would eat at her meals, rather than eating a meal staff had selected for her; and, she was permitted to choose an after dinner snack if she completed dinner without ruminative vomiting. Experimenters report rumination decreased to near zero within 8 months, weight increased to her target range, and these improvements maintained over the next 16 months. This multicomponent treatment included both antecedent (e.g., selecting own food, selecting own schedule, selecting own task materials) and consequent (e.g., differential reinforcement, reinforcement, and extinction) components. These authors employed an A-B-C design, and so functional control between the interventions and the ruminative vomiting was not demonstrated.

Other Interventions

Beginning in the 1960s with the research by White and Taylor (1967) and others, conceptualizations of rumination exhibited by people with intellectual disabilities have generally come from a behavior analytic orientation and have considered the behavior to be learned and maintained by contingencies of reinforcement. Interventions derived from this formulation have involved management of contingencies surrounding the rumination.

Before this, and continuing to more recent times, conceptualization of rumination exhibited by infants and by typically developing adolescents and adults with eating disorders (e.g., anorexia nervosa or bulimia nervosa) tend to be more psychodynamic, family systems, or generally psychological in nature. Interventions derived from these formulations are described next.

Nurturing therapy. In their work with infants who were failing to thrive, Gaddini and Gaddini (1959) conducted direct observations of infants' eating and ruminating, and family interviews regarding the course of pregnancy, infant's development, and family dynamics. They hypothesized that "immature and inadequate" (p. 176) personalities possessed by mothers resulted in the infants' developing somatic symptoms, which included the rumination. The solution to this was for a nurse to provide surrogate mothering, or nurturing, or for the infant's own mother to enhance quality and quantity of attention given to the infant. This intervention reportedly led to remission of life-threatening rumination for five of six infants within weeks to years. The sixth infant, however, succumbed to pneumonia before rumination could be eliminated.

Menking et al. (1969) cited inadequacy of nurturing provided by a mother diagnosed with schizophrenia to her son as causal for the infant's rumination. They reported "striking improvement resulted from kindness and affectionate care. The observations confirm that a disturbed emotional maternal-child relation is the cause of this disorder" (p. 802). Given the enhanced nurturing provided by nursing staff, the child's rumination remitted over the course of 4 weeks. Finally, Franco et al. (1993) reported two case histories in which rumination exhibited by infants was remedied by "intense nurturing" (p. 95). They reported, "One month of treatment is often necessary to suppress the behavior, with concurrent family therapy helpful in maintaining gains after hospitalization" (p. 95).

These results sound encouraging, but methodological descriptions in these studies do not permit replication of procedures to determine the extent to which similar results might be obtained with similar or different participants. Further, one criticism of this type of therapy has been the length of time required for the rumination, often reported to be life threatening, to remit (White & Taylor, 1967; Lang & Melamed, 1969). Indeed, the illness to which one of six participants served by Gaddini and Gaddini (1959) succumbed—pneumonia—has been cited among possible sequelae of rumination (Clauser & Scibak, 1990; Gal et al., 2011; Starin & Fuqua, 1987). It is this lag between introduction of the nurturing intervention and remittance of the rumination that resulted in others considering interventions, such as contingent electric shock and contingent aversive tastes, that would produce more rapid remediation (Lang & Melamed, 1969; Marholin et al., 1980; Sajwaj et al., 1974; Toister et al., 1975; White & Taylor, 1967).

Treatment of rumination exhibited by typically developing adolescents and adults. Rumination in typically developing adolescents and adults most often occurs in the context of anorexia nervosa or bulimia nervosa (Khan et al., 2002). Given this, treatment for this behavior takes place in the context of treatment of the overarching eating disorder. Fullerton et al. (1992), Tamburrino et al. (1995), and Khan et al. (2002) reported that various combinations of inpatient psychiatric milieu therapy, monitored meals, locked bathrooms, frequent monitoring by another person, and individual, group, and family therapy produce alleviation of rumination.

Translation of Research to Practice

The evolution of pre-treatment assessment, treatment selection, and treatment assessment for rumination over the decades spanning the 1950s through the 2010s appear to parallel the evolution of pre-treatment assessment, treatment selection, and treatment assessment in other behavioral difficulties during this time. Earlier reports of assessment and treatment of rumination were primarily from a psychodynamic perspective (e.g., Gaddini & Gaddini, 1959). Psychodynamic or more traditionally psychological assessment and formulation of treatment still precedes treatment of rumination for some infants (Franco et al., 1993) or adolescents or adults diagnosed with anorexia or bulimia (Fullerton et al., 1992; Tamburrino et al., 1995).

However, beginning in the 1960s, researchers increasingly considered rumination as an operant behavior, evolving and maintaining as a function of environmental events, and so interventions involved altering consequence events (e.g., White & Taylor, 1967), and/or antecedent events (Foxx et al., 1979). It was not until the late-1990s that the literature included specific mention of pre-intervention functional assessment or functional analysis of rumination, from which interventions for the behavior were determined and assessed. This evolution is described in more detail in the section that follows.

We acknowledge that rumination is a problem that could have a number of etiological variables that must be considered, in addition to antecedent and consequent conditions. In particular, conditions such as motility disturbances, gastroesophageal reflux, and swallowing dysfunction may contribute to this behavior (Babbitt et al., 1994). It is logical that prior to, or concurrent with assessment of environmental events that may or may not be related to rumination, medical and other professionals who are expert in assessment of swallowing and other behavior of the gastrointestinal tract conduct their assessments, which can result in either ruling out these contributing factors, or treating them through other appropriate means. Indeed, a number of authors have called for an approach to assessing rumination that crosses medical and behavioral disciplines (Babbitt et al., 1994; Fredericks et al., 1998).

Of course, a cross-disciplinary evaluation of rumination is most likely to occur when rumination has already been determined to be problematic. By this time, medical and social sequelae may already be taking their toll (Matson & Kuhn, 2001). Two instruments have been developed that can serve as pre-assessment screens to determine whether rumination is or may become a problem before its problematic nature has become obvious. The Screening Tool of Feeding Problems (STEP), developed by Matson and Kuhn (2001), is a 23-item informant based assessment through which a qualified individual elicits responses from an informant regarding frequency and severity of various eating related behavioral difficulties. Informants respond to each item by indicating that the nominated behavior has not occurred in the last month (rated zero), occurred between one and ten times (rated a one), or occurred more than ten times in the last month (rated a two). For items with frequency ratings of one or two, the informant then indicates whether the behavior is not a problem (rated a zero), is a mild problem (rated a one), or a severe problem (rated a two). This instrument contains two items pertaining to rumination and vomiting, and examination of psychometric properties of this instrument, and of these items in particular, indicates good internal, temporal, and inter-rater consistency, and has good predictive validity. A parallel form of this instrument, the Screening Tool of Feeding Problems Applied to Children (STEP-CHILD) (Seiverling, Hendy, & Williams,

2011) includes the same items from the STEP pertaining to rumination and vomiting, and this instrument, too, has sufficient psychometric properties.

For those already exhibiting rumination to the extent that they are experiencing medical or social sequelae, it is clear that assessment and intervention is necessary. For those who may be exhibiting pre-critical forms of this behavior, though, screening with either the STEP or STEP-CHILD could trigger further evaluation that may be helpful. Moreover, a prudent course of action for one who may exhibit difficulty with rumination would be screening with either the STEP or STEP-CHILD, followed by medical, nutritional, and speech-and language or occupational therapy evaluation to rule out or control for medical or physiological difficulties, followed by functional assessment or analysis of the rumination, and management of the contingencies controlling this behavior, if appropriate.

Pre-treatment assessment. Psychodynamic case formulations of rumination considered a difficult-to-define deficient mother–child relationship dynamic, i.e., "rumination seemed to occur in relationship to a particular tension whose immediate motivation was not easily understandable" (Gaddini & Gaddini, 1959, p. 179), in which "frustration experienced by the ruminating infant that is due to insufficient gratification coming externally leads the baby to produce internal gratification through rumination" (p. 181). In the mid-1960s, researchers began considering rumination as an operant behavior, evoked under particular circumstances and maintained by consequent events (Lang & Melamed, 1969; Smeets, 1970; White & Taylor, 1967).

Reports of interventions for rumination based on an operant account were published through the next three decades, most including pre-intervention assessment that documented parameters of rumination (e.g., count, rate, duration, and/or latency to onset following termination of a meal) or topography during baseline data collection. Although some researchers reported baseline data in graphic, time-series format (see Galbraith et al., 1970; Libet et al., 1973, for example), some did not, and instead described baseline observations in text or in summary tables (see Smeets, 1970; White & Taylor, 1967). While time-series analysis did permit examination of level, trend, and variability of the rumination prior to implementing a procedure, researchers were unable to depend on this method for identifying variables evoking or maintaining the rumination. Given this, interventions during this time were selected on the basis of fortuitous observations (i.e., Daniel, 1982; Thibadeau et al., 1999), or on conceptual extensions of prior research (i.e., Davis et al., 1980; Foxx et al., 1979; Sajwaj et al., 1974; Toister et al., 1975). While these reports describe effectiveness of the procedures implemented, and a number included demonstration of functional control over the rumination by the intervention (i.e., Conrin et al., 1982; Foxx et al., 1979; Libet et al., 1973), none included a pre-treatment functional assessment or functional analysis.

The purpose of pre-intervention functional assessment or functional analysis is to identify contingencies that evoke and maintain the behavior of concern, such that interventions can then be developed that address those variables. This sort of assessment is now considered a standard practice in applied behavior analysis (Behavior Analyst Certification Board, 2014). Although applied to repetitive behaviors (Rincover, Newsom, & Carr, 1979) and self-injury (Iwata, Dorsey, Slifer, Bauman, & Richman, 1982) in people with intellectual disabilities earlier, this essential aspect of treatment planning and evaluation did not appear in the rumination literature until 1997. At that time, Lockwood et al. (1997) reported conducting a descriptive functional analysis, documenting antecedent and consequent conditions to their participant's rumination. From this assessment, they determined that vomiting (a component of rumination) was evoked by demands from staff, was directed toward staff, and resulted in reduction in demands. The intervention package developed on the basis of this analysis consisted of positive reinforcement for compliance with instructions, restitution following vomiting, escape extinction, and the participant choosing her meals, rather than staff selecting her food for her. Although their design did not permit demonstration of functional control, data do indicate a reduction to near zero in vomiting, which was maintained for more than 16 months.

More recently, experimental functional analysis has been applied to rumination. In such an analysis, one exposes the participant to a variety of conditions for a standard period of time, typically using an alternating treatments design. Conditions often include the following:

1. Escape, in which the participant is given instructions to engage in a typically encountered task on a schedule, and instructions are terminated for a set period of time contingent on the targeted behavior. No other attention is provided during this condition. This condition assesses for both evocative effects of instructions and for social negative reinforcement value of instruction termination.
2. Attention, in which the targeted response results in social attention (e.g., "Stop that," "Quit doing that," and so forth), and no other attention is given except this contingent attention. This condition assesses for potential positive reinforcement by contingent attention.
3. Tangible, in which the targeted response gains access to a tangible item (e.g., preferred leisure item, small amount of food, and so forth), and no other access to these stimuli occurs. This condition assesses for social positive reinforcement by contingent access to tangibles.
4. Alone, in which the participant is observed alone, with or without leisure materials, but no instructions and no contingent attention or access to tangibles is given, and no programmatic consequences follow occurrence of the behavior. In contrast to the three prior social contingency conditions, this condition assesses for maintenance by nonsocially mediated reinforcement.
5. Control, in which the participant is present with an experimenter or therapist, who does not interact with the participant, in a room in which preferred materials are freely available. This condition provides a comparison for other conditions, given that it is devoid of either social positive or negative reinforcement contingencies, but maintains the presence of another person.

Level, trend, and variability of targeted behavior are compared across conditions through visual analysis of the graphed data, and the analyst determines which contingency or contingencies maintains the behavior.

Lyons et al. (2007) conducted an experimental functional analysis for two adolescents with intellectual disability who exhibited rumination, using Escape, Attention, and Control conditions, and substituting a No-intervention condition for the Alone condition. No-intervention condition procedures mirrored the Alone condition, but an adult who was not interacting with the participant in any manner was present in the room. Using an alternating treatments design, functional analysis data indicated maintenance by nonsocially mediated reinforcement for both participants. A similar procedure was used by Wrigley et al. (2010) for an adolescent girl with severe intellectual disability, involving only Escape, Alone, and Attention conditions; one conducted by Kliebert and Tiger (2011) for an 11-year-old boy diagnosed with severe intellectual disability that incorporated Attention, Escape, No-Interaction, and Control conditions; analyses conducted by Sharp et al. (2012) for two adults diagnosed with autism and severe intellectual disability involving Alone, Attention, Escape, and Control conditions; and an analysis conducted by Woods et al. (2013) for rumination exhibited by a man diagnosed with intellectual disability and employing all five standard conditions all found the behavior to be maintained by nonsocially mediated reinforcement. Wilder et al. (2009) implemented Attention, Escape, and Control conditions both before and after meals with a gentleman with autism and profound intellectual disability, and found zero rumination prior to meals, despite condition, and maintenance by nonsocially mediated reinforcement for rumination that occurred after meals.

Both descriptive functional assessment and functional analysis can be time consuming endeavors, requiring a specialized skill set. Time spent in assessment, important though it is, is also time spent delaying treatment. Matson et al. (2005) reported on utility of the Questions About Behavioral Function (QABF) (Matson & Vollmer, 1995) as a questionnaire for use in pretreatment assessment of rumination and other feeding and eating related problems. This instrument is a 25-item informant-based rating scale with five subscales, four of which reflect the Attention, Escape, Tangible, and Control conditions of standard functional analysis procedures, and an additional Physical subscale, which examines the extent to which the targeted behavior may be evoked by physical discomfort or reinforced by its attenuation. These authors reported that administration of this instrument with informants of 125 individuals with feeding or eating problems found that the most frequently identified maintaining consequence for rumination was nonsocially mediated reinforcement, but that other contingencies (e.g., social positive and social negative reinforcement) were also sometimes nominated as operative. Given this, and the relative rapidity with which the QABF can be administered, this instrument, combined with direct observation, may in some instances have utility with regard to determining course of intervention that is comparable to a functional analysis.

Treatment selection. Psychodynamic formulations of rumination typically resulted in interventions designed to address rumination by ameliorating a difficult-to-define deficient mother–child relationship dynamic (Gaddini & Gaddini, 1959), as described in the *Nurturing* section, earlier in this chapter. More recent, traditional psychological case formulations have resulted in nurturing therapy for infants (Franco et al., 1993), and involvement in group or individual talking therapy or family therapy (Fullerton et al., 1992; Tamburrino et al., 1995). Williamson et al. (1989) added self-managed contingent access to a patient's own jewelry to her group therapy treatment for rumination.

Treatment selection in many studies published between the 1960s and 1990s that examined rumination from an operant standpoint involved either logical extension of interventions first published for other problems to treatment of rumination, or treatment selection based on fortuitous experimenter observations. Punishment was the primary mode of treatment, but the exact stimulus used as the punisher varied over time. White and Taylor (1967) conceptualized rumination as an operant behavior, and employed contingent electric shock, citing advantage this treatment had over nurturing treatments with regard to rapidity of alleviation of rumination. A number of researchers subsequently elected this intervention for their participants, each citing the success reported by White and Taylor (e.g., Galbraith et al., 1970; Lang & Melamed, 1969; Luckey et al., 1968; Toister et al., 1975).

Concern with acceptability of contingent electric shock contributed to selection of punishment by contingent oral administration of lemon juice by Libet et al. (1973) and Sajwaj et al. (1974). Citing effectiveness of the contingent lemon juice procedure, but concerned with the perceived aversive nature of contingent aversive tastes, Foxx et al. (1979) opted to conduct a satiation procedure combined with contingent oral hygiene. The latter component still included presentation of a stimulus some might consider unappealing, but had in its favor the normative nature of this stimulus being used to counteract breath odor, and potential oral health benefits of its use. Singh et al. (1982) replicated the oral hygiene component, and found it efficacious in reducing rumination.

Citing concern with the perceived acceptability of contingent electric shock, Smeets (1970) applied contingent removal of social stimuli to rumination of his adult participant, citing prior use by Wolf, Birnbauer, Williams, and Lawler (1965) in implementing this procedure to reduce vomiting. Similarly, Davis et al. (1980) reported contingent use of music as effective in treating other behavioral difficulties, and as less aversive than either aversive tastes or contingent electric shock, and so applied contingent termination of ambient music combined with a verbal reprimand in their treatment for rumination. Concerned with aversive nature of previously reported interventions, Daniel (1982) based his contingent exercise procedure on a fortuitous observation that his participant did not ruminate when he was walking. Conrin et al. (1982) similarly implemented DRO, which had previously been applied by other researchers to treatment of other behaviors, to rumination, citing their concern for acceptability of prior interventions.

Treatment selection took a different turn with advent of pre-intervention functional assessment and functional analysis. Lockwood et al. (1997) and Rhine and Tarbox (2009) matched the functional aspects of their multicomponent interventions to the perceived functions of events surrounding their participants' rumination, as indicated by pre-intervention functional assessment. Similarly, Heering et al. (2003), Lyons et al. (2007), Wilder et al. (2009), Wrigley et al. (2010), Kliebert and Tiger (2011), Sharp et al. (2012), and Woods et al. (2013) all conducted experimental functional analyses of their participants' rumination. In each of these instances, functional analysis revealed that the behavior was maintained by nonsocially mediated reinforcement. Resulting interventions either altered the probability of rumination by presenting frequent access to potentially matched stimuli as reinforcers (Heering et al., 2003; Kliebert & Tiger, 2011; Lyons et al., 2007; Rhine & Tarbox, 2009; Sharp et al., 2012; Wilder et al., 2009; Woods et al., 2013), or combinations of interventions that included antecedent interventions and reinforcement procedures. None of the studies surveyed that involved pre-intervention functional analysis or functional assessment included a punishment-based intervention, save for restitution employed by Lockwood et al. (1997).

Treatment assessment. The extent to which researchers employed designs that permitted assessment of effects of various interventions was one of the criteria that separated literature that did meet evidence standards from literature that did not (Table 25.2). Many studies reported improvement in rumination and attributed this improvement to procedures employed. Only a relatively small number of studies have actually reported research designs permitting determination of functional control over rumination by interventions. A determination that it was the intervention(s) that produced the change in rumination, and not other variables, would be necessary in order to conclude that an intervention is evidence-based.

The earliest, and most frequently used design in examining efficacy of rumination treatments is the withdrawal design. This design involves collecting baseline, or pre-intervention data, introducing the intervention when stable baseline data are attained, withdrawing intervention once a stable intervention effect has been attained, and then reintroducing intervention. This method of evaluation permits examination of extent to which the data path that results from initial introduction of intervention differs from that which would be expected had intervention not been introduced; extent to which the data path returns to its pre-intervention pattern when intervention is withdrawn and baseline procedures are reintroduced; and extent to which the change in behavior that followed the first introduction of intervention is produced following the second introduction of intervention. When the data path that follows initial introduction of intervention differs from that observed during baseline, and when the data path trends back toward baseline levels when intervention is withdrawn, and when the change in the data path observed after initial introduction of the intervention is observed following second introduction of intervention, then one can say that functional control over the behavior has been demonstrated by the intervention.

Libet et al. (1973) and Sajwaj et al. (1974) employed very similar withdrawal designs, in which baseline data collection on percentage of intervals in which rumination occurred was followed by introduction of contingent presentation of lemon juice. Following stable reduction in rate of rumination, intervention was temporarily withdrawn, and frequency of rumination trended toward its baseline level. Reintroduction of contingent lemon juice procedure was followed by resumption of the greatly lowered frequency of rumination, which eventually tended toward zero frequency. Carroll et al. (2011) and Thibadeau et al. (1999) also employed simple withdrawal designs in assessing efficacy of noncontingent reinforcement and satiation, respectively, in treating rumination. Conrin et al. (1982) lengthened the durations of their targeted interresponse times in the context of a withdrawal design. McKeegan et al. (1987) and Glasscock et al. (1986) employed withdrawal designs, which demonstrated functional control of their basic procedures over their participants' rumination, and then introduced additional interventions to further reduce the behavior.

A withdrawal design, by its nature, typically involves withdrawal of an intervention for an extended period of time in order to examine extent to which the intervention did or did not produce change in the behavior. For a behavior such as life-threatening rumination, a prolonged withdrawal would not be desirable. Rhine and Tarbox (2009) conducted their evaluation of a gum-chewing intervention using an alternating treatments design, in which they compared rate of rumination when their participant was and was not gum chewing, with gum chewing and no gum chewing conditions alternating on a session-by-session basis. This design permitted rapid examination of the effects of this intervention.

Some have employed multiple baseline designs. These designs, too, do not require withdrawal of an intervention, and, instead, stagger intervention across participants or across behaviors. Foxx et al. (1979) demonstrated efficacy of satiation plus oral hygiene as they began baseline data collection for both of their participants, and sequentially introduced first the satiation procedure, then the satiation procedure plus oral hygiene, across both participants. When the data path changes only when the intervention is implemented for the first participant, remains constant when the other participant remains in the baseline condition and the data path changes when the intervention is implemented for the second participant, then functional control is demonstrated. Similarly, Singh et al. (1982) implemented a multiple baseline design across participants and meals, and found their contingent oral hygiene procedure to be efficacious. Although a treatment withdrawal is not required for a multiple baseline design, both Lobato, Carlson, & Barrera (1986) and Sisson et al. (1988) incorporated withdrawals into their multiple baseline designs, thereby increasing the confidence with which one could determine that the interventions produced the reductions in rumination.

Wilder et al. (1997) incorporated an alternating treatments design, in which they compared effects of three interventions with each other, into a withdrawal design. This study began with a baseline phase, during which no intervention was implemented, followed by a treatment phase, in which the comparison using the alternating treatments design was conducted; followed by a return to a baseline phase, and then a best-treatment phase, during which two values of the intervention determined to produce the greatest effect during the alternating treatments design comparison (e.g., satiation for 30 min after a meal versus satiation for 60 min after a meal) were compared. This more complex design permitted these researchers to relatively quickly evaluate effects of three interventions against each other and against no intervention, and then to examine how much of the best intervention was needed to produce a meaningful reduction in rumination.

More recently, pre-intervention functional analysis has permitted development of interventions hypothesized to address functional relations maintaining the rumination, and then to assess those interventions by comparison with the participant's performance under the functional analysis control condition. Lyons et al. (2007), Wilder et al. (2009), Kliebert and Tiger (2011), and Woods et al. (2013) did just this, and identified noncontingent reinforcement procedures as most effective in reducing rumination for their participants. Wrigley et al. (2010) likewise conducted a pre-intervention functional analysis, and through this and a subsequent treatment comparison phase, were able to identify a multicomponent intervention addressing both antecedent and consequent variables that greatly reduced rumination for their participant.

Conclusion

Rumination is a potentially life-threatening behavior (Fredericks et al., 1998), which also carries with it other health effects (Gal et al.,

2011) and social stigmatization (Sisson et al., 1988), and which can consume sufficient time that it impedes one's ability to learn other skills (Beukelman & Rogers, 1984). This behavior is said to occur in between 5 % (Kuhn & Matson, 2002) to 10 % (Ball et al., 1974) of people with intellectual disabilities, and is inversely related to degree of intellectual disability (Gal et al., 2011). Rumination also occurs in some typically developing infants, and has been hypothesized to occur when inadequately nurturing relationships between the infant and her or his caregivers result in the infant somehow stumbling upon the first instance of rumination, which itself produces sufficient reinforcement (given the backdrop of inadequate reinforcement occurring within the context of the caregiver) that the rumination increases in frequency. This behavior also occurs in some typically developing adolescents and adults who are diagnosed with anorexia nervosa or bulimia nervosa (Weakley et al., 1997; Williamson et al., 1989).

Rumination topographies typically involve regurgitating previously swallowed food or drink, experiencing that in one's mouth with or without chewing or otherwise orally processing, possibly expelling some, but also with reswallowing. This behavior often occurs following meals (Lyons et al., 2007; Marholin et al., 1980; O'Neil et al., 1979), but for some can occur near continuously (Humphrey et al., 1989).

Early reports suggest that rumination in people with intellectual disabilities is maintained by the stimulation that this behavior, itself, produces. While screening instruments such as the QABF (Matson & Vollmer, 1995) may suggest that rumination may have other functions (Matson et al., 2005), functional analyses of rumination have found that this behavior has been, indeed, maintained by nonsocially mediated reinforcement. It is noted, however, that those participating in published functional analyses of rumination have not included infants or typically developing adolescents or adults, and so functions in this population have not yet been demonstrated.

Early reports on treatment of rumination were based on formulations derived from a psychodynamic orientation, and involved nurturing therapy, through which enhanced quality and frequency of attention was provided to infants by nursing staff or others (and often not the parent), with reports of resolution of rumination occurring over a number of weeks or months (Gaddini & Gaddini, 1959; Menking et al., 1969). Early reports of this behavior in children and adults diagnosed with intellectual disabilities, however, often included a learning-based formulation. Researchers working from this perspective typically provided aversive consequences following rumination (i.e., electric shock or aversive tastes), given the concern with the extended treatment period needed to reduce this life-threatening behavior, and the greater rapidity with which contingent aversive stimuli might reduce the behavior (White & Taylor, 1967).

Concerns with the social acceptability and possible physical side effects of interventions involving contingent presentation of aversive stimuli led some to examine effects of interventions thought to be less aversive. These included contingent oral hygiene (Foxx et al., 1979; Singh et al., 1982), contingent exercise (Daniel, 1982), differential reinforcement (Conrin et al., 1982; Davis et al., 1980; Smeets, 1970), and antecedent interventions involving presenting noncontingent access to food or varying qualities or quantities of foods typically presented (Foxx et al., 1979; Rast et al., 1984, 1985; Yang, 1988).

Many reports detailing treatment of rumination in people with intellectual disabilities do not meet the criteria detailed by Kratchowill et al. (2010) to *Meet Evidence Standards*, or *Meet Evidence Standards with Reservation*. Some studies did not report use of experimental designs that permit examination of the extent that changes in rumination were attributable to the intervention implemented (i.e., Davis et al., 1980; Luckey et al., 1968; White & Taylor, 1967). Some studies did not report interobserver agreement data or other determination that the data reported were reliable (i.e., Beukelman & Rogers, 1984; Daniel, 1982; Toister et al., 1975). Findings of these studies, interesting though they are, must be viewed with caution, given these limitations.

Procedures reported in studies that did meet criteria to be identified as meeting evidence standards or meeting evidence standards with reservations were next examined to determine the strength of the evidence base behind those procedures in treatment of rumination. Procedures were said to have *Strong Evidence* when they were reported in at least five studies that had met evidence standards or met evidence standards with reservation; conducted by at least three independent research teams; and with effects demonstrated across at least 20 participants (Kratchowill et al., 2010). Procedures meeting only two of these criteria were said to have a *Moderate Evidence* base, and procedures meeting fewer than two of these criteria were said to have *Little Evidence* base. Our review of the rumination literature resulted in only Satiation having a *Strong Evidence* base. No procedures were found to have a *Moderate Evidence* base. Despite numerous research reports detailing interventions for rumination, particular procedures have not had sufficient replications within studies that *Meet Evidence Standards* or *Meet Evidence Standards with Reservations* to permit accumulation of any in sufficient number to meet the thresholds for number of reports or number of participants to meet the *Moderate Evidence* criterion (Table 25.3).

A variety of procedures have been found to meet the *Little Evidence* criterion (Table 25.3). Each of these was reported in studies that *Meet Evidence Standards* or *Meet Evidence Standards with Reservations,* but, again, have had insufficient replications across studies and across participants to permit a rating of either *Moderate Evidence* or *Strong Evidence*. Nonetheless, the procedures have been shown efficacious in the studies in which they were reported, and include: (1) punishment by contingent aversive taste (Glasscock et al., 1986; Sajwaj et al., 1974; Sisson et al., 1988); (2) punishment by contingent oral hygiene (Foxx et al., 1979; Singh et al., 1982); (3) differential reinforcement of other behavior (Conrin et al., 1982); (4) altered rate of food presentation (McKeegan et al., 1987); (5) liquid rescheduling (Heering et al., 2003; Sharp et al., 2012); (6) noncontingent access to nonnutritive reinforcer (Carroll et al., 2011; Rhine & Tarbox, 2009; Wilder et al., 2009); and (7) multicomponent interventions (O'Neil et al., 1979; Wrigley et al., 2010). Clearly, additional research is needed examining efficacy and parameters of efficacy for these procedures before they can be said to have Strong *Evidence* base, promising though they are.

Pre-intervention assessment has changed over the last six decades. Although previously diagnosed only after the person with an intellectual disability was experiencing poor health effects of the behavior (Matson & Kuhn, 2001), several informant based assessments—the STEP (Matson & Kuhn, 2001) and STEP-CHILD (Seiverling et al., 2011) are now available, which would permit screening for rumination in this at-risk population before the behavior has produced untoward sequelae. Similarly, at least one functional analysis screening instrument—the QABF (Matson & Vollmer, 1995)—has been demonstrated to produce a rapid assessment of functional relations governing rumination that are similar to those that have been reported through lengthier descriptive or experimental functional analysis. This is important, because time spent in assessment is time during which intervention is delayed. Use of the QABF in assessing functions of rumination may permit more rapid introduction of intervention than would use of another functional analysis or assessment procedure.

The last 60 years have seen advances in functional analysis and treatment of rumination. Coinciding with these advances were changes from aversive consequence-based to more benign, antecedent-based interventions. Additional research is needed to assess efficacy and parameters of efficacy of current interventions that have limited evidence base. In addition, given the availability of screening instruments for use with at-risk population, future research should examine the extent to which preventive procedures may be put in place to reduce prevalence of this behavior among people with intellectual disabilities.

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Pica

26

Don E. Williams and David McAdam

Introduction

Pica refers to the persistent eating of nonedible items. The term pica comes from the Latin term for magpie, a bird famous for having a voracious indiscriminate appetite (Danford & Huber, 1982). Both nonhuman organisms (e.g., cats, dogs, buffalo) and humans engage in pica. Persons who display pica may eat a wide variety of items including nonedible plants, rock salt, small pieces of plastic toys, jewelry, soiled diapers, cigarette butts, cloth, screws, nuts, bolts, coins, and rubber gloves used in hospitals and care facilities (McAdam, Breidbord, Levine, & Williams, 2012; McAlpine & Singh, 1986; Singh, 1997; Williams, Kirkpatrick-Sanchez, Enzinna, Dunn, & Borden-Karasack, 2009). Some persons with pica only target specific items (e.g., cigarettes), whereas others display indiscriminative pica and routinely ingest a wide variety of objects depending on what is available in their current environment (Foxx & Martin, 1975). In some cases, pica may be associated with a nutritional deficit or associated with cultural practices or folk medicine (Ali, 2001).

The topography of pica also may vary significantly across individuals with intellectual and developmental disabilities (Donnelly & Olczak, 1990; Favell, McGimsey, & Schell, 1982). Some people appear to mouth objects but only occasionally swallow them. Other people place objects in their mouth and swallow them quickly. The ingestion of nonedible items can result in various medical complications requiring surgery, or other medical problems, such as intestinal parasites, poisoning, choking, repeated respiratory problems, whipworms, and death (Foxx & Martin, 1975; McAlpine & Singh, 1986; Williams & McAdam, 2012). For example, McLoughlin (1988) reported the case of a 22-year-old man with intellectual and developmental disabilities who died from a chest infection reportedly related to a long history of pica. Williams and McAdam (2012) and McAlpine and Singh (1986) suggested that pica may be under identified, underreported by professions (e.g., physicians, special education teachers), and undertreated by clinicians.

Diagnosis and Prevalence

The recently published *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5), and the International Classification of Diseases, Tenth Edition, are the two most

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commonly used diagnostic criteria for pica. The definition of pica in DSM-5 was revised in order to eliminate the requirement for the onset of the disorder in childhood. The definition of pica was moved to the feeding and eating disorders section from the feeding and eating disorders of infancy or early childhood section. This revised definition now better accounts for the display of pica by people with no history of pica in childhood (e.g., pica onset associated with dementia) or an unknown developmental history. There are three common features across these diagnostic systems including (a) the persistent eating of one or more nonnutritive substances for a month or longer, (b) the display of pica to be intellectually inappropriate, and (c) if pica occurs as part of the clinical course of another mental disorder (e.g., schizophrenia). It must be severe enough to warrant additional independent attention from a clinician.

The prevalence of pica in persons with intellectual and developmental disabilities reported in the literature has varied considerably, and there are no recent prevalence data. Several researchers have also reported that pica is more prevalent among individuals with severe intellectual disabilities (Ali, 2001). Danford and Huber (1982) conducted a chart review of 991 persons with intellectual and developmental disabilities living in an institution and found that 16 % of the persons for whom a chart review was conducted engaged in pica. Danford and Huber's operational definition of pica was expanded to include the ingestion of nonfood items and the ingestion of underprepared foods (e.g., raw eggs), excessive amounts of food (e.g., a cube of butter), and possibly contaminated food (e.g., food in a garbage can or on the floor). With this expanded definition, the figure of 16 % rose to more than 25 %. A statewide prevalence survey of all 13 public residential facilities in Texas by Griffin, Williams, Stark, Altmeyer, and Mason (1986) found that 17 % of males and 8 % of females identified in the survey as self-injurious were reported to engage in pica.

Both researchers and clinicians could benefit from additional documentation of more recent clinical incidence of pica and the systematic study of its prevalence. The results of pica prevalence surveys—most are more than 30 years old—should be viewed with caution for several reasons. First, much of the information we have on pica is based on systematic chart reviews, and the occurrence of pica may be underreported in medical and clinical records. Second, studies have used varying operational definition of pica. Third, the majority of studies have been conducted with individuals who live in large care facilities (e.g., institutions, eight-person community-based group homes). Finally, there are no current prevalence studies on pica. Thus, we have no recent incidence and prevalence data on pica for individuals with intellectual and disabilities in less restrictive settings or with specific populations of persons with developmental disabilities. For example, there is no recently published study of the incidence and prevalence of pica of young children with autism who live in the community with their parents despite frequent reports of concerns to clinicians and educational teams.

Assessment of Pica

Contemporary functional assessment standards suggest that an assessment of the operant variables maintaining pica should be conducted to aid in the development of a function-based behavior treatment plan, whenever possible. Functional assessment methods can be divided into two categories: (a) indirect and (b) direct. Indirect methods include questionnaires and interviews. Direct methods include both correlational and experimental approaches. Indirect methods alone are often not adequate for determining the operant function of problem behavior. Therefore, given the potential severity of pica and the potential for serious consequences, we recommend that a functional analysis should always be conducted (Hanley, Iwata, & McCord, 2003). However, it might be feasible if automatic reinforcement is the presumed function to just run an extended alone condition sessions (Iwata & Dozier, 2008). To date, the pica behaviors of the vast majority of persons with intellectual and developmental disabilities who have participated in a functional analysis are maintained by nonsocial factors (i.e., automatic reinforcement).

The professional in charge of the development, implementation, and evaluation of intervention programs for dangerous pica should, at a minimum, have BCBA certification with several years of related clinical experience with pica. We have learned that licensed professionals in other disciplines rarely have the professional training, experience, and supervision that certified BCBAs have. Therefore, if a licensed psychologist or social worker, for example, claims to be qualified to assess and treat pica, they should find the coursework and supervised experience of the BCBA credential helpful.

Pica is the only topography of self-injurious behavior (SIB) that requires unique health, safety, and medical considerations. Numerous studies have used physician-approved items authorized for a certain level of consumption of nonedible items in both baseline and intervention phases of studies. This use of items that are inedible, but not considered dangerous (i.e., baiting), has helped in the practice of behavior analysis by making it safe to perform an experimental functional analysis (Piazza et al., 1998). Despite a fairly extensive literature in support of baiting, some clinicians and researchers may be reluctant to authorize baiting.

Researchers have used different diagnoses of pica, and this contributes to different prevalence figures for pica. We have suggested using the DSM-IV-R (now the DSM-5) definition for research (Williams & McAdam, 2012). However, the use of this definition (DSM-5), while good for research, is a limiting definition for practitioners and recipients of services. The DSM-5 definition of pica requires observation of outcomes or direct observations of at least two pica incidents in a month. Who observes and collects data to substantiate the diagnoses of pica? Many psychologists and behavior analysts rely on indirect measures (e.g., questionnaires or incident reports). The traditional diagnosis of pica either seems too time-consuming for direct observation by a behavior analyst or occurs at such low rates that the time involved for behavior analysts to reliably identify those with pica may be too labor intensive. However, reliable data must be recorded to verify the diagnosis and to rule out mouthing objects only. A clinical method for doing this satisfactorily has yet to be demonstrated.

The requirement that two pica events must occur in a 30-day period is an unnecessary limitation of the definition of pica. This is a rigid requirement that could preclude a pica diagnosis if an individual displays serious pica incidents only six to eight times per year, for example. Interestingly, we know of no other self-injurious behavior with such a limit on the diagnosis, although repeated incidents are usually documented. Because one incident of ingestion of a nonedible item could be lethal, we think the imposition limiting the diagnosis places people with intellectual and developmental disabilities at a higher risk of harm. In addition, it may delay a diagnosis and possibly preclude early intervention for the pica behavior. The severity or intensity of pica also should be a concern. For example, if a person was found eating rocks, her physician would likely order an X-ray. It is possible to distinguish between severe or highly dangerous pica from less serious pica by reviewing an individual's medical history.

Evidence-Based Treatments

One of the most recent, comprehensive meta-analysis of the pica literature included 35 studies and 59 participants (McAdam et al., 2012). Studies included had a baseline and intervention, and two effect size measures were calculated (i.e., percentage of nonoverlapping data and percentage of zero data). Excluded were studies with unreadable data graphs, treatment-only analyses of intervention packages, alternating treatment designs, and comparisons of two or more treatments that did not include a baseline comparison. Criteria based on research evaluation and independent replication as presented by (Chambless and Hollon 1998) were employed. The following were the key findings of the meta-analysis: (1) There is well-established evidence for the effectiveness of these behavioral procedures for the short-term treatment of pica: noncontingent reinforcement, environmental enrichment, and overcorrection.(2) There is limited evidence for the effectiveness of these behavioral procedures for the short-term treatment of pica: physical restraint and response blocking.(3) There is insufficient evidence for the effectiveness of these behavioral procedures for the short-term treatment of pica: physical restraint and aversive stimulation. Sturmey (2014) remarked upon the similarities in outcomes of the aforementioned meta-analysis by McAdam et al. (2012) and the one by Hagopian, Rooker, and Rolider (2011). The agreements between the two systematic review papers on the treatment of pica were achieved despite the independence of the two studies. We present the behavioral treatments in detail, including most recent studies, what was done, and the outcomes of each study.

Well-Established Treatments for Short-Term Effectiveness

Noncontingent reinforcement (NCR). Noncontingent reinforcement is the delivery of the reinforcer independent of the response or on a time-based delivery of reinforcer (Vollmer, Iwata, Zarcone, Smith, & Mazaleski, 1993). A number of studies have demonstrated that the noncontingent delivery of food or toys may successfully reduce pica to manageable levels. Favell et al. (1982) reduced the pica of three adolescents with profound intellectual disabilities through the noncontingent presentation of toys (e.g., small balls, rubber rings) and popcorn. Noncontingent popcorn was provided to give participants an alternative source of sensory stimulation. Piazza, Hanley, and Fisher (1996) and Piazza et al. (1998) conducted two studies that built on the work of Favell et al. (1982). Initially, Piazza et al. (1996) showed that the cigarette pica of a 17-year-old male with severe intellectual disability and autism was maintained by a physiological variable (i.e., nicotine). Then, the pica was reduced by implementation of a treatment package that included noncontingent delivery of preferred foods and a vocal reprimand contingent on pica (e.g., “no butts”). Piazza et al. (1998) conducted an analogue functional analysis of the pica of three participants with intellectual and developmental disabilities and demonstrated that pica was maintained by automatic reinforcement or a combination of automatic reinforcement and social attention. The pica was treated with a combination of attention and access to preferred activities provided noncontingently.

Environmental enrichment. Environmental enrichment can be defined as maximizing reinforcement rates in an environment, including preferred toys, objects, and activities, and making them available to individuals. To this definition, we may add (1) provision of positive reinforcement to teach children how to use preferred stimuli (see Horner, 1980) and (2) adequate floor space (see Boe, 1977). Environmental enrichment was used by Favell et al. (1982) to deliver popcorn as alternate oral stimulation in place of pica. The premise of environmental enrichment is that reinforcers are maximized through increased availability of preferred activities, materials, or toys. There may be multisensory furniture to appeal to a variety of client or student preferences. Increased floor space might be provided (see Boe, 1977), who reduced aggression in a group of 24 children by evaluating the effects of toys present, noncontingent reinforcement, and floor space. Prevention of deprivation states is also a goal of environmental enrichment. A limitation of this approach is that the participant will likely satiate at some point. Environmental enrichment is typically used as part of a treatment package. For example, Falcomata, Roane, and Pablico (2007) found it necessary to add time-out (TO) to environmental enrichment in an interesting study to gain stimulus control of pica.

Overcorrection. Overcorrection refers to two specific procedures: (a) restitution and (b) positive practice. Restitution consists of requiring a person to correct their actions to a state that is vastly improved from what existed prior to the occurrence of a challenging behavior. Positive practice consists of having a person engage in an adaptive alternative behavior that is incompatible with the targeted challenging behavior. A number of studies have used overcorrection to reduce pica. In an early study, Foxx and Martin (1975) used overcorrection to reduce pica and coprophagy. Contingent on the display of pica, the participants were required to spit out the targeted object, brush their teeth with toothbrush soaked in mouthwash, clean their hands and nails, and clean their immediate environment (e.g., mop the floor). Overcorrection produced a clinically significant reduction in the pica of all participants.

In a more recent study, Ricciardi, Luiselli, Terrill, and Reardon (2003) combined alternative practice training and the positive practice component of overcorrection to reduce the pica of a 7 year-old boy with autism who routinely ingested wood chips, stone, paper, and small plastic objects. During alternative practice training, the participant was stopped from picking up an item to ingest and was prompted to throw it in the trash can with the vocal prompt, "Where does it belong? In the trash." After successfully discarding the item, the participant was required practice throwing small items in the trash ten times. The results of an ABAB design demonstrated that the intervention produced a clinically significant reduction in pica that was maintained at a 4-month follow-up. The use of overcorrection is not recommended unless the individual can easily be managed without intense physical opposition. Except for the study by Ricciardi et al. (2003), overcorrection has not been used to treat pica for over a decade. Of course, if it seems appropriate, the date last used is not a factor in considering its use.

Limited Evidence of Clinical Efficacy for Short-Term Treatment

Physical restraint. Physical restraint has been used in a number of studies with pica. We present the following studies that used less restrictive types of restraint involving holding arms or wrists for a minute or less. Winton and Singh (1983) treated pica exhibited by a 19-year-old with profound intellectual disabilities by comparing briefly holding arms to the side for 10 s versus 30 versus 1 min release criteria. Pica was reduced from 22.7 % of intervals per 15 min session to 3 %. Within the framework of an alternating treatment design embedded within a multiple-baseline design, the durations of brief physical restraint were compared. Physical restraint consisted of holding the participants' hands to their side for the full duration of the restraint. All three durations of physical restraint were clinically effective; however, no maintenance data were collected, so confident conclusions could not be reached about long-term effectiveness.

Singh and Bakker (1984) used brief duration holding arms to side for 10 s. The two participants, a 21-year-old female with profound intellectual disabilities and a 20-year-old female with profound intellectual disabilities, were significantly improved. The first participant engaged in pica for 32.2 % of intervals and only 1.3 % after treatment. The second participant was at 10.8 % of interval pretreatment and 0.9 % after treatment. Again, an alternating treatment design was used. Paniagua, Braverman, and Capriotti (1986) used physical restraint (arms held in rigid vertical position for 30 s) as part of a multicomponent intervention package to reduce the pica of a 4-year-old girl with a profound intellectual disability. Pica was reduced from 52 % of intervals to less than 10 % during a 10-min session. A multiple-baseline design was used, and the results obtained replicated earlier studies.

LeBlanc, Piazza, and Krug (1997) used an alternating treatment comparison of physical restraint (i.e., canvas arm sleeves, a helmet, and face mask) versus response blocking for a 4-year-old girl with profound intellectual disability. During the response blocking condition, the participant did not wear any protective equipment. Response blocking consisted of pushing the participant's hand holding the pica item down before she could place it in her mouth. The results of the alternating treatment analysis demonstrated that both procedures successfully eliminated pica. LeBlanc et al. suggested that response blocking was the more appropriate treatment because it resulted in the display of fewer negative vocalizations and increased the participant's opportunities for social interactions (i.e., response blocking was a less restrictive treatment option than mechanical restraint).

The overall results of studies using physical restraint demonstrate that the approach is a potentially effective intervention. The use of physical restraint may be warranted for individuals who display potentially life-threatening pica and when other less restrictive interventions have failed or cannot be implemented due to risk of harm issues (e.g., history of ingesting potentially fatal items like glass or vinyl gloves). These studies demonstrate clearly that restraint is effective in the treatment of pica.

Response blocking. Response blocking requires the caregiver to be as close to the participant as necessary to physically block access to an item. Blocking usually involves the use of hands and forearms to block pica attempts. Blocking in some cases may include grasping a client's wrist; attempts to retrieve potentially dangerous items in the hands or mouth of the client may involve intrusive activities which are restraint. Response blocking has been identified as a procedure that can be used effectively as a component of a treatment package (Hagopian, Rooker & Rolider, 2011). However, Rapp, Dozier, and Carr (2001) found that response blocking alone did not reduce pica sufficiently and a side effect emerged—aggression. McCord, Grosser, Iwata, and Powers (2005) investigated two variations of response blocking and discovered that response blocking may only reduce pica if used early in the chain and if the implementation is so consistent that virtually no responses are missed by therapists, thus preventing the placement of pica on an intermittent schedule. These authors also suggested that response blocking alone may not be adequate and another intervention may need to be incorporated into the intervention package.

Other factors often overlooked in the response blocking literature are age, size, and quickness of participants. Obviously, response blocking may work well with 4-year-old children. Large, strong, and quick children or adults with pica are extremely difficult to control and may require restraint to prevent access to or ingestion, even when assigned one-on-one staff members when nonedible items are freely available in what can be termed a non-pica-safe environment. Another factor to consider is that physical proximity necessary to implement response blocking may be aversive for some individuals. Nevertheless, response blocking may be a necessary part of treatment for some individuals with pica and intellectual and developmental disabilities.

Interventions with Insufficient Experimental Evidence for Clinical Efficacy

Differential reinforcement. Differential reinforcement has been used in several published studies to reduce pica. Two specific schedules of differential reinforcement have been used: differential reinforcement of other behavior (DRO) and differential reinforcement of alternative behavior (DRA). DRO consists of the delivery of a reinforcer contingent on the absence of a problem behavior for a prespecified period (e.g., 30 s, 5 min). DRA consists of the reinforcement of an alternative behavior to the targeted challenging behavior according to specific schedule of reinforcement (FR1; FR3). Smith (1987) used an intervention package including differential reinforcement of alternative behavior to reduce the pica of a 23-year-old man with a profound intellectual disability in a sheltered workshop. Contingent upon touching an item, the participant was verbally prompted not to touch the item and to continue with the scheduled vocational activity. Verbal praise and token reinforcement also were provided contingent on engagement in the vocational activity and for engagement in any other functionally incompatible behaviors. Baseline rates were 21.6 per day and differential reinforcement rates were 3.7 per day.

Donnelly and Olczak (1990) used a differential reinforcement procedure to reduce the cigarette pica of two men with profound intellectual disabilities. In this study, small sips of coffee were provided according to a fixed-time schedule contingent on the chewing of sugarless gum (a behavior hypothesized to be functionally incompatible with pica). The results of an ABAB reversal design demonstrated that the intervention package produced a significant reduction in pica in brief experimental sessions conducted in a small treatment room. Baseline mean latency of pica was less than 10 s and session data were greater than 800 s.

Several recent research studies have used differential reinforcement of alternative behavior to teach individuals with intellectual and developmental disabilities to throw potential pica items in the trash or hand them to another person instead of ingesting them. Goh, Iwata, and Kahng (1999), for example, used response blocking and DRA to reduce the cigarette pica exhibited by individuals with profound intellectual disability. Contingent on attempted pica, response blocking (e.g., the therapist placing a hand between the participant's hand and mouth) was used to prevent the participant from placing the item in his or her mouth, and the participant was differentially reinforced for handing the pica item to the therapist. The results of a multiple-baseline design across participants showed that differential reinforcement and response blocking successfully reduced the cigarette pica of three of the four participants. Hagopian, Gonzales, Rivet, Triggs, and Clark (2011) expanded on Goh et al. (1999) by demonstrating that response blocking and differential reinforcement significantly reduced the pica behavior of two participants with autism and a severe intellectual disability. All attempts by the participants to place an object in their mouth were blocked, and the participants were differentially reinforced with verbal praise and food for putting the potential pica items in the trash or for using them appropriately. Response blocking and differential reinforcement was demonstrated to successfully reduce both participants' pica, and results obtained were shown to generalize across settings and people.

Contingent visual screening. Contingent visual screening is the placement of a blindfold over the eyes immediately following the target behavior. The duration of the screening is typically 10–60 s. Singh and Winton (1984) used this procedure in perhaps the first application with pica behavior. A blindfold was applied for 1 min, resulting in significant reductions of pica in various settings. A decade later, Fisher, Piazza, Bowman, Kurtz, and Lachman (1994) compared ten reinforcers and punishers in an antecedent analysis. Visual screening was found to be the most effective procedure for reducing pica for all three of the participants who experienced pica at high rates prior to treatment. The ages of the participants ranged from 3–5 years. Diagnoses included profound intellectual disability and pervasive developmental disorder (5-year-old), severe intellectual disability and seizure disorder (3-year-old), and severe intellectual disability and pervasive developmental disorder (the other 3-year-old). Baseline rates of pica were 4.5, 3.8, and 4.9 per hour. Rates decreased by at least 90 % before baiting sessions were conducted in the family homes and other places.

Contingent aversive stimulation. Contingent aversive stimulation involves the presentation of an aversive stimulus contingent on the occurrence of pica. Both aversive tastes and auditory stimuli have been used to reduce pica. For example, Ferreri, Tamm, and Wier (2006) reduced the pica (e.g., biting off or swallowing pieces of plastic toys) of a 4-year-old boy with autism through the use of a contingent aversive stimulation. The boy had a variety of aversions to food, and he was observed to engage in gagging and spitting when given tapioca pudding to eat. Toys the participant attempted to bite off pieces to swallow were coated in tapioca pudding. When the boy placed the toys coated in tapioca pudding in his mouth, he had a reaction consistent with taste aversion (e.g., gagging, crying, and spitting). After placing the toys coated with pudding in his mouth several times, the boy stopped engaging in pica, and the outcome obtained generalized throughout the boy's preschool. Rapp et al. (2001) used a contingent auditory stimulus to reduce the pica of a 6-year-old girl with autism. Initially, several less restrictive interventions were tried but failed to produce a clinically significant reduction in pica. After the failure of noncontingently presented food, vocal reprimands, and response blocking, the effectiveness of 83 dB tone presented for 2–3 s was evaluated. In the second tone condition, the volume of the tone was increased to 90 dB, and after the tone was provided contingent on the approach to items that the participant had a history of ingesting, a significant reduction in pica was observed. The reduction in pica obtained was maintained during generalization probes to novel settings.

Discrimination training. Several research studies have included a discrimination training component in their intervention package. Discrimination training is based on the hypothesis that some persons with intellectual and developmental disabilities lack the ability to discriminate food from nonfood items; thus, they are at an increased risk for eating nonedible items. Discrimination training for pica consists of teaching participant to only eat items placed on a specific object (e.g., a specific place mat, a red plate) using differential reinforcement. To date, all published studies that have used discrimination training also have included at least one punishment-based component. For example, Johnson, Hunt, and Siebert (1994) taught two adolescents with profound intellectual disabilities to only eat items placed on a specific placemat using differential reinforcement. In addition, they were taught to use a simple sign to demand more food. Contingent on pica, the targeted nonfood item was removed from their mouth, and their face was washed for 15 s. In a second example, Bogart, Piersel, and Gross (1995) used discrimination training and differential reinforcement to teach a 21-year-old woman to discriminate food from nonfood items. Contingent on the occurrence of pica, the participant's face was covered with the bib (facial screening) she was wearing, and her hands were held to her side for 15 s. The use of discrimination training may be particularly clinically useful for individuals with intellectual and developmental disabilities who engage in indiscriminate pica (i.e., eat a wide variety of nonedible items). However, to date, no published studies have examined the clinical effectiveness of discrimination training without the inclusion of punishment-based strategies.

While some reviews of the pica literature do not address generalization and maintenance, effective treatment of potentially highly dangerous behavior must include what has been referred to as the generality issue (see Baer, Wolf, & Risley, 1968). There are studies that address generalization and maintenance. For example, Kern, Starosta, and Adelman (2006) demonstrated excellent strategies for generalization and maintenance of pica treatment. Participants were Orlando—an 8-year-old boy with severe intellectual disabilities and pica—and Matthew, aged 18 and diagnosed with autism and severe intellectual disabilities. Matthew's pica had resulted in two hospitalizations. Initial baseline and treatment were carried out in a small room. Intervention involves blocking pica attempts; however, it was noted that aggression often occurred when blocking was used. Kern et al. stated: "Blocking resulted in reduction of pica, but not attempts" (p. 140). Both clients had data collected in two settings initially, and these settings were expanded to include observations in two additional settings. Observations were expanded to 30 min and then through the day. During training, Orlando was taught to turn pieces of paper (baited items) to staff, and, when he did, he was praised and given an edible item. A reversal was carried out in which baseline was repeated. The reinforcement schedule was moved from FR1 to FR2. A 10-s latency was also used. Matthew's training was expanded to the classroom and the local discount store. It is important to note that training in turning in inedibles for edibles continued in other settings. Baseline data were not collected in other settings for Orlando. For Matthew, any pica or attempts were blocked, or staff tried to block them. The results showed rates of pica attempts approaching zero.

Summary of Interventions

Virtually all published studies of behavioral treatment show reductions in pica (McAdam, Sherman, Sheldon, & Napolitano, 2004; McAdam et al., 2012). However, when one looks at evidence-based treatments, interesting results can be seen. The meta-analysis by McAdam et al. (2012) found that only three behavioral interventions were *well-established treatments* for short-term treatment of pica: environmental enrichment, noncontingent reinforcement, and overcorrection. Furthermore, only *limited evidence* was found for physical restraint and response blocking. One of the findings was that there were no behavioral treatments with long-term maintenance and generalization efficacy that met the criteria for evidence based. *Insufficient evidence* was found for visual screening, contingent aversive stimulation, and discrimination training. These findings do not mean, for example, that overcorrection should be used in the treatment of pica and visual screening should not. It may mean that not enough research has been done to make such a determination. In general, clinicians are expected to use the least restrictive treatment that is likely to be effective. In addition, clinicians commonly use two or more treatments as a treatment package.

Some recent literature reviews on pica have declared that positive approaches are the preferred interventions and researchers are therefore no longer researching the effectiveness of aversive procedures. These views are not necessarily an accurate description of the status of the current, most recent research in behavioral treatment of pica. For example, of the six most recent intervention studies, three (Falcomata et al., 2007; Ferreri et al., 2006; Ricciardi et al., 2003) used punishment alone or together with another procedure, and another three used response blocking alone or with other procedures (Hagopian, Rooker & Rolider, 2011; Kern et al., 2006; McCord et al., 2005). While some consider response blocking a form of restraint, others may not. Response blocking, which typically requires staff to be within a foot or so of the target client, or close enough to block, may not appear to be restrictive in brief sessions, but in much longer sessions, it is likely an aversive stimulus for many clients. Several studies reported aggression as a side effect of response blocking, suggesting a possible escape response from an aversive stimulus (blocking or proximity necessary to carry out blocking).

As described above, the current published literature has documented that behavioral treatment procedures can be used to reduce, and in some cases suppress, pica to near-zero levels. A 90 % reduction in pica and pica attempts is a wonderful reduction for low-rate pica, but for high-rate pica, how does a clinician move toward further reductions or generalization if the rate is still 40/day or 3/h? There are a number of limitations that affect the strength of the conclusions that can be reached. In addition, there is a slight gap between what the literature on pica is and what some professionals say it is.

The choice of treatment options by families and caregivers can only be made if there is accurate representation of what the data show and how those data are represented to families. For example, authors of literature reviews or case studies may declare in their discussion that a study or procedure reduced pica. A reduction is better than an increase; however, is this term—without data—the best we can do in a scientific study of behavior? Other reviewers may simply declare a procedure to be effective and present no evidence of efficacy other than using the term "reduced." As an alternative, in their review of pica interventions, McAdam et al. (2004) reported data from each study for both baseline and intervention. Such precise reporting of data in literature reviews is invaluable and highly recommended. In their review, Lundervold and Bourland (1988) used another method for presenting results of aggregate single-subject data. They classified each article reviewed on a 3-point scale: 0 = reduction by 50 % or less (ineffective), 1 = reduction by 51–70 % (effective), and 2 = reduction by 71–100 % (highly effective).

Practice Recommendations

Because there have been no major prevalence surveys of pica in the last 30 years, there may be a need for recent prevalence estimates, both in institutionalized and community settings. The Behavior Problem Inventory (Rojahn, Matson, Lott, Esbensen, & Smalls, 2001) is one tool that can be used for this purpose. This rating scale can be used, because individual self-identify by engaging in a serious episode of pica (McAlpine & Singh, 1986). Because only the most severe pica incidents seem to occur without previous notice or assessment, a survey of staff or families to determine a history of pica should be considered in schools, clinics, and institutions.

Behavior analysts who are certified by the Behavior Analyst Certification Board should be available in all public and private schools, clinics, and institutions. The behavior analyst seeks consent for service prior to any involvement in someone's care. Some programs track pica incidents by use of a pica incident report to ensure thorough reviews. This is essential for the prevention of pica incidents.

The first step in the clinical intervention process is to obtain a medical evaluation. Consent for behavioral assessment is next and typically includes specific protocols. The behavior analyst plans and conducts a risk assessment of pica and behavioral procedures (see Bailey & Burch, 2011). If pica is deemed dangerous, evidence-based treatment components most likely to be successful should be considered. A risk assessment is conducted not only for pica but also for any proposed behavioral procedures. This assessment is typically presented to the supervisor and team members for review and approval.

The behavior analyst is responsible for overseeing the methods used for protecting and preventing pica by limiting access to nonedible items in a pica-safe environment. A pica-safe environment includes adequate numbers of well-trained residential staff, ongoing staff training in pica, and pica prevention through on-site monitoring and feedback. Consent is also required for this strategy.

A functional behavioral assessment should be conducted using safe, nonedible baited items that a physician has authorized. Generally, a comprehensive treatment plan is developed after the assessment. Consent for behavioral treatment plans for pica may start with noncontingent reinforcement, environmental enrichment, and/or differential reinforcement—sometimes called level one interventions. This plan may require feedback from a peer review committee before it is submitted to the Human Rights Committee for review and approval.

Level two interventions also require consent and include restrictive procedures (e.g., response cost, response blocking, brief restraint [e.g., 10 s, 30 s], non-exclusionary time-out [e.g., time-out ribbon], and visual screening). These procedures are typically used only for highly dangerous pica behavior after level one interventions have proven ineffective.

Practitioners should begin treatment using brief sessions to evaluate the effects of each intervention, and once the results of the evaluation are complete, the effective components can be used as a package of treatments needed to rapidly gain control of the dangerous pica.

Once treatment is successful, generalization should be programmed across settings and staff that are typically encountered by the individual. Family and/or guardians should be on-site as much as possible for involvement in the assessment and treatment decision making. If the individual is capable of self-determination, consent should be obtained from the individual as well. The essence of behavioral treatment for pica should focus on the quality of life of the individual and not on mere reduction of a problem behavior.

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27

Aggressive Behavior

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Introduction

Individuals with intellectual and developmental disabilities (IDDs) have an increased risk for the development of challenging behavior such as aggressive behavior. Aggressive behavior is common in this target group, and it is most often targeted for intervention (see Jahoda, Willner, Pert, & MacMahon, 2013). The aim of this chapter is to provide a review of the evidence-based strategies for aggressive behavior in individuals with IDD. After defining aggression, we summarize studies on its prevalence and associated risk factors. We then provide a selective review of the evidence-based treatments for aggression in individuals with IDD. Studies are reviewed on the effectiveness of anger management treatment, behavioral interventions, psychotropic medications, and mindfulness-based procedures. Finally, we provide guidelines for the treatment of aggressive behavior in this target group.

There is no uniform definition in the literature on aggression of individuals with IDD. What the definitions of aggression in the literature on IDD have in common is that they result in some type of harm, emotional distress, and/or property destruction. We define aggressive behavior as behavior that (potentially) results in injury or harm in another person or in property destruction

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without consideration of whether the aggressive behavior is deliberately exhibited or not (Didden et al., 2012).

Aggression encompasses different types of challenging behavior. Aggressive behaviors may be aimed at another person or directed toward the environment. Singh et al. (2013) operationalized physical aggression as hitting, slapping, punching, and kicking another person that results in pain or injury. Verbal aggression was operationalized as any oral threat of harm or physical aggression or use of abusive language toward another person.

Some researchers have stated that emotional states such as anger should be included in the definitions of aggressive behavior. A state of anger and increased arousal is often a precursor of and risk factor for aggressive behavior. Self-injurious behavior is usually not considered a type of aggressive behavior though studies have yielded a positive association between these two topographies (see, e.g., Tenneij, Didden, Stolker, & Koot, 2009).

Aggressive behavior has a number of adverse consequences. It is one of the strongest predictors of crisis intervention re-referrals, admission to residential facilities, and use of psychotropic medication. Many individuals can no longer live in the family home and reside in special residential placements or inpatient mental health services which often involve high levels of security and/or intrusive pharmacological interventions, seclusion, or sedation. Aggressive behavior can make it difficult to form and maintain relationships and lead to exclusion from educational, work, and social settings. Furthermore, such behavior may generate stress for family members, is correlated with staff burnout and stress, and may affect negative attitude and interactions with service users (Jahoda et al., 2013). Aggressive behavior in children with IDD is significantly associated with burnout and emotional exhaustion among teachers and special education support staff.

Very little is still known about trajectories of aggressive behavior throughout the lifespan of individuals with IDD. Challenging behaviors, including aggressive behaviors, emerge early and tend to persist over time.

Epidemiology of Aggressive Behavior

Relatively many studies on the prevalence of aggression and its associated (risk) factors have been conducted in individuals with IDD. Sigafoos, Elkins, Kerr, and Attwood (1994) conducted a survey on aggressive behavior among 2412 persons with IDD in Queensland (Australia). Two hundred and sixty-one individuals were identified who engaged in at least one form of aggressive behavior, yielding an overall prevalence of 11 %. The relative prevalence of aggressive behavior was higher among institutionalized persons (35 %) when compared to those living in group homes (17 %) or other community-based facilities (3 %). More males (64 %) than females showed a type of aggressive behavior. Most were described as functioning in the severe/profound (54 %) or moderate (31 %) range of IDD. Most individuals showed more than one topography of aggression. In another population-based study, Emerson et al. (2001) found aggression occurring in 7 % of individuals with IDD. In non-population-based studies, aggression is the most common type of challenging behavior, with studies reporting prevalence rates ranging from 9 % to higher than 50 % (see Jahoda et al., 2013; Tenneij et al., 2009).

McClintock et al. (2003) conducted a meta-analysis of risk factors for challenging behaviors (including aggression) in individuals with IDD. Factors identified were gender (with males having higher rates of aggression than females), level of IDD (with lower levels of IDD showing an increased risk), autism spectrum disorder, and communication deficits. Also, anger and violence, impulsivity, and mental health problems (e.g., depression) were identified as being risk factors for aggression in individuals with IDD. Tenneij et al. (2009) explored risk factors for aggression in a sample of 108 individuals with mild to borderline IDD who were referred to an inpatient treatment facility. Results of this study show that antisocial behaviors, impulse control problems, psychotic behaviors, mood-related behaviors, and self-injurious behavior increased the likelihood of severe aggression in these individuals.

Crocker, Prokic, Morin, and Reyes (2014) explored associations between aggressive behavior and mental health problems in 296 adults with mild or moderate IDD who lived in the community. Results showed that there was a positive relationship between mental health problems and aggressive behavior. Factors that need to be considered when examining risk markers include the interaction of many variables that may hinder drawing firm conclusions. For example, type of setting is not often reported and may play an important role in deciphering whether this impacts particular risk markers (see Healy, Lydon, & Murray, 2014).

Increased rates of aggression have been found in individuals with IDD who have a genetic disorder. For example, Arron, Oliver, Moss, Berg, and Burbidge (2011) investigated prevalence rates of physical aggression in several syndrome groups. They found that physical aggression was most common in Smith–Magenis syndrome (74 %) and in Angelman syndrome (73 %) and, to a lesser extent, in cri du chat, fragile X, and Prader–Willi syndrome, with rates of 70 %, 52 %, and 43 %, respectively. Compared to a control group (46 %), aggression was significantly higher for Angelman and Smith–Magenis syndromes.

Powis and Oliver (2014) conducted a review of 39 studies reporting prevalence rates of aggressive behavior in syndrome groups. The results imply that certain syndrome groups (e.g., Prader–Willi, Angelman, fragile X; estimates over 70 %) show a stronger association with aggressive behavior than other groups (e.g., Down, Williams; estimates below 15 %). Variables that were associated with high levels of aggressive behavior were autism spectrum disorders, communication deficits, impulsivity, and stereotypic behavior. These characteristics are often found among the first group of syndromes.

Evidence-Based Treatments

In this section, we review the evidence based on the four categories of intervention for aggressive behavior in individuals with IDD: anger management treatment, behavioral interventions, psychotropic medications, and mindfulness.

Anger Management Treatment

The most common therapy designed to help individuals with problems in the emotion of anger is anger management treatment (AMT; Novaco, 1975). Like many other treatment programs in the field of CBT, this is a composite treatment with a number of components each designed to address the emotion of anger in different ways. One of the essential aspects of AMT is to stress that anger is a normal emotion and that it can be dealt with in ways that will not place the individual in difficult situations. Most people with IDD who have problems with the emotion of anger will have found themselves in extremely difficult situations from time to time. Typically, the way in which they express their anger will have got them into trouble with others around them, may have resulted in exclusion from day placements, or may even have caused them to jeopardize their tenancy or living arrangements. Therefore, in these cases, there have been adverse consequences from the expression of anger. One of the strengths of AMT in comparison to behavioral interventions (see below) is that it promotes an ability in individuals to learn skills that can be used in different situations. In relation to offenders who live in community settings, Taylor and Novaco (2005) have written that while behavioral interventions might be applied in institutional settings, AMT allows individuals to apply anger control techniques in a large variety of settings through applying the principles of emotional control to new situations.

AMT relies on a number of components all of which built toward the control of anger in real situations. One of the first essential components is to rehearse ways in which the individual can control their arousal. This is generally done through the use of relaxation exercises. There are a number of different forms of relaxation exercise, but the main one is abbreviated progressive relaxation in which the participant tenses and relaxes major muscle groups including arms, torso, head, neck and shoulders, buttocks and thighs, and legs and feet. Abbreviated progressive relaxation techniques also focus on breathing as a way of both regulating respiration and focusing attention.

This method of arousal reduction is common in AMT, but other ways of controlling arousal are quite acceptable such as simple relaxation through breathing exercises or other relaxation methods such as behavioral relaxation (Sturmey, Lindsay, Yause, & Neil, 2014). The important aspect is that the person is able to reduce his or her own arousal. Most AMT approaches use arousal reduction methods at an early stage (e.g., Willner, Jones, Tams, & Green, 2002).

A second component in AMT is to develop a better understanding of the person's own and others' emotion. Here, there are likely to be exercises on understanding a range of emotions including anger. It will also foster an understanding of different aspects of emotion including the behavioral, physiological, cognitive, and affective components of emotion. Typically, treatment should promote an understanding of these various aspects in relation to emotions such as happiness, sadness, jealousy, anxiety, anger, and so on. The therapist can also encourage an understanding of the difference between emotions such as anxiety and anger. Another component of AMT is to encourage the participant to maintain a diary of situations that may have caused them to be angry during the week. This diary helps the person to reflect on their anger, on the way in which kind affects their life and also provides information to the therapist on situations that provoke such difficulties for the client that will be used later on treatment to construct an anger hierarchy.

The next component is the construction of the anger hierarchy itself. This is made up of a series of idiomatic situations that make the individual angry. Some aspects of this anger hierarchy may have emerged from the weekly diaries and review of incidents in the week prior to the therapeutic session. A further component of AMT is cognitive restructuring. This is based on the relationship between arousal and cognitions. Some authors have demonstrated that individuals with IDD who have a propensity to anger may have a tendency to construe threat in situations where they feel arousal (see Jahoda, Pert, & Trower, 2006). This perception of threat may lead to an interpretation of the arousal as one of anger with corresponding behavioral consequences to deal with the perceived threat, i.e., aggression. The importance of the cognitive restructuring is to help the person make realistic appraisals of the situation. The next component involves a series of problem-solving exercises to deal with situations of perceived threat. The problem-solving exercises are likely to involve accurate self-perception, arousal reduction, effective communication, and action alternative to aggression. These problem-solving exercises are likely to involve role-play and discussion about understanding the other person's point of view in situations. This may impinge directly on the perception of threat in that perspective taking is likely to involve some understanding that the other person is not presenting a threat from their point of view.

The final, crucial component is that of stress inoculation. Stress inoculation was first developed by Meichenbaum (1985) and involves the introduction of personalized stress-inducing stimuli to the individual under conditions where they are supported to control their arousal and stress reactions. It is usually done in a graded manner, in the case of AMT, using the anger hierarchy. It can be done in imagination, through role-play, and in actual situations while encouraging and supporting the client to use coping skills they have learned during other parts of the AMT process. Therefore, AMT is a series of components including arousal reduction, understanding emotion, cognitive restructuring, keeping a record of anger situations, developing an anger hierarchy, problem-solving exercises, and stress inoculation. This is a complex amalgamation of methods that have not been evaluated separately, and there have been a number of studies of AMT as a treatment program.

Single case studies. Research evaluating anger treatment began with a number of publications reviewing successful case studies. Black and Novaco (1993) described the successful treatment of a man with mild ID who presented repeated episodes of physical and verbal aggression. They adapted the AMT approach for people with IDD including a cognitive preparation phase that involved understanding emotion and an introduction to relaxation, a skill acquisition phase (including additional sessions on arousal reduction and the development of coping strategies), and the final phase including stress inoculation to individually tailored situations. Treatment lasted over 28 sessions, and improvements were monitored through observations of aggressive incidents, observations of prosocial behavior, and an individualized anger diary. There were improvements on all behavioral measurements with reductions in the frequency of recorded aggressive behavior and increases in prosocial behavior. Improvements were maintained during a 21-week follow-up period.

Subsequent to this case report, there were a number of case studies on group and individual AMT on people with IDD. Rose (1996) reported a 16-session program with three men and two women who were treated using a group therapy format that included self-monitoring of feelings of anger, arousal reduction through relaxation, identification of personal triggers for anger, emotional recognition, the development of coping skills, and self-instructional training. Reports from carers suggested that all participants had fewer aggressive incidents per month following treatment. Moore, Adams, Elsworth, and Lewis (1997) used a variant of AMT in an 8-session group therapy format to treat two men and four women with mild to moderate IDD. By the end of treatment, there was a 39 % reduction in aggressive incidents, and an informal 6-month follow-up suggested that these improvements were maintained. Further case studies (King, Lancaster, Wynne, Nettleton, & Davis, 1999; Rose & West, 1999; Rossiter, Hunniset, & Pulsford, 1998; Walker & Cheseldene, 1997) have all reported similar improvements following some form of AMT.

Lindsay and colleagues (Allan, Lindsay, Macleod, & Smith, 2001; Lindsay, Allan, Macleod, Smart, & Smith, 2003) presented a series of case studies on violent offenders with IDD. Allan et al. treated five women with mild IDD all of whom had convictions for violence. They conducted a group format including the usual aspects of psychoeducation, arousal reduction, role-play of anger provocation incidents, problem-solving exercises, exercises on emotional recognition, and stress inoculation through imagination of anger-provoking situations. Treatment lasted around 40 sessions and was assessed using self-report measures, reports of aggressive incidents, and an anger diary. Participants were also assessed using videotaped role-plays in anger-provoking situations. Improvements were reported on all measures for all the women, and these improvements maintained at 15-month follow-up. Only one of the women had another incident of violence.

In a follow-up study, Lindsay et al. (2003) reported on six men with mild IDD all of whom had been involved with the criminal justice system for reasons of aggression and violence. Treatment was similar to that described by Allan et al. (2001), and there were improvements on all measures which were maintained at 15-month follow-up. None of the men had been violent at 4-year follow-up. While these case evaluations have all demonstrated positive outcomes from a treatment using AMT principles, none of them have been conducted according to the controlled design recommended in evidence-based guidelines (e.g., Chambless & Hollon, 1998). They have not been controlled case studies nor have they had measures taken after the introduction of each of the many methods used in the AMT. Therefore, the effectiveness of these methods has not been verified either by staggering the baseline for each of the participants (thereby introducing methods for each individual at a different point in the program) or by returning to baseline conditions. Indeed, it is impossible to return to baseline conditions for these participants once they have been taught cognitive and behavioral skills to control their anger. Once learned and used, these skills cannot then be unlearned. While this presents experimental difficulties for the validation of treatment, from the point of view of society, it is less problematic. The fact that people reduce their violence across a number of settings is a strength, whether or not specific potent elements have been identified. These case studies have strengths that previous case studies lacked. The first is that participants continued to live in community settings, indicating social validity. A second strength is that follow-up periods in these case studies, at 15 months and 4 years, were significant.

A well-controlled study on three cases has been conducted recently by Travis and Sturmey (2013). Three participants, selected because of the high frequency of their aggressive responses, were treated using a behavioral approach that focused on the identification of anger-provoking situations and using repeated trials to support these individuals in using "socially acceptable replacement responses" rather than aggression. Essentially, this controlled treatment study focused on the stress inoculation aspect, using situations that, in AMT terms, emerged from the anger hierarchy. For these authors, the preparation phase consisted of teaching on replacement responses. They used a multiple baseline design across participants with the treatment approaches being introduced in a staggered fashion, to control for the passage of time. All participants demonstrated a huge reduction in aggressive responses from 54 % to 79 % at baseline to 9 % to 12 % following the introduction of treatment with a corresponding increase in replacement responses. There was also a significant increase in escorted community access. These improvements only occurred when the treatment procedures were implemented. However, there was no follow-up in this study, and in many services for violent individuals (e.g., offender services), follow-up periods over months and years are an essential aspect of effectiveness. These case studies have been important in the establishment of the feasibility of AMT for people with anger problems.

Controlled group studies. Interestingly, one of the first studies to evaluate the effects of AMT was a randomized controlled trial (RCT). Benson, Johnson Rice, and Miranti (1986) used modifications of the Novaco treatment components in a group application across four conditions (self-instruction, relaxation training, problem solving, and a combined condition) with community-based clients. They obtained significant effects on self- and staff-rated outcome measures and role-play ratings but found no significant differences between the groups and conditions. It should be noted that in this controlled trial, all the conditions involved active treatments.

A second RCT was conducted by Willner et al. (2002) with 16 participants with IDD who were randomly allocated to a treatment group and a waiting list control condition. Two participants dropped out leaving seven in each group. This study was built on the work of Benson et al. (1986) by using the *anger inventory* (Benson & Ivins, 1992) and a provocation index completed by both participants and carers. The methods described were the normal AMT procedures over nine sessions. The participants in the treated group showed substantial improvements in anger ratings that further improved relative to their own pretreatment scores at a 3-month follow-up. There were no equivalent improvements in the control group and at posttreatment. There was a large effect size for the difference between groups. These authors also found that the degree of improvement during treatment was strongly and positively correlated with IQ. The intervention was significantly shorter than that reported in previous studies (e.g., Allan et al., 2001; Benson et al., 1986) with no loss of efficacy.

The field of AMT has seen several other controlled group studies with one randomized control design. Lindsay et al. (2004) included participants referred from the courts and criminal justice agencies to a community forensic IDD service. This was a waiting list control study with several outcome measures, including a provocation inventory (the *Dundee Provocation Inventory*; Alder & Lindsay, 2007), provocation role-plays, and self-report diaries that were repeated before treatment and at several points in a follow-up period of 15 months. They compared 33 participants who received 40 sessions of AMT with 14 who made up a waiting list control condition for 6 months. Control participants were seen by community nursing staff but did not receive any form of anger treatment until after the cessation of the study period. For the AMT group, there were significant within-group improvements on all measures. In posttreatment comparisons between the two groups, there were no differences on the Dundee Provocation Inventory, while the self-report diaries and the anger provocation role-plays showed significant differences between groups. These improvements were maintained at follow-up. The study also reported on the number of aggressive incidents and re-offenses recorded for both groups. At the post-waiting list assessment point (6 months follow-up), 45 % of the control group had committed another assault, while at the posttreatment assessment point (9 months), 14 % at the treatment group had committed a further incident of assault. Analysis on this data revealed a significant difference between groups. Therefore, although the follow-up period was relatively short, there was some evidence that AMT had a significant impact on the number of aggressive incidents recorded in these participants.

Taylor and colleagues have conducted a series of waiting list control studies on AMT (Taylor, Novaco, Gillmer, & Thorne, 2002, Taylor, Novaco, Gillmer, & Robertson, 2004, Taylor, Novaco, Gillmer, Robertson, & Thorne, 2005). All participants had been detained under sections of the England and Wales Mental Health Act (1983) for reasons of cognitive impairment (IDD) and abnormally aggressive or seriously irresponsible behavior. Taylor et al. (2002) compared ten men allocated to the AMT condition with ten on the waiting list. Treatment was guided by a manual (Taylor & Novaco, 2005) and delivered individually to participants over 18 sessions. Participants in the treatment group reported significantly lower anger intensity, and key nurse ratings supported these improvements showing modest gains for the treatment group. Taylor et al. (2005) employed the same detailed protocol with 20 participants (some of whom had been in their 2002 study) allocated to the AMT condition and 20 to the waiting list control. Scores on self-reported anger disposition and reactivity indices were significantly reduced following intervention in the treatment group compared with scores for the control group, and these differences were maintained at a 4-month follow-up. Staff ratings of study participants' anger disposition converged with self-report ratings but did not reach statistical significance. Although this study did not randomize participants, it did have the strength of using a treatment manual with a waiting list control condition and a 4-month follow-up.

In the final waiting list control comparison, Rose, Loftus, Flint, and Carey (2005) compared 50 participants who received a form of AMT with 36 controls. Outcome was measured using a provocation inventory administered at pretreatment, posttreatment, and 3- to 6-month follow-up. Between-group comparisons showed a statistically significant treatment effect, but examination of clinical significance was more equivocal with only 11 of the 50 participants in the intervention group showing reliable clinical change. A reduction in provocation inventory scores was more likely to occur if a participant was accompanied by a member of staff who knew them. The results on reliable clinical change suggested that although improvement was statistically significant, the approach may not be as effective as seems apparent from the initial statistical analysis.

Willner et al. (2013) conducted a randomized controlled trial of AMT with 179 people with IDD identified as having problems with anger. Treatment, lasted 12 weeks, was delivered by care staff who were guided by a treatment manual, and assessments were conducted at pretreatment, posttreatment, and a 10-month follow-up. There were no significant improvements on the primary provocation self-report measure, and any treatment gains were modest. However, keyworkers reported that treated individuals had significantly lower provocation scores and treated individuals reported significantly greater use of coping skills following treatment.

Behavioral Interventions

In comparison to treatment approaches that focus on altering conditions and processes that are "within the skin" (Skinner, 1993, p. 24) such as levels of neurochemicals and cognitive processes, behavioral interventions can be defined by their focus on the external environment. Specifically, behavioral approaches to the treatment of aggression are designed to alter behavior–environment interactions through some combination of (a) teaching new behaviors, (b) environmental arrangement or enrichment, (c) altering contingencies of reinforcement, and/or (d) manipulation of schedules and routines (e.g., Baer, Wolf, & Risley, 1968; Brosnan & Healy, 2011; Keenan & Dillenburger, 2011). Behavioral interventions for aggression are predicated on research demonstrating that aggression, like other topographies of challenging behavior in individuals with IDD, is learned via operant conditioning and occurs because the individual engaging in aggression is able to control his or her environment by obtaining or avoiding specific stimuli (Doehring, Reichow, Palka, Phillips, & Hagopian, 2014; Matson, Bamburg, Cherry, & Paclawskyj, 1999). For example, a person may learn to be aggressive as a means to attract attention, to gain access to preferred items or activities, and/or to avoid undesirable tasks, people, or other stimuli when these potentially reinforcing consequences reliably follow acts of aggression (e.g., Brosnan & Healy, 2011; Dawson, Matson, & Cherry, 1998). From this paradigm, aggression may be conceptualized, in some cases, as a type of nonverbal communication (e.g., Carr & Durrand, 1985; Matson, 2009).

Behavioral treatment of aggression typically follows a two-step process (i.e., functional assessment followed by function-matched intervention). First, assessments designed to elucidate the function of aggression (i.e., the reinforcement contingencies maintaining aggression) are conducted. A functional behavioral assessment (FBA) involves some combination of:(a) Observations of the individual in his or her natural environment (e.g., home, work, school) in which the changes in the environment that follow aggression are noted and correlations between aggression and subsequent environmental changes are then used to infer the function (or communicative intent) of aggression.(b) Systematic interviews in which indirect information regarding aggression and its potential function is sought from caregivers.(c) Systematic manipulations to a controlled environment are made to directly test for causal relationships between aggression and specific putative reinforcers (e.g., Lydon, Healy, O'Reilly, & Lang, 2012). The latter is typically referred to as a functional analysis and is considered the most accurate means for identifying the operant function of challenging behavior, including aggression, in people with IDD (e.g., Lydon et al., 2012). Regardless of the combination of FBA procedures utilized, the purpose is to inform the second step of this process, the selection of an appropriate function-matched intervention.

This process of functional assessment followed by function-matched intervention has been repeatedly identified as the approach with the most supporting evidence within the corpus of studies focused on the treatment of aggression in people with IDD. For example, Didden, Korzilius, Van Oorsouw, and Sturmey (2006) completed a meta-analysis of 80 studies involving behavioral and psychotherapeutic treatments of challenging behavior in people with mild IDD. Aggression was the most common topography of challenging behavior represented in the sample of studies, and behavioral intervention (as opposed to cognitive behavioral therapy or some other psychotherapeutic approach) was the most common approach to treatment. Two effect size calculations (i.e., percentage of nonoverlapping data [PND] and percentage of zero data [PZD]) were used to compare behavioral interventions informed by functional analysis results to behavioral interventions derived from some other form of FBA and to studies that did not endeavor to identify an operant function prior to intervention. Results of that meta-analysis reveal that interventions derived from functional analysis were associated with significantly larger effect sizes than those based on descriptive FBA methods. Further, behavioral interventions were found to be more effective than psychotherapeutic approaches. The conclusions of Didden et al.'s review have been replicated and extended by more recent reviews that have included individuals with IDD ranging from profound to mild IDD and with other diagnoses (e.g., autism) that are associated with both IDD and aggression (e.g., Brosnan & Healy, 2011; Doehring et al., 2014; Matson, 2009).

The most common behavioral interventions for aggression in people with IDD include extinction, reinforcement, and some form of antecedent manipulation (Brosnan & Healy, 2011; Doehring et al., 2014; Matson, 2009). These intervention components, although occasionally used alone, are most often combined as multicomponent intervention packages (Matson, 2009). The most common multicomponent interventions are functional communication training (FCT) and other forms of differential reinforcement (Brosnan & Healy, 2011; Doehring et al., 2014). However, the use of aversive stimuli (punishment) is also a form of behavioral intervention that may be warranted when other treatments have failed to produce the desired effects and/or when the severity of the aggression is such that a person's life or physical well-being is sufficiently endangered and other less restrictive treatments are not possible or when other approaches are determined to be unlikely to be as efficient in terms of time to take effect and magnitude of reduction (e.g., Adams & Allen, 2001; Tilli & Spreat, 2009).

Extinction. Extinction is a process that involves terminating the contingency between a specific behavior (e.g., aggression) and the reinforcer that maintains that behavior (Lerman & Iwata, 1996). For example, if an individual engages in aggression in order to gain access to a preferred snack, then that snack would not be delivered for a period of time following aggression. Similarly, if an individual is aggressive in order to avoid doing a specific task, then the requirement that the task be completed is not withdrawn following aggression (referred to as avoidance/escape extinction). Finally, if aggression is maintained by an increase in attention following aggression, then extinction involves withholding attention following aggression (referred to as planned ignoring). Doehring et al. (2014) reviewed 101 studies involving behavioral interventions for a total of 150 people with developmental disabilities (91 % had an IDD and 57 % of that group had IDDs classified as severe or profound) who engaged in severe challenging behaviors, the second most common of which was aggression (self-injury being the most common), and found that 27 % of participants ($n = 40$) in the included studies received treatments that involved extinction.

Although extinction is an active ingredient in many multicomponent behavioral intervention packages (e.g., Hagopian, Fisher, Sullivan, Acquisto, & LeBlanc, 1998), when challenging behavior no longer produces the desired reinforcer as a result of an extinction procedure, the individual may engage in more frequent or intense challenging behavior before the challenging behavior is reduced. In other words, when extinction is applied to aggression, without some other mitigating intervention component, the individual may initially become more aggressive before aggression is reduced below baseline levels. This phenomenon is referred to as an extinction burst (Lerman & Iwata, 1995, 1996). For example, O'Reilly, Lancioni, and Taylor (1999) evaluated the use of extinction to treat aggression (i.e., biting, scratching, and hitting) of a 10-year-old boy with mild IDD. A functional analysis indicated that his aggressive behaviors were maintained by attention from family members. When aggression was placed on extinction (i.e., attention was not given following aggression), aggression initially increased from a mean of approximately 20 % of intervals across three baseline sessions to a mean of approximately 47 % of intervals during the first two intervention sessions, before eventually reducing to 0 % of intervals in subsequent intervention sessions. O'Reilly et al. demonstrate that extinction may ultimately be effective but highlights the need for caution, particularly when applied to aggression.

Differential reinforcement. Reinforcement is the foundation of the overwhelming majority of behavioral interventions and is the essential active ingredient within intervention packages that involve teaching a new behavior. Reinforcement involves the presentation (positive reinforcement) or removal (negative reinforcement) of a stimulus contingent upon a target behavior that results in that behavior occurring more often in the future (Cooper, Heron, & Heward, 2007). Differential reinforcement is a behavior reduction strategy that involves a combination of extinction and reinforcement in which the behavior selected for reduction (e.g., aggression) is placed on extinction and an alternative behavior (or the omission of some behavior) is reinforced (Cooper et al., 2007). Doehring et al.'s (2014) review reported that 34 % of participants across the 101 studies reviewed received some form of differential reinforcement.

There are several variations of differential reinforcement that can be applied to the treatment of aggression in people with IDD. Variations of differential reinforcement are defined by the contingencies of reinforcement involved, and, in regard to the treatment of aggression, the most common variations are differential reinforcement of incompatible behavior (DRI), differential reinforcement of other behavior (DRO), and differential reinforcement of alternative behavior (DRA) (Chowdhury & Benson, 2011; Doehring et al., 2014; Petscher, Rey, & Bailey, 2009). DRI involves reinforcing a specific replacement behavior that cannot physically co-occur with the challenging behavior. For example, DRI for a child that kicks other people in order to obtain access to a preferred item might involve denying access to the preferred item following a kick (extinction) and providing the item when the child is sitting on the floor with legs crossed (a behavior physically incompatible with kicking). DRO involves reinforcing any behavior at all that occurs within a specified period of time as long as the target challenging behavior is absent. For example, a woman that hits other people every 30 min on average could be reinforced following 30 min intervals during which no hitting occurred, in essence reinforcing whatever behavior other than hitting did occur. Finally, DRA involves reinforcing a specific behavior that is not necessarily physically incompatible. For example, a man that pinches caregivers could be reinforced for using a speech-generating device (SGD) that enables him to request assistance, attention, and preferred items even though he could still push a button with one hand and pinch with the other.

Barker and Thyer (2000) treated the aggressive behaviors of a 26-year-old man with moderate IDD employed at a vocational center with DRO. The aggressive behaviors (e.g., inappropriate sexual advances, physical attacks, and verbal threats of violence) occurred daily and were of sufficient severity that his employment was in jeopardy. During a 5-day baseline phase, he engaged in a mean of 3.2 acts of aggression (as well as other challenging behaviors) per hour. During intervention, the man's work day was divided into 15 min intervals, and following every interval during which no challenging behavior occurred, the man was given a choice between stickers that could later be exchanged for access to preferred activities. After 7 days of DRO, the mean rate of challenging behavior decreased to 0.65 challenging behaviors per hour, with a mean on the last 2 days of treatment of 0.2 per hour. Although this example did not involve a reversal to baseline due to the severity of the aggression and cannot be considered an experimental design, it does illustrate the potential for DRO to reduce severe aggression in a man with moderate IDD.

Chowdhury and Benson (2011) reviewed 31 studies published between 1980 and 2009 that involved 48 participants with either severe/profound IDD (58 %) or mild/moderate IDD (42 %) between the ages of 18 and 66 years old (majority between 18 and 30 years old) that received differential reinforcement to reduce challenging behavior, with the most common topographies being self-injury and aggression. Fifteen of the 31 studies found differential reinforcement alone to be effective in reducing challenging behavior, ten studies utilized differential reinforcement as part of an effective multicomponent intervention but did not isolate the contribution of the differential reinforcement component of the package, and six studies found differential reinforcement alone to be ineffective, and the desired reduction in challenging behavior was achieved only after adding a punishment component.

Functional communication training (FCT). When the reinforcers used within DRI or DRA are matched to the reinforcers found to be maintaining challenging behavior during the FBA process and the behavior selected for reinforcement is conceptualized as a form of communication to replace the challenging behavior (e.g., the use of an SGD, picture exchange communication, speech, manual sign), the intervention is referred to as FCT (Carr & Durrand, 1985). Differential reinforcement may not always utilize the maintaining reinforcers identified during an FBA but, by definition, involves extinction, whereas FCT does utilize the same reinforcers found to be maintaining challenging behavior but may not always involve extinction (Davis, Fredrick, Alberto, & Gama, 2012; Dura, 1991; Petscher et al., 2009; Rooker, Jessel, Kurtz, & Hagopian, 2013). Specifically, FCT reduces aggression by first identifying the communicative intent of aggression (e.g., to request attention, a preferred item/activity, or a break from work) and then teaching a replacement behavior that functions as a means to communicate those same requests and results in the same reinforcer as the challenging behavior (Durand & Merges, 2001). FCT is most effective when the replacement communication behavior requires less effort than the challenging behavior (e.g., pushing a button on an SGD may require less effort than aggression), results in equal or higher quality reinforcement on a more consistent basis than the challenging behavior, and is a preferred response modality by the individual receiving treatment (Ringdahl et al., 2009). FCT is one of the most frequently researched interventions for reducing aggression (Brosnan & Healy, 2011; Matson, 2009). Doehring et al. (2014) identified FCT as the primary intervention for 27 % of participants across the 101 reviewed studies.

Several literature reviews on the effectiveness of FCT have been published. Although not specific to aggression in people with IDD, these reviews focus on multiple topographies of challenging behavior (including aggression), other populations that commonly present with IDD (e.g., autism), and/or on the specific procedures involved in FCT (e.g., prompt-fading strategies), and each of these reviews has reported FCT to be effective in reducing challenging behavior in people with IDD and/or developmental disabilities associated with IDD (e.g., Durand & Merges, 2001; Falcomata & Wacker, 2013; Hagopian, Boelter, & Jarmolowicz, 2011; Mancil, 2006; Mirenda, 1997; Snell, Chen, & Hoover, 2006; Tiger, Hanley, & Bruzek, 2008). Further, FCT has been reported to be effective when implemented alone and in combination with other treatment components including noncontingent reinforcement (NCR), punishment, and other forms of differential reinforcement (Mancil, 2006; Rooker et al., 2013). Additionally, FCT may result in reductions in challenging behaviors not directly targeted during intervention. For example, Schieltz et al. (2011) found that when FCT was used to treat aggression, self-injury, and property destruction in a group of ten preschool children with developmental disabilities and IDD reductions in other behaviors (e.g., hand flapping, spinning in circles, crying, and screaming) not directly targeted during intervention were also observed. FCT undoubtedly meets the common criteria used to identify well-established evidence-based practices (e.g., Chambless & Hollon, 1998; Cook & Odom, 2013; Horner et al., 2005; Kurtz, Boelter, Jarmolowicz, Chin, & Hagopian, 2011).

Koegel, Stiebel, and Koegel (1998) used FCT to reduce aggressive behavior directed at younger siblings by older siblings with IDD in three families. In all three cases, the aggressive behavior was being maintained by attention from the parents, access to toys, and/or by escaping from aversive sounds made by the younger sibling (e.g., banging high chair tray, crying). The function-matched replacement behaviors included making appropriate verbal requests for attention, requesting toys that the older sibling did not want and giving those toys to the younger sibling, and alerting the parent that the infant was making too much noise (e.g., "[baby's name] needs help"). The parents were taught to implement FCT by therapists that visited the home and delivered prompts, corrective feedback, and praise both prior to and during actual occurrences of aggression in the home. In addition to FCT, parents were also taught environmental arrangement and other antecedent manipulations to help preclude the occurrence of aggression. Results demonstrated that, in all three homes, (a) parents were able to implement FCT and the antecedent manipulations, (b) the intervention produced large reductions in aggression, (c) the children and parents reported increased levels of overall happiness, and (d) nonfamily members reported increased levels of comfort while visiting the family.

Antecedent-based interventions. In contrast to treatments involving intervention components implemented after the occurrence of some behavior (i.e., reinforcement, punishment, and extinction), antecedent-based interventions are proactive approaches to the treatment of challenging behavior that involve changes to the environment, routines, and presentation of tasks made prior to the occurrence of challenging behavior that result in a reduced likelihood that challenging behavior will occur (Kern, Choutka, & Sokol, 2002). Antecedent-based treatment approaches may be based on the results of an FBA or functional analysis (e.g., Luiselli, Dunn, & Pace, 2005) or may involve the inclusion of choice opportunities and/or environmental enrichment without prior functional assessment (e.g., Fava & Strauss, 2010). An attribute of antecedent-based treatment components is that they often preclude the occurrence of aggression (and other challenging behaviors), and thus the reductive effect may be immediate; however, a weakness noted in the literature is that interventions that involve only antecedent-based components (i.e., those lacking a consequence-based strategy within the intervention package) do not teach new appropriate behaviors, and, therefore, withdrawal of the intervention may result in the reoccurrence of aggression, perhaps even at levels higher than baseline (Luczynski & Hanley, 2013).

For example, Luczynski and Hanley (2013) randomly assigned matched pairs of 12 preschool children who engaged in hitting, pinching, grabbing, slapping, and other topographies of aggression and challenging behavior and who were considered at risk for school failure due to delays in communication and self-help skills to either a treatment condition that involved components designed to teach communication and self-help skills or to a condition that emphasized antecedent-based components (i.e., ensuring sufficient attention, toys and task materials were present at all times to preclude the need for aggression maintained by access to those stimuli). This study demonstrated that children in the first group acquired communication and self-help skills, whereas children in the second group did not acquire new skills. Further, when returned to baseline conditions, the antecedent-based intervention group experienced an increase in aggression, while the skill instruction group's decrease in aggression was maintained.

Although the Luczynski and Hanley (2013) study highlights one emerging concern regarding antecedent-based interventions used alone during early childhood, this group of intervention components has been repeatedly demonstrated to be effective in reducing aggression in people with IDD (e.g., Ebanks & Fisher, 2003; Fava & Strauss, 2010; Kern et al., 2002; Luiselli et al., 2005; Mueller, Wilczynski, Moore, Fuislier, & Trahant, 2001; Phillips & Mudford, 2011; Piazza, Contrucci, Hanely, & Fisher, 1997). In fact, antecedent-based intervention components were identified as the most commonly used treatment components by Brosnan and Healy (2011) and Doehring et al. (2014) with the later reporting that 40 % of participants across the 101 reviewed studies received some form of antecedent-based intervention. The concern noted by Luczynski and Hanley may not be relevant when antecedent interventions are used as part of a multicomponent intervention package and/or may be of less concern when aggression is severe and antecedent supports can be reasonably maintained. For example, Luiselli et al. (2005) evaluated the aggression of 15 children and adolescents with IDD caused by brain injury living in a community-based residential school. All of the participants had behavioral intervention plans that called for physical restraint in the form of protective holds (i.e., "placing the student in either a seated or supine position while physically immobilizing his or her arms and, if necessary, legs" [p. 54–55]). There were a total of 107 instances in which a protective hold was required within a 2-month period across participants with one participant accounting for 28 % ($n = 30$) of occurrences. A functional assessment was conducted for that participant to determine the settings during which most protective holds occurred. An antecedent-based intervention was derived from this assessment and involved reducing the amount of time she spent in these settings, offering more choices between activities during the day, changing the nature of instructional tasks to be potentially less aversive (e.g., increased focus on functional skills outside of a classroom setting), and other modifications to environments and routines designed to preclude the occurrence of aggression. A withdrawal design modified to evaluate varying degrees of antecedent manipulation (e.g., varying choice opportunities and types of choice) indicated that the antecedent-based intervention reduced the number of protective holds required by more than 75 % in the final phase of the study.

Noncontingent reinforcement (NCR) is a specific type of antecedent-based intervention that has been used to treat aggression in people with IDD that is well supported in the research based (e.g., Borrero & Vollmer, 2006; Brosnan & Healy, 2011; Phillips & Mudford, 2011; Ringdahl, Christenson, & Boelter, 2009). NCR involves delivering the reinforcer found to be maintaining aggression irrespective of the behavior of the person receiving intervention and, in doing so, renders the challenging behavior unnecessary (Carr, Severtson, & Lepper, 2009; Tucker, Sigafoos, & Bushell, 1998). For example, Phillips and Mudford (2011) conducted an FBA to identify attention as the reinforcer maintains the aggression (forceful grabbing) of a 24-year-old man with severe IDD. Three intervention components including activity choice, extinction, and NCR were evaluated in different combinations across a modified withdrawal design with a 17-month follow-up phase. Offering a choice for different activities (also an antecedent-based intervention) combined with extinction (staff gave very minimal attention while escaping from the grasp) resulted in only a minimal decrease in grabbing from baseline. However, when NCR (providing attention for at least 15 s every 5 min regardless of behavior) was added to the treatment package, grabbing decreased substantially, with the final five sessions (out of 15 total intervention sessions and reversals) containing no instances of grabbing. These effects were maintained (following booster training sessions with staff) at 17 months.

Punishment. Unfortunately, reinforcement- and antecedent-based interventions alone may not always be sufficient to treat all cases of aggression in people with IDD, and intervention components classified as punishment are occasionally deemed necessary to ensure the safety of the individual with IDD and their caregivers. Punishment involves the contingent presentation of stimuli (sometimes referred to as aversives) and/or the contingent removal of stimuli (e.g., loss of preferred items) that results in a decrease in a targeted behavior (e.g., aggression). Punishment ranges from relatively benign procedures, such as time out, reprimand (e.g., Charlop-Christy & Haymes, 1996), overcorrection (i.e., repairing or correcting damage caused by the target behavior), and response cost (e.g., Foxx & Mendl, 2007), to more invasive procedures such as restraint (e.g., Tilli & Spreat, 2009). Punishment was implemented with 11 % of the participants across the 101 studies reviewed by Doehring et al. (2014) and in six of the 18 studies reviewed by Brosnan and Healy (2011). Although the use of punishment with people with IDD is controversial, people with IDD have a right to effective treatment, and, in some severe cases, effective treatment necessitates punishment (Adams & Allen, 2001; Foxx, 2003; Rooker et al., 2013).

Psychotropic Medications

Psychotropic medications are used regularly for the management of problem behavior including aggression and self-injurious behavior (SIB) in people with IDD in the absence of a diagnosed psychiatric disorder (Deb, Unwin, & Deb, 2015). This practice is controversial because these medications are not licensed for this purpose, the scientific evidence to support their use is often lacking, these medications could potentially cause long-term adverse effects, and once started withdrawal of these medications is difficult (Hemmings, Deb, Chaplin, Hardy, & Mukherjee, 2013). Psychotropic medications used for this purpose include antipsychotics; antidepressants; mood stabilizers including antiepileptics, psychostimulants, opioid antagonists, and beta-blockers; and antianxiety medications (Deb, 2013). In this chapter, we have summarized the evidence for psychotropic medication, but a fuller description of the evidence is provided in Chap. 13 (Deb, 2016).

Systematic reviews have found that the highest number of randomized controlled trials (RCTs) is on new generation antipsychotics, particularly risperidone (Deb, Sohanpal, Soni, Unwin, & Lenôtre, 2007; Unwin & Deb, 2011) and aripiprazole (Deb et al., 2014). There are also primarily crossover RCTs on the opioid antagonist naltrexone involving children (Roy, Roy, Deb, Unwin, & Roy, 2015a) and adults (Roy, Roy, Deb, Unwin, & Roy, 2015b) with autism spectrum disorder (ASD) and/or IDD. There are also a few poor-quality dated RCTs on the mood stabilizer lithium and one on carbamazepine that included only ten participants (see review by Deb et al., 2008). There is a small crossover RCT of an antidepressant clomipramine that recruited only ten patients in the study (see review by Sohanpal et al., 2007).

Risperidone. There are three RCTs of risperidone among adults with IDD (Gagiano, Read, Thorpe, Eerdekens, & Van Hove, 2005; Tyrer et al., 2008; Van Den Borre et al., 1993). Two of these studies showed that risperidone was significantly better than placebo in improving problem behavior, but Tyrer et al.'s study did not find a significant difference in outcome among groups treated with risperidone, haloperidol, and placebo. There are six RCTs among children with IDD with or without ASD (Aman, De Smedt, Derivan, Lyons, & Findling, 2002; Buitelaar, van der Gaag, Cohen-Kettenis, & Melman, 2001; Research Units on Pediatric Psychopharmacology (RUPP), 2002; Shea et al., 2004; Snyder et al., 2002; Van Bellinghen & De Troch, 2001). RUPP (2002) and Shea et al. (2004) primarily included children with ASD, some of whom also had IDD, whereas Aman et al. (2002) and Snyder et al. (2002) primarily included children with IDD but excluded those who had ASD. Of these four studies, only the RUPP study (2002) was not sponsored by a pharmaceutical company. McDougle et al. (1998) in an RCT showed that some core symptoms of ASD improved significantly in the risperidone group compared with the placebo group. Many of these children also had IDD, and some showed problem behavior such as aggression as well. All these studies showed a significant improvement in problem behavior in the risperidone group compared with the placebo group. Three of the RCTs involving children were continued for many weeks using open-label designs (Findling, Aman, Eerdekens, Derivan, & Lyons, 2004; RUPP Continuation Study, 2005; Turgay, Binder, Snyder, & Fisman, 2002). These studies showed that the efficacy of risperidone had been maintained over 52 weeks, and medication adverse effects were by and large tolerable.

Aripiprazole. Deb et al. (2014) have recently published a systematic review on the efficacy of aripiprazole in the management of problem behavior among people with IDD with or without ASD. The authors reported two RCTs (Marcus et al., 2009; Owen et al., 2009) that included 75 and 218 children with ASD with and without IDD, respectively, in a parallel design RCT over an 8-week period. Both these studies have been carried out by the pharmaceutical company that produces aripiprazole, and it is not clear whether there is any overlap among the participants in these two studies. Both studies have reported significant improvement in behavior in the aripiprazole group compared with the placebo group. There was an open-label extension of one study (Marcus et al., 2011a) following the RCT that included 330 children, which showed that the improvement shown in the aripiprazole group during the RCT lasted for 52 weeks and the adverse effects were tolerable (Marcus et al., 2011b). Deb et al. (2014) have also found another 12 studies of either prospective or retrospective case reports that reported improvement in most people with IDD treated with aripiprazole. The authors concluded that there is a need for more carefully designed RCTs into the use of aripiprazole in the management of problem behavior including aggression in people with IDD and/or ASD independent of pharmaceutical companies.

Antidepressants. It is difficult to draw any conclusion on the efficacy of antidepressants in managing aggression in people with IDD as apart from a small crossover RCT (Lewis, Bodfish, Powell, & Golden, 1995); the rest of the studies included in the systematic review by Sohanpal et al. (2007) are case reports. Improvements were largely reported in SIB and perseverative/compulsive behaviors in the context of depression and anxiety for which these drugs are indicated. In a number of cases, deterioration in behavior is reported which may have been caused by the adverse effects of some of the antidepressants.

Mood stabilizers (lithium and antiepileptic medication). Deb et al.'s (2008) systematic review revealed three small primarily crossover RCTs of lithium of which only two are published in a peer-reviewed journal (Craft et al., 1987; Tyrer, Walsh, Edwards, Berney, & Stephens, 1984) and the other one was published as book chapter (Tyrer, Aronson, & Lauder, 1993). Although all these studies showed that a proportion of clients treated with lithium improved, it was not clear whether this improvement was significant compared with the placebo group, and also the outcome measures used were not validated and standardized. Therefore, it is difficult to draw any definitive conclusion on the efficacy of lithium for the treatment of aggression in people with IDD. There are other concerns regarding the use of lithium such as the need to carry out regular blood tests which may not be possible for a number of people with IDD, narrow therapeutic range between effective and toxic serum level, lithium toxicity, and a high chance of relapse if lithium is withdrawn. Among other mood stabilizers such as antiepileptics, only a small RCT involving ten clients is available on the use of carbamazepine (Reid, Naylor, & Kay, 1981), and the rest of the studies are case series. As mood stabilizers such as carbamazepine and sodium valproate are used regularly to treat aggression in people with IDD (Unwin & Deb, 2008a, 2008b), there is an urgent need to carry out properly designed RCTs involving these drugs notwithstanding the practical difficulties of carrying out RCTs in this population (Oliver-Africano et al., 2010).

Opioid antagonists. The opioid antagonist drug naltrexone has been used to treat problem behavior in children with ASD with or without IDD. A recent systematic review by Roy et al. (2015a) has found ten studies that used an RCT design. Two studies used a parallel design ($n = 59$), and the rest of the studies used a crossover design. The number of children included in these studies ranged from 4 to 20. Less than half of the studies showed a statistically significant improvement in irritability and hyperactivity in the naltrexone group compared with the placebo group, but none has shown any significant effect on the core symptoms of ASD. Roy et al. (2015b) in their recent systematic review have included ten crossover trials of naltrexone for the treatment of primarily self-injury in adults with ASD with or without IDD. The number of participants included ranged between 4 and 24 and the study period ranged from 4 to 17 weeks. Only two studies found a significant improvement in the naltrexone group compared with the placebo. Eleven (9 %) out of overall 124 participants included in these ten studies reported minor adverse effects. Because of the small number of participants included, a relatively short period of follow-up, and lack of significant results, it is difficult to draw any definitive conclusion about the efficacy of naltrexone in the treatment of SIB and aggression among adults with ASD and/or IDD.

Antianxiety medication. King and Davanzo (1996) reported in a prospective uncontrolled study of 26 adults with IDD (age range 25–63 years) (46 % male) on the effect of buspirone 25–60 mg/day (average 52 mg/day) on aggression and/or SIB in people with IDD. This study did not show any improvement from buspirone. There is little evidence currently to recommend any antianxiety medication for the long-term management of problem behaviors including aggression in people with IDD. The benzodiazepine group of medications carries the risk of tolerance and dependence in the long run. The evidence for the effectiveness of buspirone is currently poor; therefore, it cannot be recommended. However, for the general population, some selective serotonin reuptake inhibitors (SSRIs), selective norepinephrine reuptake inhibitors (SNRIs), an antiepileptic medication pregabalin, and an antipsychotic quetiapine are now recommended treatments for anxiety-related disorders (Bandelow et al., 2008; NICE guide on the management of anxiety disorders; www.nice.org.uk). In the field of IDD, some antipsychotics are prescribed in a smaller than antipsychotic dose to manage problem behaviors with the assumption that at a lower dose antipsychotics may work as antianxiety medications, although the evidence to support this assumption currently is not available from the literature.

Beta-blockers. Ward, Tharian, Roy, Deb, and Unwin (2013) have recently published a systematic review on the use of beta-blocker medications such as propranolol, nadolol, acebutolol, metoprolol, and oxprenolol in the treatment of problem behavior in children and adults with IDD. They found 14 studies primarily on propranolol, dose ranging up to 340 mg a day, that included between 1 and 19 participants. However, as none of these studies are RCTs, it is difficult to draw any definitive conclusion on the efficacy of beta-blocker medications in the treatment of problem behavior including aggression among people with IDD.

Psychostimulants. Most studies of psychostimulants have been used on people with a diagnosis of attention deficit hyperactivity disorder (ADHD). Therefore, almost all the studies used ADHD symptoms as outcome measures than problem behavior or aggression per se, although problem behaviors are often included in the outcome measures as part of the ADHD symptoms. Therefore, it is difficult to find any evidence to prove the effectiveness of psychostimulants specifically for the management of problem behavior or aggression per se in people with IDD without a diagnosis of ADHD. One study by Aman and Singh (1982) used an RCT design to compare methylphenidate with placebo for the management of different problem behaviors among 28 participants (aged 13.6–26.4 years) with IDD. Overall, no significant effect was found from the medication.

Mindfulness

A relatively novel intervention approach to aggression in individuals with (mild) IDD is mindfulness. Singh, Wahler, Adkins, and Myers (2003) have developed a procedure called "mediation on the soles of the feet" with which individuals are taught to recognize the precursors of aggression, to disengage their attention to the precursor(s), and to focus their attention to a neutral point of the body (i.e., Soles of the Feet (SoF)). Precursors of aggression may be behaviors and/or emotions that precede a type of aggression and that increase the likelihood of aggression. Mindfulness may be viewed as a coping strategy with which the individual may prevent the occurrence of aggressive behavior. In their first published study, Singh et al. explored the effectiveness of SoF in a 27-year-old man with mild IDD who was admitted to a psychiatric hospital to control his (verbal and physical) aggression. Following baseline, he was taught a simple meditation procedure to divert his attention from an emotionally arousing internal or external event to an emotionally neutral part of his body. Through this procedure, the individual is able to focus his mind back on the body and calm down and think about alternative ways to react to the event that triggered the arousal. The individual is guided through the steps of SoF meditation, which include finding a natural posture, breathing naturally while allowing the emotions and thoughts to flow without trying to stop or respond to them, and then shifting the attention to the soles of the feet. This is continued until calmness and clarity of mind are established. The final step includes walking away from the situation or a nonaggressive response to the situation. Training was provided during 30-min supervised role-play and practice sessions held twice a day for 5 days, supplemented with homework practice assignments. He also was encouraged to use SoF in multiple contexts. Results showed that within 1 year staff as well as self-reported verbal and physical aggression was reduced to zero levels, which were maintained at a 1-year follow-up. He also showed clear improvements in self-control skills during treatment and at follow-up. Likewise, staff and client injuries, restraints, and PNR medication were all reduced to zero levels, while the socially and physically integrated activities within the community showed a dramatic increase as a result of the intervention.

Singh et al. (2006) have adapted the mindfulness-based intervention for use with staff members working with clients with IDD who show aggression behaviors. Fifteen group home direct care staff were provided with behavioral training and later with mindfulness training to explore their effect on aggressive behaviors. Staff was responsible for 18 clients (aged 25–47 years), six in each group home, who had profound or severe IDD and of whom 11 showed aggressive behavior. Data were collected in a multiple baseline design across group homes, and results show that compared to baseline the number of staff interventions for aggression decreased substantially following mindfulness training (and only modestly following behavioral training). Mindfulness-based training was more effective than behavioral training in increasing the number of activities by clients and improving staff satisfaction and decreasing staff's use of restraint and interventions for aggression.

Since their first study, Singh and his colleagues have conducted studies on the effectiveness of mindfulness in a variety of target groups and in different settings (i.e., forensic and community settings). Most studies have employed single-subject designs. But Singh et al. (2013) performed a randomized controlled trial in which they assessed the effectiveness of the SoF procedure for the treatment of aggressive behavior in a sample of 34 individuals (between 17 and 34 years of age) with mild IDD who lived in the community. They were assigned to either the SoF group or a waiting list control group. A 12-week baseline phase was followed by a 12-week intervention phase and follow-up. During the SoF training, parents and staff taught (through instructions and modeling) the use of various techniques to the individuals, and each weekday they practiced with the individuals during daily 15–30-min sessions. Staff and parents followed the step outlines in the manualized treatment protocol, and reliability measurements yielded high treatment fidelity. Results revealed that both the number of verbal and physical aggression was much lower in the SoF condition compared to the control condition. Further significant reductions to (near) zero levels of aggression were seen during the follow-up phases.

The results of the studies by Singh and his colleagues suggest that a mindfulness-based procedure is highly effective in reducing aggressive behavior of individuals with IDD. Favorable results were replicated in a series of studies by this research group. These results, however, need to be replicated by other independent researchers before conclusions may be drawn on whether mindfulness is evidence-based practice for aggression in individuals with IDD.

Translation of Research to Practice

Aggressive behavior is a heavy burden for everyone involved, and it often runs a long course with a major risk of social exclusion. A range of psychological, contextual, and biological risk factors may contribute to the risk of aggressive behavior in individuals with IDD. The chance that a given individual with IDD may develop aggressive behavior is the result of a complex and dynamic interaction between such risk factors. The risk factors for aggressive behavior in a given individual should be synthesized within a case formulation. Case formulations have been developed for a variety of treatment approaches for psychological and behavioral problems in persons with and persons without IDD (see, e.g., Didden, 2009; Sturmey, 2009). Case formulations may take different forms depending on the theory of the aggressive behavior. A case formulation provides a comprehensive and coherent model of set of hypotheses about the causes and maintaining (risk) factors that explain aggression in a given individual. Next to this, it provides directives for designing interventions that are based on these hypotheses and which are supported by empirical research (also see Sturmey & Didden, 2014).

Although there has been a considerable amount of work on the effectiveness of AMT, evaluations have been completed on AMT as a complex conglomerate of treatment approaches. This is of interest because some of these methods may contribute nothing to the effectiveness of the approach as a whole, while others may indeed reduce the effectiveness or work against the effectiveness of the more potent procedures. Most studies on AMT have used manualized treatment, a condition recommended in all guidelines for evidence-based treatments. AMT and other anger treatments that employ stress inoculation procedures fulfill the requirements for well-established treatment. Relaxation treatments have been assessed separately in relation to both the reduction of anxiety and the reduction of aggression. McPhail and Chamov (1989) conducted a randomized controlled trial which compared a small group of six participants with IDD who received 12 sessions of abbreviated progressive relaxation with a control group who had a storytelling condition. Participant's IDD ranged from profound to mild, and they were selected because they regularly displayed destructive behavior in activity groups. The results demonstrated significant and substantial reductions in disruptive behavior for participants receiving relaxation with no changes in the control condition. Unfortunately, at 12-week follow-up, disruptive behavior had returned to baseline levels. There have been no equivalent studies on most other aspects of AMT including emotional recognition, cognitive restructuring, the establishment of an anger hierarchy, or presenting information concerning the purpose of anger. As has been indicated, there has been one study demonstrated the effectiveness of the stress inoculation aspect of AMT (Travis & Sturmey, 2013). Therefore, there is evidence that relaxation coupled with stress inoculation and a focus on adaptive responses to these situations are effective components of AMT.

A large number of studies have been published on the effectiveness of behavioral interventions for challenging behavior (e.g., aggressive behavior) in individuals with IDD. There is strong evidence from reviews and meta-analyses that behavioral interventions are effective in reducing aggression in this target group. Especially, extinction procedures, procedures of differential reinforcement, and functional communication training are strategies of evidence-based practice. Before implementing a behavioral intervention, the function(s) of the aggressive behavior should be determined using functional assessment. Results from several meta-analyses show that functional assessment prior to intervention predicts high treatment effect sizes (see, e.g., Didden et al., 2006). Functional assessment provides clinicians with information about alterations to the social and/or physical context and adaptive skills that need to be strengthened.

On the basis of the scientific evidence currently available, it is difficult either to recommend or to refute the use of psychotropic medications for the management of problem behaviors such as aggression in people with IDD. Good-quality evidence is available only for risperidone among children with IDD and/or ASD. In the absence of an overall evidence for psychotropic medications, guidelines have been developed in order to provide advice to clinicians when using psychotropic medications for the management of problem behaviors including aggression in people with IDD (Banks et al., 2007; Deb et al., 2009; Einfeld, 2004; Reiss & Aman, 1998; Unwin & Deb, 2010). These guidelines advise that a thorough assessment of the causes and effects of the problem behaviors including organic, psychiatric, psychological, and social factors should be carried out before a medication is prescribed. Before initiating medication, a formulation should be documented including the assessment and a rationale for the use of medication. Non-medication-based management of problem behaviors and aggression should always be considered and be used either instead of or along with medication when necessary. People with IDD and their caregivers as well as the multidisciplinary team should be fully involved in the decision-making process from the outset (Hall & Deb, 2008). There are accessible versions of information leaflets (with audio versions) on psychotropic medications (Unwin & Deb, 2007) freely available for downloading from the web (http://www.ld-medication.bham.ac.uk) which should be distributed to people with IDD and their caregivers when prescribing psychotropic medications.

Teaching functional skills, emotion regulation skills, and cognitive skills results in improved control over the lives of individuals involved. However, we agree with Jahoda et al. (2013) who have noted that "Supporting people … is more than delivering individual interventions. It is also about helping those family or staff members providing the support to manage the practical and emotional impact of the person's aggressive behavior, and sustain their relationships" (p. 97).

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28

Stereotypy

John T. Rapp and Marc J. Lanovaz

Introduction

Individuals with intellectual disabilities often engage in one or more forms of repetitive behaviors such as body rocking, hand flapping, head rolling, object twirling, and echolalia (Bodfish, Crawford, Powell, & Parker, 1995). These repetitive behaviors are commonly referred to as stereotypy in the research literature on challenging behaviors (De Winter, Jansen, & Evenhuis, 2011; Lloyd & Kennedy, 2014). Given that stereotypy may take on many forms, Rapp and Vollmer (2005) proposed three defining characteristics to differentiate stereotypy from other forms of challenging behaviors. According to Rapp and Vollmer, stereotypy is characterized by (a) repetition, (b) movement invariance, and (c) persistence in the absence of social consequences. In other words, stereotypy is a category of repetitive invariant behaviors that have a nonsocial function; however, note that Rapp and Vollmer excluded repetitious, injurious behaviors from the category of stereotypy. Lanovaz and Sladeczek (2012) extended this definition to include vocal forms of stereotypy, which they defined "as any repetitive sounds or words produced by an individual's vocal apparatus that are maintained by nonsocial reinforcement" (p. 148).

These definitions of stereotypy include both structural and functional characteristics of the behavior. Thus, motor and vocal stereotypy may refer to behaviors with different forms but that share a common function. Assuming that two topographically similar repetitive behaviors have different functions, it is also possible for one to be considered as stereotypy and the other not. For example, the repetitive vocalizations of a child who repeats previously heard words to generate reinforcing auditory stimulation would be labeled as vocal stereotypy, whereas the repetitive vocalizations of another child who repeats words to access attention would not. It should be noted that other researchers have excluded the functional component from their definition of stereotypy (e.g., Cunningham & Schreibman, 2008; Kennedy, Meyer, Knowles, & Shukla, 2000). If we excluded the functional component, the repetitive vocalizations of both children in our previous examples would meet the definition of vocal stereotypy.

The main concern with excluding the functional component of the definition is that structurally similar behaviors with dissimilar functions may need considerably different treatments

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(Iwata, Pace, Cowdery, & Miltenberger, 1994; Kennedy et al., 2000; Wacker et al., 1990). In our previous examples, the child who sought auditory stimulation may benefit from listening to music on a regular basis, whereas the one who sought attention would rather benefit from learning how to request age-appropriate forms of attention. As such, the clinical utility of using the label "stereotypy" is limited unless the definition also includes a functional component. Moreover, researchers have clearly shown that motor forms of stereotypy are maintained by nonsocial reinforcement in at least 85 % of cases (Healy, Brett, & Leader, 2013; Matson, Bamburg, Cherry, & Paclawskyj, 1999; Querim et al., 2013). These results indicate that repetitive and invariant behaviors maintained by social consequences are uncommon. The current review will thus adopt a functional definition of stereotypy and make recommendations for behaviors maintained by nonsocial reinforcement. Practitioners and researchers who are faced with repetitive behaviors maintained by social reinforcement should use function-based interventions recommended for other topographies of challenging behavior (e.g., self-injurious behavior, aggression).

Innocuous behaviors such as singing in one's car and playing simple video games sometimes share defining characteristics with stereotypy. Although repetitive, invariant, and maintained by nonsocial consequences, these behaviors are not typically considered as problematic. Practitioners and researchers should be cautious to treat only forms of stereotypy that (a) are a significant departure from social or cultural norms in which the person with an intellectual disability is integrated and (b) considerably interfere with the individual's daily functioning, health, social inclusion, or learning given its frequency, duration, and/or intensity. As such, we do not recommend the treatment of generally accepted forms of stereotypy (e.g., masturbation, singing) unless the frequency, intensity, or context warrants intervention.

Unlike many types of challenging behaviors (e.g., aggression, destruction, self-injury), stereotypy does not necessarily produce direct harm to one's self or others. However, stereotypy has been associated with a number of behavioral deficits, which underline the importance of targeting it for reduction. First, to some extent, researchers have shown that engaging in stereotypy may interfere with learning new behavior (e.g., Chung & Cannella-Malone, 2010; Koegel & Covert, 1972; Lang et al., 2009; Lang, O'Reilly, et al., 2010). In a recent review, Lanovaz, Robertson, Soerono, and Watkins (2013) found that reducing engagement in stereotypy may increase engagement in socially appropriate behavior, suggesting that stereotypy may interfere with their occurrence. Second, higher levels of stereotypy have been associated with more significant impairments in adaptive behavior, social skills, and executive functioning as well as with the presence of self-injurious behaviors in individuals with intellectual and developmental disabilities (Bodfish et al., 1995; Evans, Kleinpeter, Slane, & Boomer, 2014; Gabriels, Cuccaro, Hill, Ivers, & Goldson, 2005; LeMonda, Holtzer, & Goldman, 2012; Matson, Cooper, Malone, & Moskow, 2008; Matson, Kiely, & Bamburg, 1997; Matson, Minshawi, Gonzalez, & Mayville, 2006; Richman et al., 2013). Reducing stereotypy may potentially improve the functioning of the individual and eventually facilitate social inclusion. Finally, Jones, Wint, and Ellis (1990) have shown that engaging in stereotypy may be a barrier to the inclusion of individuals with intellectual disabilities. Their results indicated that adolescents held more negative attitudes toward individuals who engaged in stereotypy than those who did not, which strongly supports the importance of reducing stereotypy in community settings.

Epidemiology of the Behavior

Several studies have examined the prevalence of stereotypy in children and adults with intellectual and developmental disabilities, but all have used structural definitions of stereotypy (e.g., Bodfish et al., 1995; Bodfish, Symons, Parker, & Lewis, 2000; Goldman et al., 2009; Lundqvist, 2011; Poppes, Van der Putten, & Vlaskamp, 2010; Rojahn, Matson, Lott, Esbensen, & Smalls, 2001). The issue of function notwithstanding the impact of using a structural definition should be minimal given that these behaviors are maintained by nonsocial reinforcement for a high proportion of individuals (>85 %). In one of the only studies using direct observational measures, Goldman et al. (2009) reported that approximately 30 % of children with low IQ (i.e., <80) and 70 % of children with low IQ and autism spectrum disorders (ASD) engaged in one or more forms of motor stereotypy. Furthermore, children with ASD engaged in higher frequencies and in a larger variety of forms of stereotypy. Using parental ratings, Medeiros, Curby, Bernstein, Rojahn, and Schroeder (2013) found a higher prevalence in cohorts of younger children with Down syndrome (68 %), developmental delay (84 %), and at risk for autism (99 %). The difference may be due to the younger age, more severe cognitive deficits, and the use of parental ratings in the latter sample. Most other studies involving children with intellectual disabilities, ASD, or both have produced consistent results showing that the prevalence of stereotypy is higher in children with comorbid ASD and in those with lower IQs or lower levels of functioning (Campbell et al., 1990; Carcani-Rathwell, Rabe-Hasketh, & Santosh, 2006; Hattier, Matson, Macmillan, & Williams, 2012; Mayes & Calhoun, 2011; Medeiros, Kozlowski, Beighley, Rojahn, & Matson, 2012).

In a study with adults, Bodfish et al. (1995) found that approximately 60 % of adults with intellectual disabilities engaged in stereotypy. In a subsequent study involving individuals with severe to profound intellectual disability, Bodfish et al. (2000) noted that approximately 80 % and 90 % of individuals with and without comorbid autism, respectively, engaged in at least one form of stereotypy and that individuals with autism exhibited more forms. Other studies have found that the percentage of adults with intellectual disabilities that engaged in stereotypy varied between approximately 30 % and 80 % (e.g., Grey, Pollard, McClean, MacAuley, & Hastings, 2010; Lundqvist, 2011; Poppes et al., 2010; Rojahn et al., 2001). The large discrepancy is most likely due to the heterogeneous samples across studies; as with children, adults with ASD with lower levels of functioning or lower IQ engaged in higher levels of stereotypy (Rojahn, Wilkins, Matson, & Boisjoli, 2010). The main limitation of the prevalence estimates is that most previous studies with both children and adults did not include a specific measure for vocal stereotypy, which most likely resulted in an underestimation of prevalence.

Typically developing children also engage in stereotypy as infants, but the behavior tends to fade as they grow older (Berkson & Tupa, 2000; MacLean, Ellis, Galbreath, Halpern, & Baumeister, 1991; Symons, Sperry, Dropik, & Bodfish, 2005; Thelen, 1979). The problem in children with intellectual disabilities is that stereotypy persists and may even increase when the behavior begins declining in children with typical development (Berkson, 2002; Berkson, Tupa, & Sherman, 2001; MacDonald et al., 2007; Richman & Lindauer, 2005). This persistence in stereotypy has also been observed in children raised in socially deprived environments (e.g., Beckett et al., 2002; MacLean, 2004). Several hypotheses have been proposed to explain the emergence and maintenance of stereotypy in individuals with intellectual disabilities (e.g., Guess & Carr, 1991; Hutt, Hutt, Lee, & Ounsted, 1964; Lewis, Gluck, Bodfish, Beauchamp, & Mailman, 1996; Lovaas, Newsom, & Hickman, 1987). However, the behavioral and the neurobiological interpretations are the only two hypotheses that have amassed substantial empirical support in the research literature (Lanovaz, 2011).

The behavioral interpretation hypothesizes that engaging in stereotypy generates a sensory reinforcing consequence, which maintains the behavior (e.g., Lovaas et al., 1987; Rapp, 2008). This process is referred to as automatic reinforcement in the behavior analytic research literature (Kennedy, 1994; Vollmer, 1994). Stereotypy is thus an operant behavior that is maintained by nonsocial reinforcement contingencies (i.e., independent of the social environment). For example, a child with intellectual disability may put nonedible objects in her mouth because the behavior generates a reinforcing gustatory or tactile form of stimulation. Similarly, an adult may emit nonsensical sounds, which produce idiosyncratic reinforcing auditory stimulation. This hypothesis may explain why stereotypy is challenging to reduce: the practitioner has little direct control over the consequence maintaining the behavior. As noted by Rapp and Vollmer (2005), studies have strongly supported the behavioral interpretation by showing that (a) eliminating or attenuating the sensory consequence may extinguish stereotypy (e.g., Rapp, Miltenberger, Galensky, Ellingson, & Long, 1999; Rincover, Cook, Peoples, & Packard, 1979; Rincover & Devany, 1982), (b) stereotypy is influenced by processes known to the alter the reinforcing value of consequences (e.g., Lang et al., 2009; Lang, Koegel, et al., 2010; Lang, O'Reilly, et al., 2010; Rapp, 2004, 2007), and (c) providing contingent access to stereotypy may function as a reinforcer for other behaviors (e.g., Charlop, Kurtz, & Casey, 1990; Hanley, Iwata, Thompson, & Lindberg, 2000).

In contrast, neurobiologists have attempted to explain the maintenance of stereotypy at a molecular and physiological level. The neurobiological interpretation postulates that stereotypy is the product of brain dysfunction. More specifically, researchers have implicated the basal ganglia pathways and the dopaminergic system in the maintenance and emergence of stereotypy (Garner, 2006; Langen, Durston, Kas, van Engeland, & Staal, 2011; Langen, Kas, Staal, van Engeland, & Durston, 2011; Lewis, Presti, Lewis, & Turner, 2006; Lewis, Tanimura, Lee, & Bodfish, 2007). That is, imbalances in dopamine and in other neurotransmitters may enhance or inhibit specific pathways in the basal ganglia, which may lead to the emission of stereotypy by individuals with intellectual disabilities. From a clinical standpoint, the utility of studies examining the neurobiological basis of stereotypy is still limited for now. To date, the only treatment that has been derived from the neurobiological interpretation is the use of selective serotonin reuptake inhibitors, which may reduce stereotypy by affecting the dopaminergic system (Hollander et al., 2005, 2012; McDougle et al., 1996). Nonetheless, research on neurobiology may yield insights that eventually lead to development of new pharmacological treatments for stereotypy. The behavioral and neurobiological interpretations of stereotypy should not be perceived as incompatible; both provide descriptions of stereotypy at different levels. Neurobiology explains stereotypy at a molecular and physiological level, which may lead to the development of pharmacological interventions, whereas the behavioral interpretation examines processes that are amenable to behavior analytic interventions.

Criteria for Evidence-Based Treatments

The stereotypy literature contains numerous demonstrations of antecedent- and consequent-based interventions that decrease various forms of vocal and motor stereotypy (DiGennaro Reed, Hirst, & Hyman, 2012; Rapp & Vollmer, 2005). Although these interventions are described and critiqued within various review articles and book chapters, we reviewed the literature using the guidelines provided by Kratochwill et al. (2010) for visual analysis of treatment outcomes that are produced with single-case experimental designs (SCEDs). The Kratochwill et al. guidelines are twofold. First, design standards are imposed on each study to ensure that each demonstrates a high degree of internal validity with the stated SCEDs. Based on visual inspection of the SCEDs, each study is categorized as depicting strong evidence, moderate evidence, or no evidence. Second, evidence standards are imposed to determine the extent to which the combined outcomes across studies on each antecedent- or consequent-based intervention are empirically supported. As part of our analysis, we did not attempt to calculate effect size estimates as suggested by Kratochwill et al.

We used several criteria to categorize interventions as having strong, moderate, or no evidence. As a prerequisite for evaluating the empirical support for each antecedent and consequent intervention, we required that each study demonstrated the persistence of the target stereotypy (as defined above) in the absence of social consequences. These demonstrations could have been provided via (a) a full functional analysis showing elevated levels of stereotypy in the alone or no-interaction condition or across numerous conditions (e.g., Iwata, Dorsey, Slifer, Bauman, & Richman, 1994) or (b) three or more consecutive alone or no-interaction conditions (e.g., Iwata & Dozier, 2008; Querim et al., 2013). In a recent review, DiGennaro Reed et al. (2012) found that relatively few studies conducted a functional analysis of behavior that was a priori deemed to be stereotypy. As an additional step in the evaluative process, we also considered that sensitivity of the method that was used to measure motor or vocal stereotypy. We viewed continuous measures such as continuous duration recording and continuous frequency recording as appropriate measurement systems. In addition, we included studies that employed small interval sizes of either partial interval recording or momentary time sampling (Meany-Daboul, Roscoe, Bourret, & Ahearn, 2007; Rapp et al., 2007; Rapp, Colby-Dirksen, Michalski, Carroll, & Lindenberg, 2008; Schmidt, Rapp, Novotny, & Lood, 2013; Wirth, Slaven, & Taylor, 2014). Studies that either employed only indirect measures of stereotypy or collapsed stereotypy with other target behavior (e.g., self-injurious behavior) were excluded from our analysis. In terms of identifying interventions with strong, moderate, or no evidence, we also considered the effects on nontargeted forms of stereotypy and appropriate behavior (e.g., Lanovaz et al., 2013). For example, an intervention may consistently decrease the targeted form of stereotypy for most participants but may intermittently increase nontargeted forms of stereotypy for some participants. In this way, the positive effects for the targeted form may be undermined by increases in nontargeted stereotypy.

For the purpose of this chapter, we categorized the totality of the results for each intervention as having (a) strong evidence in the literature, (b) moderate in the literature, and (c) limited or no support in the literature. Our *strong evidence* category was based on the three general criteria offered by Kratochwill et al. (2010, p. 21) for combining studies; the criteria are as follows. First, the literature must contain at least five SCED studies that either meet evidence standards or meet evidence standards with reservations. Second, the five or more SCED studies must be published by at least three different research teams. Third, the five or more SCED studies must contain at least 20 data demonstrations across participants (note that Kratochwill et al. referred to SCED examples). Moreover, these participants had to have a reported diagnosis of intellectual disability (or mental retardation), ASD, developmental disability (or delay), or a combination. We also included a category of interventions with moderate evidence. Our *moderate evidence* category was also based on the three criteria described above; however, interventions in this category need only address two of the three criteria to fit this category (note that Kratochwill et al. did not suggest a category for moderate evidence). As the most common example, an intervention may fit into the *moderate evidence* category if five or more studies have been published by three or more research groups; however, the total combined number of SCED demonstrations across studies was less than 20. Interventions with limited or no evidence were those that did not adhere to at least two of the three criteria outline above. In some cases, the number of studies eligible in support of a given intervention was limited due to (a) failure to meet the SCED standards outlined by Kratochwill et al. (2010), (b) the evaluation of a nonspecific intervention that contained numerous antecedent- and consequent-based intervention components, or (c) both (a) and (b).

In addition to specific procedures described below, most antecedent- and consequent-based interventions require the conduct of one or more empirical preferences assessments to identify items that are either delivered contingently or noncontingently or removed contingently. Several preference assessment methods have been used repeatedly in the literature including the free-operant preference assessment method (FOPA: Roane, Vollmer, Ringdahl, & Marcus, 1998), the multiple stimulus without replacement method (MSWO: DeLeon & Iwata, 1996), the brief MSWO method (Carr, Nicolson, & Higbee, 2000), and the paired-choice method (Fisher et al., 1992). In addition, items identified with any of the aforementioned methods can be further evaluated in a competing stimulus assessment (e.g., Piazza, Adelinis, Hanley, Goh, & Delia, 2000). A detailed description of each type of preference assessment method is beyond the scope of this chapter; however, a recent study by Weldy, Rapp, and Capocasa (2014) includes links to video tutorials of the FOPA and brief MSWO methods.

Antecedent Interventions

Based on the guidelines provided by Kratochwill et al. (2010), we identified two antecedent interventions with either strong or moderate evidence. In addition, there are a handful of antecedent interventions with little or no evidence. For each of the two antecedent interventions, we describe (a) a recent study that best illustrates the effects on stereotypy and (b) the potential strengths and limitations of the intervention from a practical perspective.

Strong evidence. This section will include descriptions of antecedent interventions with considerable empirical support. As indicated in prior literature reviews (e.g., DiGennaro Reed et al., 2012; Rapp & Vollmer, 2005), noncontingent reinforcement (NCR) with matched stimulation may be the most empirically supported intervention for treating vocal stereotypy (Lanovaz, Fletcher, and Rapp, 2009; Lanovaz, Rapp, and Ferguson, 2012; Lanovaz, Sladeczek, and Rapp, 2011, 2012; Love, Miguel, Fernand, and LaBrie, 2012; Rapp, 2007; Rapp et al., 2013; Saylor, Sidener, Reeve, Fetherston, and Progar, 2012; for a review of behavioral interventions for vocal stereotypy, see Lanovaz & Sladeczek, 2012) and motor stereotypy (Dozier, Iwata, Wilson, Thomason-Sassi, & Roscoe, 2013; Goh et al., 1995; Higbee, Chang, & Endicott, 2005; Lanovaz & Argumedes, 2010; Piazza et al., 2000; Rapp et al., 1999; Simmons, Smith, & Kliethermes, 2003; Tang, Patterson, & Kennedy, 2003; Wilder, Kellum, & Carr, 2000). Piazza et al. (1998, 2000) introduced the concept of matching the overt stimulation generated by engaging with alternative items to the putative stimulation generated by engaging in automatically reinforced behavior (e.g., pica, motor stereotypy). The process for identifying matched stimuli is twofold. First, a practitioner employs a method of preference assessment to evaluate the extent to which the individual displays a relative preference for matched items. Second, a practitioner evaluates the extent to which engagement with preferred matched (or unmatched) items competes with engagement in stereotypy using a competing stimulus assessment or another brief assessment couched within an appropriate SCED.

Based on methodology articulated by Simmons et al. (2003), Lanovaz et al. (2009) and Rapp (2007) later distinguished between a structurally matched stimulus, as identified by procedures described by Piazza et al. (2000), and a functionally matched stimulus, which was not only structurally matched to the putative product of stereotypy but also was empirically demonstrated to decrease immediate engagement in the targeted stereotypy without increasing stereotypy (relative to a no-intervention baseline) after the preferred item was removed. We elaborate on procedures and methodology for identifying functionally matched stimuli in the “Translation of Research to Practice” section below. For purposes of this section, matched stimulation need only be shown to decrease immediate engagement in the targeted stereotypy.

A study by Lanovaz, Rapp, et al. (2012) illustrates the procedures for implementing NCR with continuous access to matched stimulation for decreasing vocal stereotypy for multiple participants. Although fixed and variable time schedules are variations of NCR, nearly all of the studies cited here involved NCR with continuous access to empirically identified items (the main exception being those that used edible stimuli to reduce mouthing). Based on the hypothesis that auditory stimulation from music would compete with auditory stimulation produced by engagement in vocal stereotypy, Fig. 28.1 shows that Lanovaz et al. identified each participant’s most and least preferred music genres using a variation of paired-choice preference assessment (Horrocks & Higbee, 2008). Thereafter, Lanovaz et al. demonstrated that vocal stereotypy persisted across consecutive no-interaction sessions for each of their

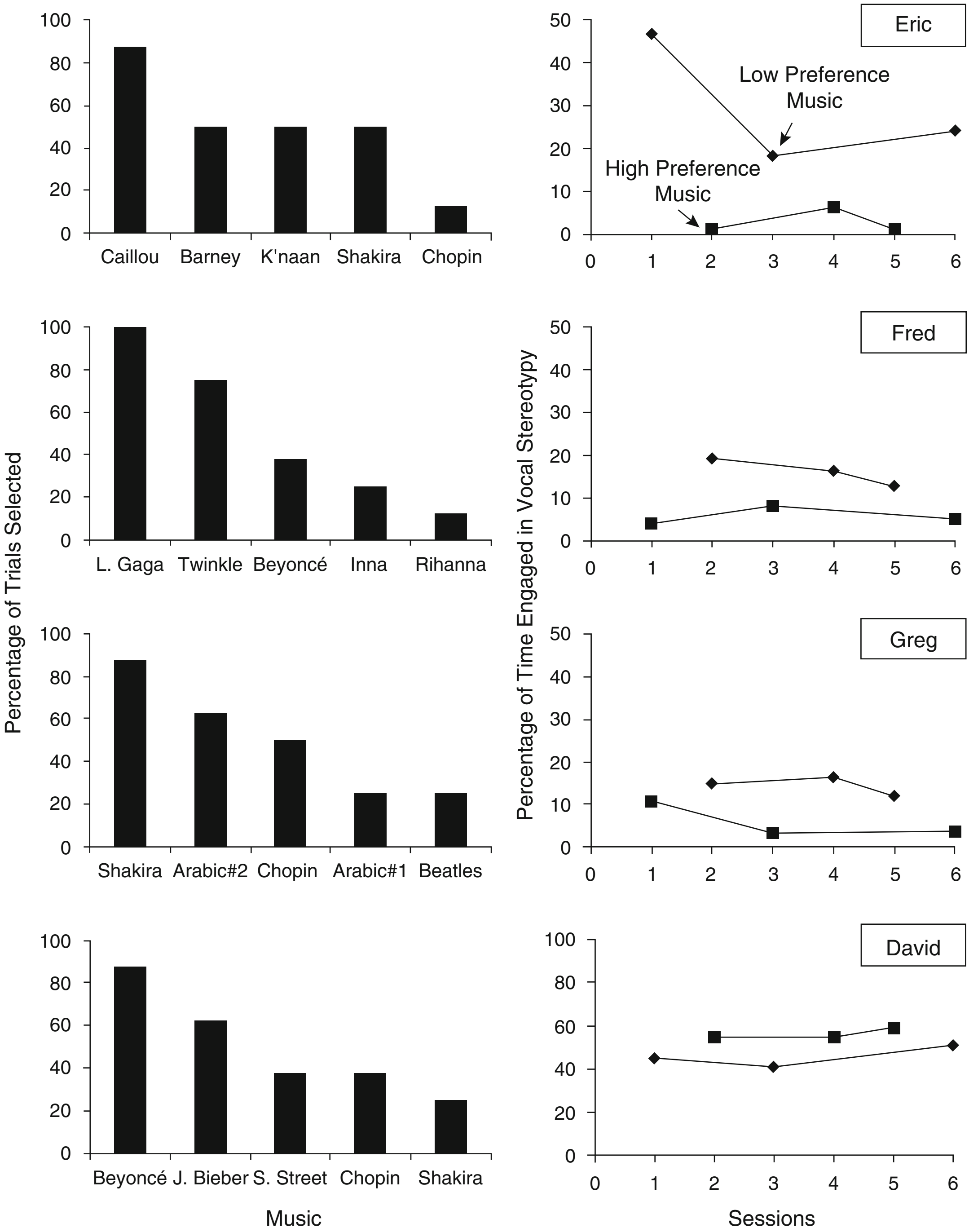

Fig. 28.1 Percentage of trials Eric, Fred, Greg, and David selected each song (*left*) and percentage of time each participant engaged in vocal stereotypy when high- and low-preference music played (*right*). Reprinted from Lanovaz, M. J.; Rapp, J. T.; and Ferguson, S. (2012). The utility of assessing musical preference before implementation of noncontingent music to reduce vocal stereotypy. *Journal of Applied Behavior Analysis, 45*, 845–851. doi:10.1901/jaba.2012.45-845

four participants. Subsequently, Lanovaz, Rapp, et al. used multielement designs to show that high-preference music produced lower levels of vocal stereotypy than low-preference music for three of the four participants during relatively brief sessions. In addition, Lanovaz et al. (see Fig. 28.2) showed that vocal stereotypy was substantially lower for the same three participants when their high-preference music was provided versus when no alternative stimulation was available.

Indeed, NCR with matched stimulation may be the most empirically supported intervention for treating vocal stereotypy and, likewise, perhaps the primary advantage of this intervention is the relative ease of implementation compared to consequent interventions (see below). Nevertheless, NCR with matched stimulation is not without potential limitations. First, engagement with alternative stimulation that is provided during NCR interventions may compete with academic engagement in much the same way as engagement in stereotypy (Enloe and Rapp, 2014; Shillingsburg, Lomas, and Bradley, 2012; but see also Lanovaz, Sladeczek, et al., 2012). As such, this intervention may not lend itself well to application during instructional segments. Second, most studies involve session durations of 10 min or less. Thus, the duration of time for which a practitioner should expect matched, preferred items to compete with stereotypy is not clear. Relatedly, it is not clear how often preference assessments should be updated in order to identify items that will compete with engagement stereotypy over time. Third, at least one recent study has shown that preferred, matched stimulation may decrease vocal stereotypy while simultaneously increasing other, previously less probable, forms of motor stereotypy (Rapp et al., 2013). On a broader level, given the different sensory consequences that are produced by engagement in vocal stereotypy versus the various forms of motor stereotypy, more research is needed to determine if NCR with matched stimulation has robust effects for decreasing the various forms of motor stereotypy, such as body rocking, hand flapping, and object spinning, among others.

Moderate evidence. The only behavioral intervention in this category is antecedent exercise. Not unlike NCR, interventions involving antecedent exercise potentially contain provisions of alternative forms of stimulation, which may compete with or substitute for stimulation generated by engaging in stereotypy (e.g., Morrision, Roscoe, and Atwell, 2011). However, interventions involving antecedent exercise differ from those involving NCR insofar as the former interventions typically involve active participation in gross motor movements that increase cardiovascular activity (e.g., jogging for 20 min), whereas the latter interventions may involve passive, sedentary consumption of ambient stimulation (e.g., listening to music or manipulating items that produce auditory stimulation).

Lang, Koegel, et al. (2010) recently reviewed group-design and SCED studies on the effects of physical exercise on problem behavior displayed by individuals with ASD. Lang, Koegel, et al. highlighted a number of interpretative problems with several studies in this area of the literature; however, they concluded that the overall results suggest individuals with ASD may benefit from regular physical activity. Several SCED (Bachman & Sluyter, 1988; Celiberti, Bobo, Kelly, Harris, & Handleman, 1997; Kern, Koegel, & Dunlap, 1984; Kern, Koegel, Dyer, Blew, & Fenton, 1982; Morrision et al., 2011; Watters & Watters, 1980) and group-design (e.g., Rosenthal-Malek & Mitchell, 1997) studies provide evidence of the effects of physical exercise for reducing one or more forms of vocal or motor stereotypy. Because the actual procedures vary from study to study (jogging is among the most common activities), the extent to which physical exercise should be referred to as a unitary independent variable is not clear. Nevertheless, physical exercise should be viewed as an intervention with moderate evidence for decreasing motor stereotypy.

A study by Morrision et al. (2011) illustrates the manner in which interventions involving antecedent exercise should be developed and implemented to decrease motor stereotypy or other problem behaviors for individuals with autism. Morrison et al. first conducted paired-choice stimulus preference assessments to identify leisure and exercise items for two individuals

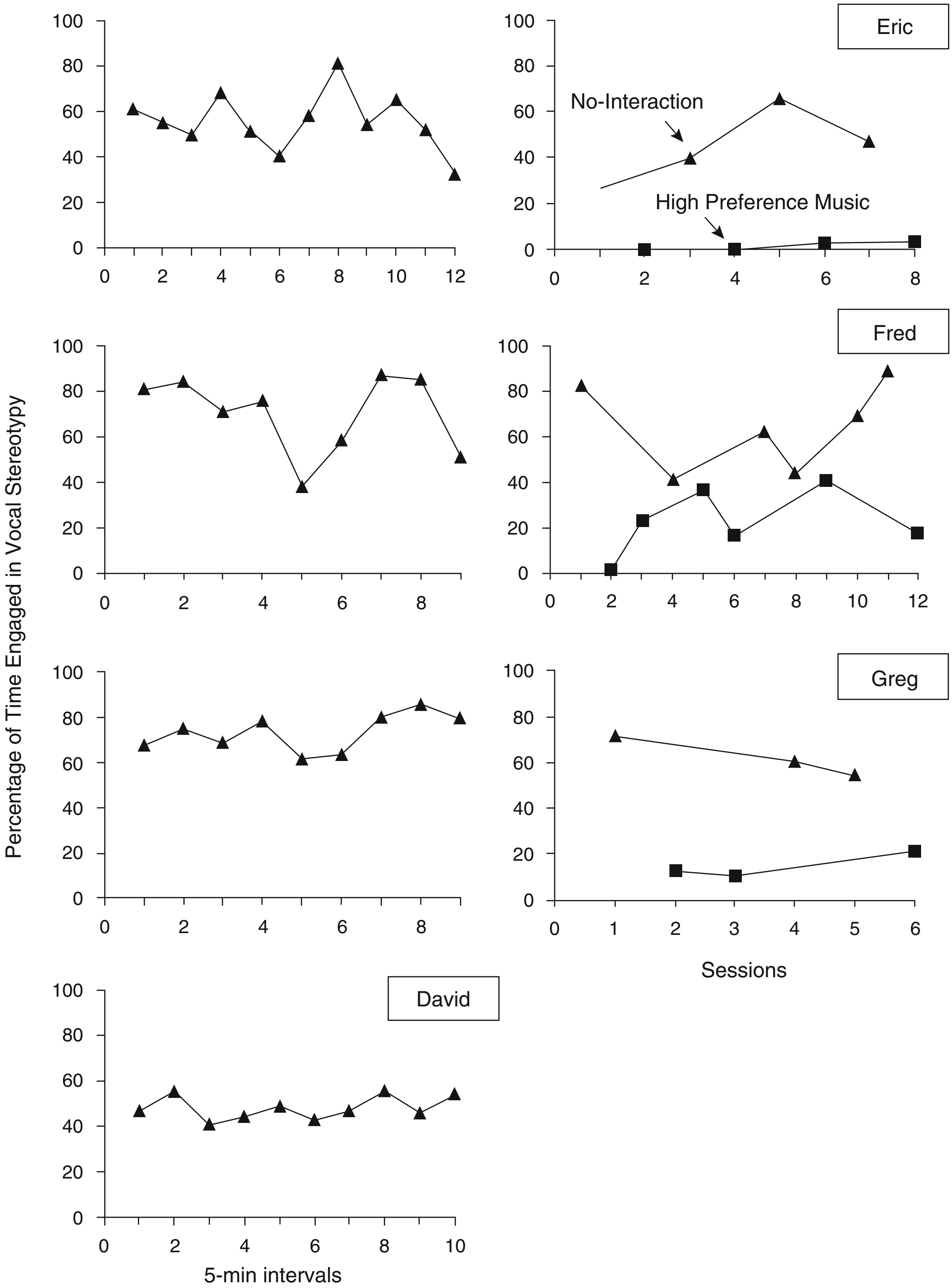

Fig. 28.2 Percentage of time Eric, Fred, Greg, and David engaged in vocal stereotypy during the free-operant observation periods (*left*) and during no-interaction and high-preference music sessions (*right*). Reprinted from Lanovaz, M. J.; Rapp, J. T.; and Ferguson, S. (2012). The utility of assessing musical preference before implementation of noncontingent music to reduce vocal stereotypy. *Journal of Applied Behavior Analysis, 45*, 845–851. doi:10.1901/jaba.2012.45-845

with autism who displayed motor stereotypy. Thereafter, Morrison et al. evaluated the separate effects of an exercise item, a leisure item, and social interaction (as a control comparison) using a three-component multiple schedule, which is a variation of a multielement design. Specifically, each session was comprised of three, 10-min components (pre-intervention, intervention, and post-intervention). As an illustration of the effects, we focus on the results of the immediate and subsequent effects of each intervention on motor stereotypy displayed by a participant named Steve. Most notably, the results for the exercise-item assessment indicated that engagement with the exercise item (a) decreased Steve's immediate engagement in stereotypy during each session and (b) exerted a residual effect such that Steve's stereotypy remains low for a period of time after the intervention was removed. Results also showed that the leisure item decreased Steve's motor stereotypy; however, in most sessions Steve's engagement in motor stereotypy often increased above pre-intervention levels after the leisure item was removed. Finally, results for the social interaction (control) assessment indicated that social interaction, alone, did not decrease Steve's engagement in stereotypy. Together, the analyses for Steve show that a specific type of physical activity decreased his immediate and subsequent engagement in motor stereotypy.

An inherent strength of interventions involving exercise is the likely health benefits that are produced by regular exercise. A potential limitation of such interventions is that procedures (e.g., prompting, reinforcement, prompt fading) are often needed to train individuals to engage in the exercise activities. In addition, some studies report that stereotypy returns to baseline levels within 45 min of the exercise intervention. As was noted for NCR, antecedent exercise is an unlikely treatment of choice during instructional segments.

Limited or no evidence. Under typical circumstances, it makes little sense to discuss interventions for stereotypy that are not supported by at least a moderate level of evidence. Nevertheless, numerous studies have employed sensory integration therapy (SIT) procedures such as body brushing, joint compression, deep pressure, hammock swinging, and weighted vests, among others, to reportedly decrease problem behavior such as vocal and motor stereotypy. Lang et al. (2012) review studies on the use of SIT for problem behavior in individuals with ASD. As a whole, Lang et al. concluded that most SIT studies did not yield positive effects on problem behavior (including motor and vocal stereotypy), and the few studies that did report positive outcomes contained one or more methodological problems. Our conclusions parallel those provided by Lang et al. (2012).

Consequence Interventions

Based on the guidelines provided by Kratochwill et al. (2010), there are four consequent interventions for motor and vocal stereotypy with strong or moderate evidence. To be defined as consequent-based intervention, the treatment in questions has to include delivery of a specified consequence for (a) engagement in motor or vocal stereotypy, (b) engagement in appropriate response (e.g., task engagement, communication), (c) not engaging in motor or vocal stereotypy, or (d) any combination of (a), (b), and (c). As with antecedent interventions, our description of each consequent intervention includes a recent study that best illustrates the effects on stereotypy, as well as the potential strengths and limitations of the consequent intervention.

Strong evidence. There is only one consequent-based intervention for stereotypy that fits into this category. Research on overcorrection procedures for stereotypy and other problem behavior spans over four decades. We should note that just because there is strong empirical support for the use of overcorrection procedures to decrease stereotypy does not mean that it should be viewed as a "first-line" intervention. Contrarily, reinforcement-based procedures with at least moderate empirical support should be implemented prior to interventions involving either positive or negative punishment (e.g., Miltenberger, 2012).

Although the literature contains various iterations of overcorrection procedures (e.g., Miltenberger, 2012), the variation that has garnered the most empirical support is positive practice overcorrection (PPOC), which involves the response contingent application of additional effort by an intervention agent in the form of repetitious engagement in an appropriate behavior (Anderson & Le, 2011; Foxx & Azrin, 1973; Coleman, Montgomery, Wilson, & Milan, 2000; Harris & Wolchik, 1979; Peters & Thompson, 2013; Roberts, Iwata, McSween, & Desmond, 1979; Rollings, Baumeister, & Baumeister, 1977; Wells, Forehand, & Hickey, 1977; Wells, Forehand, Hickey, & Green, 1977). When treating stereotypy, a typical form of PPOC involves a trainer manually guiding the individual who emitted stereotypy to manipulate a toy or leisure item for a prespecified period of time (e.g., 30 s).

A recent study by Peters and Thompson (2013) evaluated (a) the effects of PPOC on stereotypy displayed by children with ASD and (b) the extent to which the activity used in overcorrection is preferred or not preferred by the participant which alters the effects for reducing motor stereotypy. Prior to evaluating the effects of PPOC, Peters and Thompson conducted paired-stimulus preference assessments to identify high- and low-preference activities for each. Thereafter, Peters and Thompson used a multiple baseline across high and low activities with an embedded reversal for each participant; we focus on results for a participant named Max. During baseline, no social consequences were provided for Max's engagement with the activity or for his engagement in motor stereotypy. In the PPOC condition, Max's engagement in motor stereotypy was immediately followed by physical guidance from a trainer for Max to manipulate an item for 30 s. The results show that Max's motor stereotypy decreased rapidly following the implementation of PPOC. In addition, as an indirect effect of PPOC, results show that engagement with the activity that was used during the PPOC procedure increased. In this way, a positive punishment procedure may decrease problem behavior while simultaneously increasing appropriate behavior.

An obvious strength of this procedure is the concurrent acquisition of a social appropriate alternative response (e.g., playing with toys); however, such acquisition is only noted in approximately half of the studies. By contrast, a limitation, which appears to be common to most punishment procedures when intervening on nonsocially reinforced behavior, is the need to continue to implement PPOC across sessions (see below). Moreover, PPOC is a relatively invasive punishment procedure that is not viewed as a first-line intervention (e.g., Bailey & Burch, 2011).

Moderate evidence. Three consequent interventions fit this category. The first is differential reinforcement of other behaviors (DRO), which is among the oldest and most traveled behavioral interventions for problem behavior. The second intervention in this category is response interruption and redirection (RIRD), which is a relatively new intervention (at least in name). This intervention arguably contains a combination of overcorrection for engagement in stereotypy and social reinforcement for appropriate behavior (e.g., praise for appropriate speech). However, the provision of social reinforcement is typically a part of baseline sessions. As such, results across studies suggest that the consequences provided for stereotypy are the operative component of RIRD. The third class of intervention, which, like DRO, has been in application for quite some time, is response cost (RC) and time out (TO). To fit within this latter category, studies must have empirically demonstrated the participant's preference for the items that were removed or withheld contingent on stereotypy.

Differential reinforcement of other behaviors. This intervention involves delivery of one or more empirically identified preferred items contingent on the omission of the target stereotypy for a specified period of time. That is, the stimulus that is delivered following the omission of stereotypy may not be functionally related to the stimulation that is generated by engagement in stereotypy. As such, the individual must abstain from engaging in stereotypy for a specified period of time in order to access an alternative reinforcer. Numerous studies have shown that DRO with preferred items produced clinically significant decreases in motor or vocal stereotypy (Fritz, Iwata, Rolider, Camp, and Neidert, 2012; Lanovaz and Argumedes, 2010; Lustig et al., 2013; Nuernberger, Vargo, and Ringdahl, 2013; Patel, Carr, Kim, Robles, and Eastridge, 2000; Repp, Dietz, and Speir, 1974; Ringdahl et al., 2002; Shabani, Wilder, and Flood, 2001; Rozenblat, Brown, Brown, Reeve, and Reeve, 2009; Taylor, Hoch, & Weissman, 2005, but see Lanovaz and Argumedes, 2009). As a collective whole, studies in this literature meet all three criteria for demonstrating *strong* evidence; however, we have placed DRO in the category of moderate evidence for two reasons. First, although each of the aforementioned studies decreased motor or vocal stereotypy using DRO, only half of the aforementioned studies demonstrated (or attempted to demonstrate) that the DRO schedule could be thinned to a practical variation (e.g., DRO 5 min). We suspect that practitioners will find DRO with small intervals (e.g., 30 s) to be of limited utility in applied settings. Second, in about a third of the studies that did thin the DRO schedule to at least 5-min intervals, researchers implemented self-monitoring procedures with participants prior to applying DRO procedures. As such, it is not clear whether DRO procedures will decrease stereotypy to the same extent for individuals who cannot monitor their own behavior.

A study by Taylor et al. (2005) exemplifies the steps that are needed to decrease stereotypy using DRO. First, Taylor et al. demonstrated that the vocalizations of a 6-year-old girl persisted across test and control condition of a functional analysis. Next, Taylor et al. used a multielement design to show that the participant's vocal stereotypy decreased with matched toys (i.e., those that produced auditory stimulation). Subsequently, Taylor et al. used a concurrent operant assessment (i.e., a variation of a preference assessment) to demonstrate that the participant preferred to manipulate operative auditory toys (matched toys) over nonoperative auditory toys (matched toys without batteries). Using an ABCBC reversal design, where B denotes fixed-time (FT) 1 min delivery of matched, operative toys and C denotes DRO (resetting) 1 min delivery of matched, operative toys, Taylor et al. demonstrated that vocal stereotypy decreased with DRO 1 min, but not FT 1 min. Moreover, Taylor et al. showed that vocal stereotypy gradually decreased to near-zero levels as they (a) thinned the DRO schedule to 5 min and (b) implemented the intervention in novel settings. Furthermore, the authors provide long-term follow-up data indicating that the effects of the ongoing DRO intervention persisted over 9 months.

There are several important considerations when implementing DRO. First, DRO can be a complex and time-intensive intervention, particularly when the schedule involves relatively brief (e.g., 20 s), resetting intervals. Likewise, although there some general guidelines for basing the initial DRO schedule on the mean interresponse time (IRT) from baseline observations (e.g., Cooper, Heron, & Heward, 2007), guidelines for thinning the DRO schedule across sessions are less formal (but see Cooper et al., 2007, p. 479). For example, Nuernberger et al. (2013) doubled the DRO interval after every two sessions without stereotypy. Alternatively, Rozenblat et al. (2009) have shown that percentile schedules based on the IRTs of stereotypy bouts may be useful for guiding decisions about both the initial DRO schedule and schedule thinning. Second, as previously noted, some of the aforementioned studies implemented DRO procedures in conjunction with self-monitoring procedures (e.g., Nuernberger et al., 2013; Ringdahl et al., 2002). Nevertheless, results from a study by Fritz et al. (2012) suggest that when DRO is used in conjunction with self-monitoring procedures, decreases in stereotypy are likely attributable to reinforcement contingencies (e.g., the omission of stereotypy or engagement in alternative behavior). Third, studies for which researchers were able to demonstrate consistent reductions in stereotypy with DRO schedules of 5 min or longer typically included participants with developed academic repertoires (e.g., individuals who could write, follow instructions, or both).

Response interruption and redirection. Since the introduction of RIRD as a formal procedure to treat vocal stereotypy (Ahearn, Clark, MacDonald, & Chung, 2007), multiple studies have replicated the initial effects with vocal stereotypy (e.g., Ahrens, Lerman, Kodak, Worsdell, & Keegan, 2011; Cassella, Sidener, Sidener, & Progar, 2011; Colón, Ahearn, Clark, & Masalsky, 2012; Giles, St. Peter, Pence, & Gibson, 2012; Guzinski, Cihon, & Eshleman, 2012; Liu-Gitz & Banda, 2009; Love et al., 2012; Miguel, Clark, Tereshko, & Ahearn, 2009; Schumacher & Rapp, 2011) and a few studies have produced similar effects with motor stereotypy (Ahrens et al., 2011; Pastrana, Rapp, & Frewing, 2013). As described by Ahearn et al. (2007), RIRD involved two components. First, contingent on an individual's engagement in stereotypy, an intervention agent requires the participant to respond to three consecutive questions without engaging in stereotypy; this component is not unlike overcorrection. Second, the intervention agent delivers social reinforcement for appropriate vocal behavior. Based on the Kratochwill et al. (2010) criteria, there is relatively strong evidence for the use of RIRD to decrease vocal stereotypy; however, studies within the RIRD literature have employed multiple variations of RIRD procedures (Martinez & Betz, 2013). For example, some studies provided reinforcement for alternative behavior, whereas an equal number of studies did not. In addition, studies varied in the manner with which the contingent demands were provided and whether the time period wherein contingent demands were provided was removed from the total session time. As such, the extent to which RIRD should be considered a single intervention is not clear. Nevertheless, the fact that studies employing similar but not identical procedures yield comparable outcomes suggests that the procedure may be useful for some individuals in some contexts.

Results for a participant in the original study by Ahearn et al. (2007) illustrate how RIRD can be implemented to decrease vocal stereotypy. Specifically, Ahearn et al. evaluated the effects of RIRD on Mitch's vocal stereotypy using an ABAB reversal design. The authors opted to collect data on Mitch's vocal stereotypy using 10-s momentary time sampling, which is sufficiently sensitive for measuring changes in duration events (Meany-Daboul et al., 2007; Rapp et al., 2007, 2008; Wirth et al., 2014). In addition, the authors collected data on Mitch's engagement in appropriate vocalizing. During baseline, Mitch was seated in a room that was relatively devoid of alternative forms of stimulation. A teacher provided social reinforcement for Mitch's appropriate vocal responses, but she ignored Mitch's engagement in vocal stereotypy. During the RIRD phase, the teacher continued to provide social reinforcement for Mitch's appropriate vocal behavior; however, she delivered a series of social questions to Mitch contingent on his engagement in vocal stereotypy. The teacher stopped providing the social questions after Mitch responded to three consecutive questions without engaging in vocal stereotypy. Results showed that RIRD decreased Mitch's vocal stereotypy and increased his appropriate vocalizing.

As noted above, the majority of studies have evaluated the effects of RIRD, which requires vocal responses, on vocal stereotypy. By contrast, only a few studies have evaluated the effects of RIRD (Ahrens et al., 2011; Pastrana et al., 2013), which requires motor responses contingent on motor or vocal stereotypy. Nevertheless, when studies on the effects of motor RIRD are considered in conjunction with studies on PPOC, there seems to be sufficient evidence for motor RIRD and related variations. Perhaps the most noteworthy limitation of RIRD is the potential need to interrupt stereotypy on a continuous basis. Specifically, the number of times an intervention agent implements RIRD may not decrease across sessions (e.g., Cassella et al., 2011; Pastrana et al., 2013). In a recent study that compared RIRD to NCR with matched stimulation for decreasing vocal stereotypy, Carroll and Kodak (2014) found that the effects of RIRD may be overestimated when the time spent implementing the interruption and compliance sequence was not factored into the total session time. By contrast, NCR with matched stimulation was found to be a more efficient intervention than RIRD. In addition, a recent review article by Lydon, Healy, O'Reilly, and McCoy (2013) provided a generally conservative conclusion about the effectiveness of response interruption procedures for treating various types of problem behaviors displayed by individuals with intellectual disabilities.

Response cost and time out. Miltenberger (2012) defined TO as "the loss of access to positive reinforcers for a brief period of time contingent on…behavior" (p. 344), whereas Miltenberger defined RC as "the removal of a specified amount of a reinforcer contingent on…. behavior" (p. 352). Regardless of the very minor procedural variations, both RC and TO are classified as negative punishment procedures. For the purpose of this section, we combined studies that evaluated the effects of either RC or TO on stereotypical behavior. In most studies, if noncontingent, continuous access to empirically identified preferred items did not decrease motor or vocal stereotypy to clinically acceptable levels, then access to the items was briefly removed contingent on engagement in motor or vocal stereotypy (Falcomata, Roane, Hovanetz, Kettering, & Keeney, 2004; Rapp, Patel, Ghezzi, O'Flaherty, & Titterington, 2009; Shillingsburg et al., 2012; Vollmer, Marcus, & LeBlanc, 1994; Watkins & Rapp, 2014).

Falcomata et al. (2004) used an ABCACBC reversal design to evaluate the effects of NCR (matched) and NCR (matched) plus RC on vocal stereotypy emitted by a young adult with autism (Derek). During the NCR phase, Derek was provided continuous access to a radio, which was identified as highly preferred via a stimulus preference assessment. During the NCR plus RC condition, Derek had continuous access to the radio unless he engaged in vocal stereotypy. Following each instance of vocal stereotypy, an intervention agent removed the radio for 5 s. Results indicated that NCR decreased Derek's engagement in vocal stereotypy, but not to clinically acceptable levels. Subsequently, the addition of RC to NCR decreased Derek's vocal stereotypy to zero or near-zero levels. Conceptually, it is likely that the RC is effective because the stimulation generated by engagement with preferred items is momentarily more valuable than the stimulation generated by engagement in stereotypy (Falcomata et al., 2004). As such, the individual learns to abstain from engaging in stereotypy to avoid losing a more preferred consequence.

A potential strength of either RC or TO is that either can be readily implemented when NCR does not produce clinically significant reductions in stereotypy, as demonstrated in the Falcomata et al. (2004) study. Likewise, the procedures may be particularly useful during academic segments, as demonstrated in a study by Shillingsburg et al. (2012). As with other punishment procedures, however, a potential limitation of these negative punishment procedures is that decreases in the targeted stereotypy may be correlated with increases in other forms of stereotypy (Rapp, 2005).

Combining Antecedent and Consequent Interventions

The implementation of interventions involving stimulus control procedures (most often the signaled delivery of a positive punisher) is predicated on the assumption that engagement in stereotypy can be permitted in some situations (e.g., during leisure time), but not others (e.g., during instructional periods). Across studies, researchers have used various punishment procedures (e.g., verbal reprimands, response blocking, RC, RIRD, TO) for engagement in vocal or motor stereotypy and various antecedent stimuli (e.g., poster boards, wrist bands) to signal punishment delivery, and some have include reinforcement for appropriate behavior (Anderson, Doughty, Doughty, Williams, & Saunders, 2010; Brusa & Richman, 2008; Conroy, Asmus, Sellers, & Ladwig, 2005; Cook, Rapp, Gomes, Frazer, & Lindblad, 2014; Doughty, Anderson, Doughty, Williams, & Saunders, 2007; Haley, Heick, & Luiselli, 2010; Langone, Luiselli, & Hamill, 2013; McKenzie, Smith, Simmons, & Soderlund, 2008; O'Connor, Prieto, Hoffman, DeQuinzio, & Taylor, 2011; Rapp et al., 2009). Furthermore, studies vary considerably in the duration of the free access (when stereotypy is permitted) versus restricted access (when mild punishment is provided contingent on stereotypy) conditions. These variations notwithstanding, there is burgeoning empirical support for the use of stimulus control procedures to treatment motor and vocal stereotypy; however, as with RIRD, the extent to which studies in the category evaluated a common intervention is debatable. Nevertheless, because stimulus control procedures have the potential to be useful in a variety of settings, we have opted to highlight the application of such procedures in this section.

A recent study by Cook et al. (2014) evaluated (a) the extent to which verbal reprimands decreased five individuals' engagement in targeted and untargeted stereotypy and (b) whether inhibitory stimulus control of the targeted stereotypy could be acquired during a signaled punishment condition. The effects of the procedures are illustrated here for a participant named Hannah. Prior to conducting the treatment evaluation, Cook et al. (2014) showed that Hannah's body rocking and arm flapping occurred almost exclusively when music was present (see Fig. 28.3). During the NC condition, the participant had free access to engage in the targeted or untargeted stereotypy without social consequence. During the RC condition, a trainer delivered a mild verbal reprimand following each instance of the targeted stereotypy but did not specifically provide consequences for the participant's engagement in the untargeted stereotypy. Figure 28.4 shows that Hannah's body rocking (upper panel) decreased in the RC condition and remained at high levels in the NC condition. In addition, results suggest that Hannah's arm flapping decreased in the RC condition. Cook et al. also found that relatively few reprimands (upper panel, secondary y-axis) were required per session to maintain near-zero levels of stereotypy, and the RC sessions could be increased to 10 min, while the NC sessions were decreased to 1 min.

There are several issues stemming from the use of signaled punishment procedures. First, across studies it is not clear if the antecedent stimulus exerts effects when inhibitory control is not achieved. When inhibitory control is achieved, it is likely to be temporary. Second, as with RIRD, it may be necessary to deliver the punisher on an ongoing basis across sessions, which can diminish the clinical utility of the

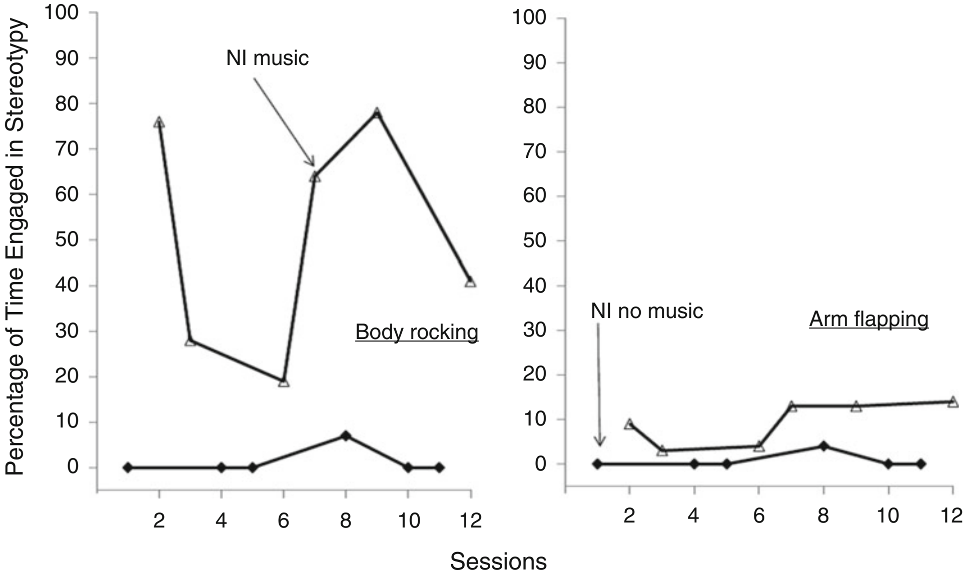

Fig. 28.3 Percentage of time Hannah engaged in body rocking (*left panel*) and arm flapping (*right panel*) during no-interaction (NI) music versus NI no music conditions. Reprinted from Cook, J. L.; Rapp, J. T.; Gomes, L. A.; Frazer, T. J.; and Lindblad, T. L. (2014). Effects of verbal reprimands on targeted and untargeted stereotypy. *Behavioral Interventions, 29*, 106–124. doi:10.1002/bin.1378

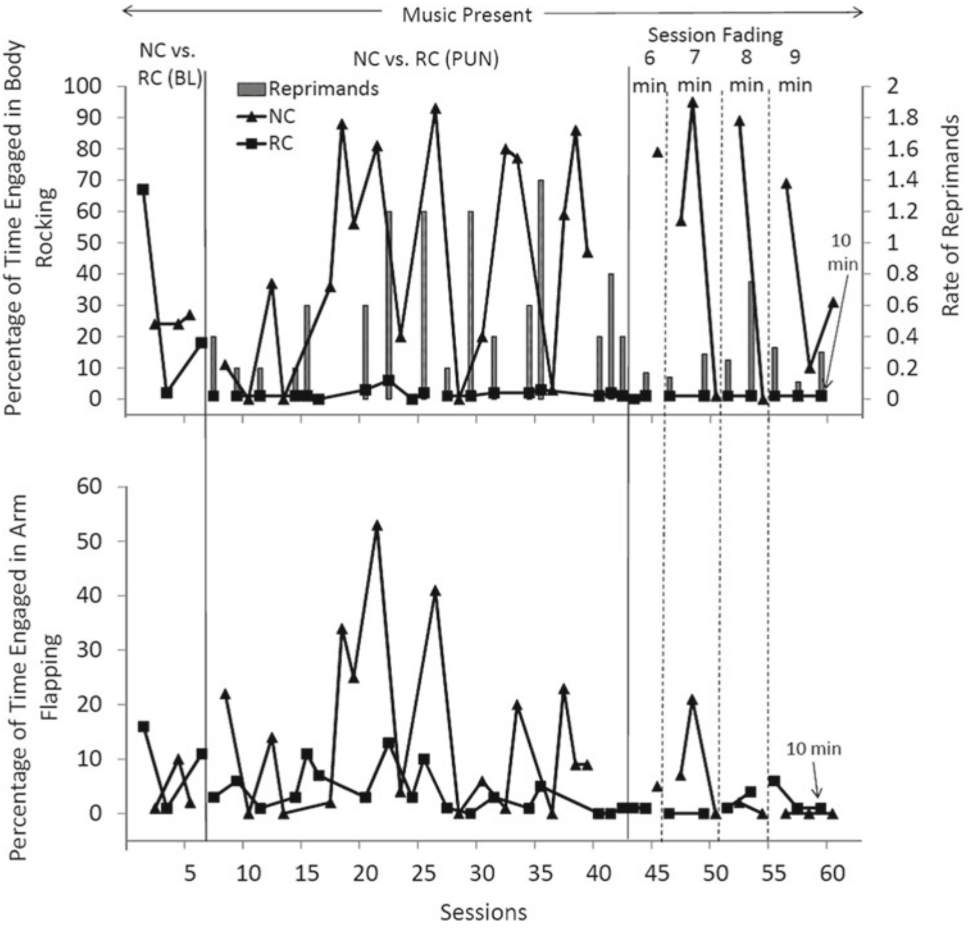

Fig. 28.4 Percentage of time Hannah engaged in body rocking (targeted; primary *y*-axis) and rate of reprimands (secondary *y*-axis) given by the experimenter (*upper panel*) and percentage of time Hannah engaged in arm flapping (untargeted, *lower panel*) during the no card (NC) versus red card (RC, baseline [BL]), the NC versus RC (punishment [PUN]), and the session-fading phases. Reprinted from Cook, J. L.; Rapp, J. T.; Gomes, L. A.; Frazer, T. J.; and Lindblad, T. L. (2014). Effects of verbal reprimands on targeted and untargeted stereotypy. *Behavioral Interventions, 29*, 106–124. doi:10.1002/bin.1378

intervention. Finally, as shown with other participants in the Cook et al. (2014) study, punishment procedures may either increase or decrease untargeted forms of stereotypy (Lanovaz et al., 2013). Practitioners may also find that it is necessary to implement one intervention in one context and a different class of intervention in another context for the same individual. For example, a trainer could use signaled RIRD, with the intention of producing inhibitory stimulus control of stereotypy during instructional segments and NCR with matched stimulation during leisure periods.

Translation of Research to Practice

Treatment selection. One common problem faced by practitioners attempting to reduce engagement in stereotypy is determining which treatment should be selected for any given individual with intellectual disability. Albeit many interventions having strong or moderate empirical support to reduce stereotypy, treatment selection remains challenging as few studies have compared one or more interventions together. Nonetheless, Lanovaz et al. (2014) recently proposed an intervention selection model for reducing engagement in vocal stereotypy. Figure 28.5 illustrates an adapted version of the model in which we incorporated the treatment of motor stereotypy. When developing the model, we considered research evidence, ease of use, context of implementation, restrictiveness, and topography of stereotypy.

For vocal stereotypy, the model recommends NCR with prompting first. The intervention involves continuous access to preferred music and prompting when the person is not appropriately engaged (e.g., playing, completing a task). Noncontingent reinforcement is recommended before other interventions for several reasons. First, NCR is easier to implement than differential reinforcement and less restrictive than RIRD or RC/TO. Second, NCR has strong empirical support in the research literature. Third, some studies suggest that music (i.e., matched stimulus typically used to reduce vocal stereotypy) does not generally interfere with ongoing behaviors, which makes it possible to implement in most contexts when headphones are used (Burleson, Center, & Reeves, 1989; Lanovaz, Rapp, et al., 2012, Lanovaz, Sladeczek, et al., 2012). Finally, the prompting component is essential as reducing stereotypy does not necessarily lead to increases in appropriate collateral behavior (Lanovaz et al., 2013). The introduction of prompting reduces engagement in motor stereotypy while strengthening engagement in appropriate behavior (Britton, Carr, Landaburu, & Romick, 2002; Lanovaz et al., 2014; Symons & Davis, 1994). By contract, attempting to reduce vocal stereotypy with NCR alone may increase motor forms of stereotypy (Rapp et al., 2013).

If the intervention fails to reduce engagement in vocal stereotypy, the model recommends the implementation of differential reinforcement and prompting. To increase the probability of success, the reinforcer should be delivered when the individual with intellectual disability is both not engaging in vocal stereotypy (i.e., DRO) and simultaneously engaging in an alternative behavior (e.g., playing, completing a task). The intervention is recommended second as it remains less restrictive than either RIRD or RC/TO but is more complicated to implement than NCR. The prompting component remains important to ensure that vocal stereotypy is replaced by socially appropriate behavior. If this intervention also fails, the final recommendation of the model is to combine NCR with prompting and RC/TO or RIRD. In addition to implementing NCR with prompting, the practitioner may either remove the preferred stimulus (music) for brief periods of time or make a series of demands or provide verbal reprimands contingent on the occurrence of vocal stereotypy (e.g., Ahearn et al., 2007; Falcomata et al., 2004; Watkins & Rapp, 2014). This intervention is recommended last as the implementation of punishment-based procedures may (a) have ethical implications (e.g., Bailey & Burch, 2011) and (b) produce several side effects such as aggressive behavior (Hagopian & Toole, 2009; Lerman & Vorndran, 2002).

The model for motor forms of stereotypy varies as NCR may involve the delivery of items that may compete with the occurrence of appropriate behavior. As such, the same sequence as vocal stereotypy is recommended only when the practitioner is aiming to reduce motor stereotypy in free or playtime periods. During this time, the practitioner can provide access to items that provide similar types of sensory stimulation (if possible) and prompt appropriate behavior when the individual is not engaged in appropriate activities (Britton et al., 2002). In work, task, or learning settings, the noncontingent delivery of tangible items may interfere with other activities in which the individual must be engaged. In these contexts, we propose that the practitioner begins by implementing differential reinforcement with prompting first. If this intervention fails to produce the desired outcome, the practitioner may add a RIRD or overcorrection. That is, engagement in motor stereotypy can be interrupted by contingent demands or be followed by an overcorrection procedure implemented by the practitioner. Although potentially effective, this approach is recommended last as it may evoke engagement in other inappropriate behavior.

It should be noted that the intervention model has yet to be empirically validated as whole, but the selection of the interventions is based on evidence available in the research literature.

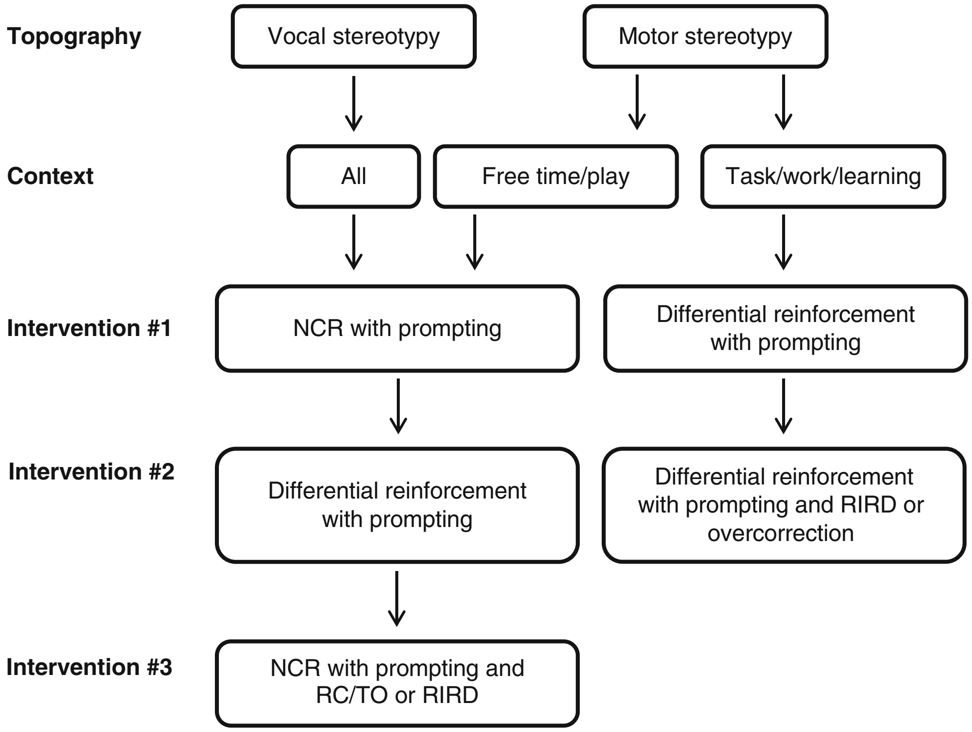

Fig. 28.5 Flowchart of proposed intervention selection model

Moreover, the model considers the advantages and disadvantages of implementing each intervention in applied settings. That said, practitioners should also consider the individual's personal characteristics and patterns of responding when setting the parameters of each intervention (e.g., reinforcement schedule, type of preferred stimuli, specific prompting protocol).

Treatment assessment. Once an intervention has been selected, its effects should be rigorously assessed and monitored. During the assessment, the practitioner should plan to (a) confirm that the repetitive behavior targeted for stereotypy are maintained by nonsocial reinforcement, (b) experimentally identify preferred stimuli to use as part of the interventions, (c) conduct a brief assessment of intervention effectiveness using a SCED, and (d) implement the intervention on a regular basis (if shown to be effective). Figure 28.6 presents a sequential assessment model adapted from Lanovaz, Rapp, and Fletcher (2010). This model outlines the steps that a practitioner should adopt when assessing the effects of an intervention to reduce engagement in stereotypy.

The first step involves conducting a functional analysis to examine whether the repetitive behaviors are maintained by nonsocial reinforcement. The most straightforward method is to conduct a series of consecutive no-interaction sessions during which the individual does not have access to social consequences (Querim et al., 2013; Vollmer, Marcus, Ringdahl, & Roane, 1995). If the repetitive behaviors persist in the absence of social consequences, the practitioner may move to the next step and conduct a preference assessment. If the repetitive behaviors extinguish, then the practitioner should conduct a new functional analysis to identify its social function and then implement a function-based treatment.

As a second step, the practitioner should conduct a preference assessment to identify the stimuli that will be provided as part of the intervention. Whenever possible, age-appropriate stimuli that matched the putative sensory product generated by the form of stereotypy should be selected. With the exception of music and edibles, we suggest that the practitioner conducts a FOPA (Roane et al., 1998) when the intervention is NCR. In this way, the assessment conditions will more closely resemble the intervention setting. For differential reinforcement, we recommend a selection-based preference assessment as the short duration of access during the assessment is similar to the type of access provided during the intervention (e.g., Carr et al., 2000; DeLeon & Iwata, 1996; Fisher et al., 1992). For edibles, the selection-based preference assessment is used regardless of the intervention as the free-choice method may lead to overeating. For music, a modified paired-choice method (Horrocks & Higbee, 2008) is typically used as providing free access to multiple musical stimuli simultaneously presents too many technical challenges and difficulties.

For the third step, the practitioner tests the effects of the selected intervention within a SCED. Intervention and no-intervention sessions are alternated semi-randomly on a daily basis to examine whether the treatment produces socially significant reductions in stereotypy. In addition to stereotypy, the practitioner should consider also measuring engagement in appropriate behavior to ensure that the intervention is not producing undesirable effects. If the intervention is planned to be implemented for short periods of time interspersed by other activities, we recommend that the practitioner also considers measuring pre- and post-intervention levels of stereotypy using the three-component multiple schedule. From a clinical standpoint, examining the post-intervention effects may be important as the practitioner will want to avoid interventions that worsen stereotypy when it is withdrawn.

As a form of treatment evaluation, the three-component multiple schedule is composed of three equal duration components: pre-intervention (first component), intervention or no-intervention (second component), and post-intervention (third component). The intervention is never implemented during the first or third components. The second component either involves the implementation of the intervention or the absence of the intervention. The practitioner conducts no more than one session per day and alternates between intervention and no-intervention conditions (in the second component only) as in an alternating treatment design. Then, the data are analyzed using procedures adapted from Lanovaz et al. (2010). First, the immediate effects (i.e., second component) of the intervention are examined by comparing levels of stereotypy when the intervention is being implemented and when it is not being implemented on graphs. If the intervention is ineffective, the analysis stops at this level and the practitioner should modify the parameters of the intervention or move on to the next intervention in the model (see Fig. 28.6).

If the intervention reduces immediate engagement in stereotypy (i.e., in the second component), the practitioner analyzes the graphs of the third component to determine its post-intervention effects. If the intervention increases subsequent (post-intervention) engagement in stereotypy, the analysis stops here and the practitioner assesses the effects of a new intervention. If the intervention reduces subsequent engagement in stereotypy, we recommend that the intervention be implemented on a regular basis in the individual's environment (see step 4). If patterns remain undifferentiated, a within-sequence analysis should be conducted. To conduct a within-sequence analysis, changes in stereotypy from pre- to post-intervention are compared across conditions. If stereotypy is lower in the third component (post-intervention) than in the first component (pre-intervention) more often in the intervention sequence than in the no-intervention sequence (or if patterns are the same), the practitioner may conclude that the intervention does not increase subsequent engagement in stereotypy and propose its implementation on a regular basis. If stereotypy is lower in the third component than in the first component more often in the no-intervention sequence than the intervention sequence, the practitioner may conclude that the intervention potentially increases subsequent engagement in stereotypy and assess the effects of a new intervention.

A study by Pastrana et al. (2013) illustrates the application of both the between-sequence and

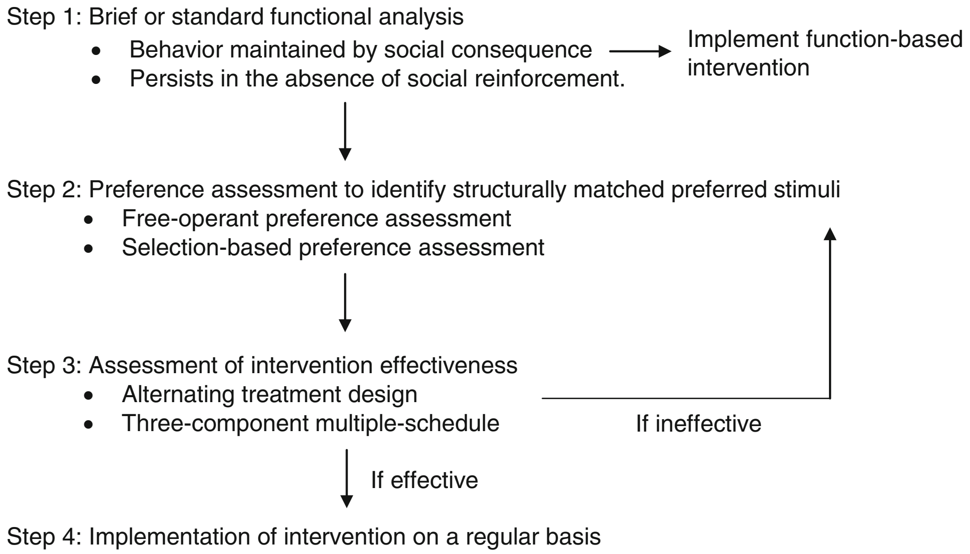

Fig. 28.6 Sequential treatment assessment model for stereotypy. Based on Fig. 28.1 from Lanovaz, M. J.; Rapp, J. T.; and Fletcher, S. M. (2010). Expanding functional analysis of automatically reinforced behavior using a three-component multiple schedule. *European Journal of Behavior Analysis, 11*, 17–27

within-sequence analyses. Specifically, Pastrana et al. evaluated the effects of motor RIRD on targeted motor stereotypy and nontargeted vocal stereotypy for Emmett. In addition, the authors tracked the frequency with which RIRD was implemented across sessions. Results of the between-sequence analysis for Emmett (see Fig. 28.7) show that RIRD (a) decreased his immediate engagement in targeted motor stereotypy, (b) did not consistently alter his immediate engagement in vocal stereotypy, and (c) did not increase his subsequent engagement in motor or vocal stereotypy. In addition, Fig. 28.7 (lower panel) shows that the need to implement RIRD did not decrease across sessions. In order to assess small changes in motivation, Pastrana et al. also conducted a within-sequence analysis of the subsequent effects of RIRD on Emmett's targeted and nontargeted behavior. Results from Fig. 28.8 suggest that RIRD did not increase Emmett's subsequent engagement in motor stereotypy (upper panel) because his engagement was higher in the third component than in the first component for one of six sessions in both sequences (RIRD and NI). In addition, "Results show that Emmett's vocal stereotypy (lower panel) was highest in the second component for one of six sessions in the NI sequence and four of six sessions in the RIRD sequence…vocal stereotypy was lowest in the second component for three of six NI sessions and for zero of six RIRD sessions" (Pastrana et al., 2013, p. 602). Taken together, results of the within-sequence analysis suggest that RIRD temporarily increased Emmett's immediate engagement in nontargeted vocal stereotypy but did not increase his subsequent engagement in either the targeted or nontargeted stereotypy. Based on the results from the between- and within-sequence analysis, RIRD may be an appropriate intervention for Emmett's stereotypy.

A variation of this approach is using a two-component multiple schedule in which stereotypy is measured only during and after the intervention (e.g., Watkins & Rapp, 2014). In these situations, the analysis remains similar with the exception that it is not possible to conduct a within-sequence analysis because the pre-intervention component is omitted. If the data paths for the first and second components are either (a) undifferentiated or (b) differentiated such that the intervention data path is lower than the baseline data path, the practitioner can move

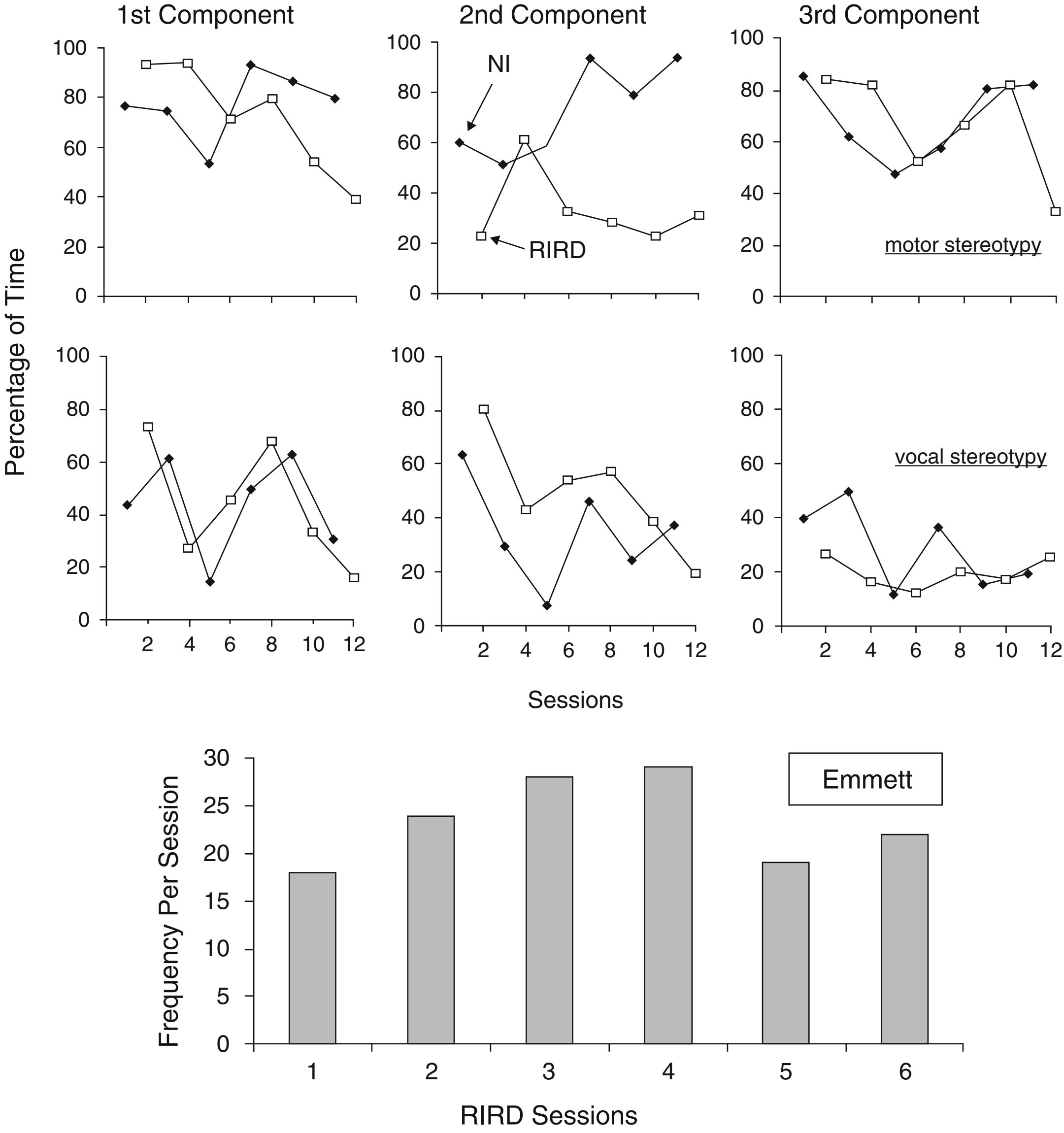

Fig. 28.7 Percentage of time Emmett engaged in motor stereotypy (*upper three panels*) and vocal stereotypy (*center three panels*) during the first, second, and third components of the no-interaction (NI) and response interruption and redirection (RIRD) sequences. Number of times we implemented RIRD across sessions during the second component of the RIRD sequence (*lower panel*). Reprinted from Pastrana, S.; J, Rapp, J. T.; and Frewing, T. M. (2013). Immediate and subsequent effects of response interruption and redirection on targeted and untargeted forms of stereotypy. *Behavior Modification, 37*, 591–610. doi:10.1177/0145445513485751

on to the implementation of the intervention on a regular basis. The final step involves the implementation of the intervention on a regular basis by staff or caregivers in the person's environment. Stereotypy should continue to be measured and monitored on a regular, but less frequent (e.g., weekly, biweekly), basis. If differential reinforcement is being implemented, the schedule should be gradually faded until it becomes realistic to implement without disruption to the routine of the individual and others in his or her daily setting.

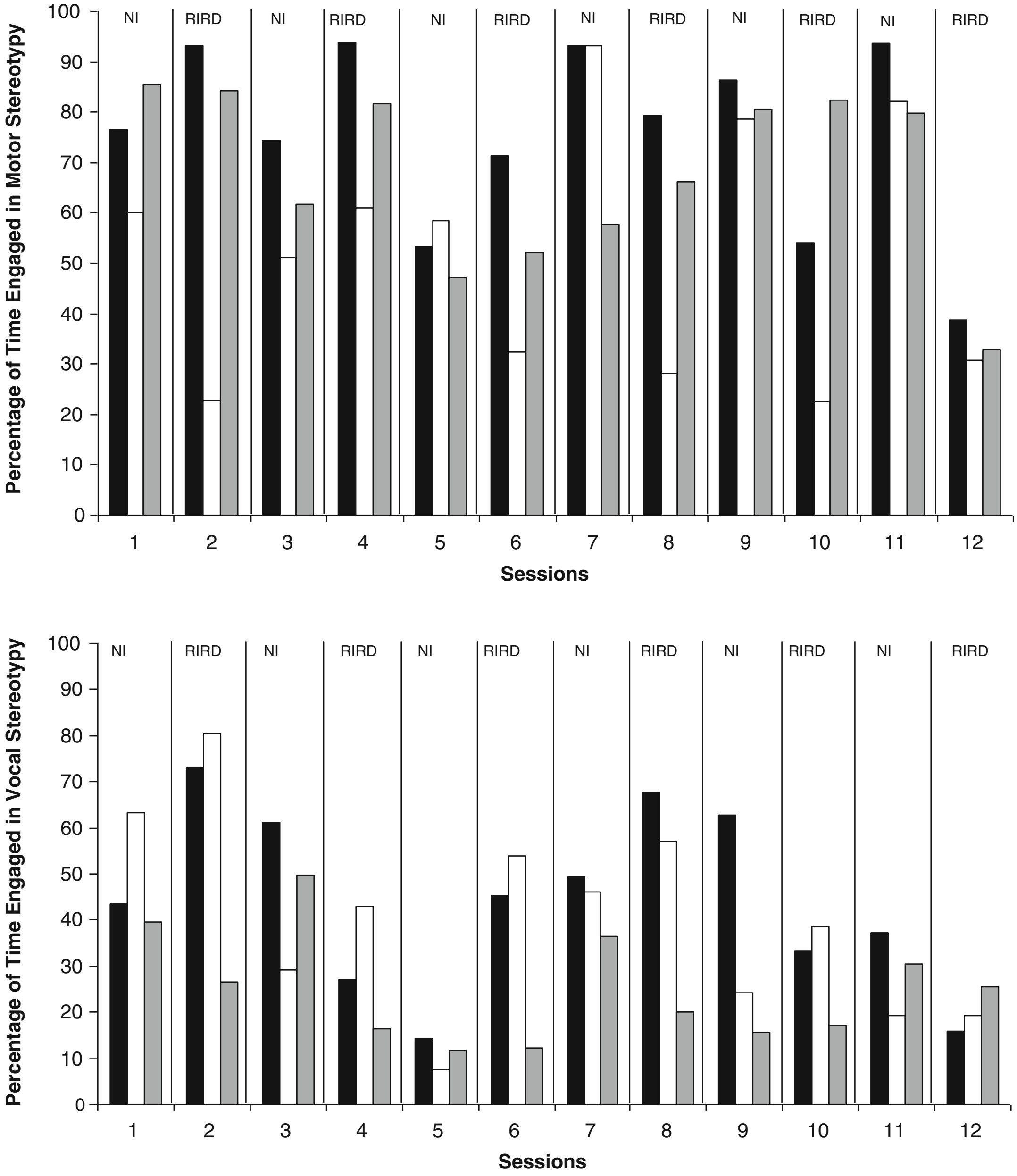

Fig. 28.8 Within-sequence analysis showing the percentage of time Emmett engaged in motor stereotypy (*upper panel*) and vocal stereotypy (*lower panel*) across the first, second, and third components of no-interaction (NI) and response interruption and redirection (RIRD) sequences. Reprinted from Pastrana, S., J; Rapp, J. T.; and Frewing, T. M. (2013). Immediate and subsequent effects of response interruption and redirection on targeted and untargeted forms of stereotypy. *Behavior Modification, 37*, 591–610. doi:10.1177/0145445513485751

Conclusions

Although this chapter outlines several empirically supported behavioral interventions, as well as a recent methodology for evaluating the immediate and subsequent effects of those interventions, treatment for motor and vocal stereotypy displayed by individuals with intellectual disabilities should continue to evolve. For example, future studies should evaluate the effects of specific combinations of antecedent and consequence interventions on immediate and subsequent engagement in targeted and nontargeted forms of stereotypy.

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Inappropriate Sexual Behavior and Sexual Offending

29

William R. Lindsay

Introduction

Since the inception of services for people with intellectual and developmental disabilities (IDD), two theoretical and practical positions have dominated views and provision for those who exhibit inappropriate sexual behavior. These two perspectives lead to a number of day-to-day difficulties and may cause arguments among staff members. The two perspectives cut across all aspects of sexuality in this client group and influence every level of service provision including sex education, the support of relationships including sexual relationships, and extending to ways in which we deal with inappropriate sexual behavior and sexual offending. They can be caricatured with the first being typified by the view that people with IDD are so naive that they cannot be considered competent in a sexual relationship and they cannot be held responsible if they commit inappropriate sexual behavior (ISB). This position was commonly seen when services were introducing sex education for people with IDD during the 1980s. Staff would comment that those individuals never thought about sexual relationships and we were just introducing a cause for discontentment or "putting ideas into their heads." This remains a significant perception for many staffs working in the field and has representation in the major theoretical position for sex offenders with IDD.

The work of Hingsburger, Griffiths, and Quinsey (1991), while never overlooking the importance of true deviant sexuality, does take into account lack of appropriate sexual experiences in the development of ISB. This theoretical position considers that the reason for ISB in the client group may be inadequate comprehension of the laws of society, inadequate understanding that such behavior is wrong, insufficient social learning of appropriate behavior, poor understanding of the nature of relationships, and little developmental experience of how to gain an interpersonal, romantic, or sexual relationship. Because of this lack of understanding, men with IDD may behave in a way that is inappropriate, but it is not because of deviance. Rather, it is due to the fact that they lack understanding of appropriate sexual behavior and the way in which people build relationships.

The second view is considerably more condemning of people with IDD and considers that there is a link between intellectual disability and crime, and that when people with IDD commit crimes, there is a higher rate of sexual offending. Terman (1911), one of the pioneers of psychometric testing, wrote that "There is no investigator who denies the fearful role of mental

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deficiency in the production of vice, crime and delinquency … not all criminals are feeble minded, but all feeble minded are at least potential criminals" (p. 11). With the influence of Mendelian theories of inheritance, advances in mental testing, and concerns about increasing numbers of people with IDD, the causal link between intellectual disability and crime seemed more pronounced. In a review of the available scientific studies, MacMurphy (1916) concluded "Mental defectives with little sense of decency, no control of their passions, with no appreciation of the sacredness of the person and the higher reference of life, become a center of evil in the community, and inevitably, lower the moral tone … perverts and venereal diseased are overwhelmingly mental defective, as in public drunkenness and shoplifting and the picking of pockets are acts of the feeble minded and one of the large proportions shown by statistics" (quoted in Scheerenberger, 1983, p. 153). Therefore, IDD was seen as a significant cause of vice and sexual offending through the turn from the nineteenth to the twentieth centuries.

Hingsburger and colleagues (Hingsburger et al., 2011; Stevenson, Lynn, Miller, & Hingsburger, 2011) have written about another choice that is required by commissioners and providers of services. This is an important choice of whether to provide treatment for sex offenders with IDD or simply to incarcerate them. The implication of treating an individual is that at some time in the future he is likely to develop skills and abilities to regulate his own sexuality so that it is no longer a requirement to provide supervision. This requires trust that he will not perpetrate another incident that will result in another victim of sexual abuse. It is more reassuring for all of the staffs involved to maintain strong supervision regimes for the whole of the person's life. Stevenson et al. (2011) wrote "treatment is the more ethical but more frightening choice" (p. 63) and went on to point out that close supervision represents "faux" reassurance. They noted that even in regimes that provide one-to-one staffing for all residents, staffs are human and cannot maintain consistency of supervision over weeks and months and years. There will be numerous occasions when even the most vigilant and conscientious of staffs are tired or distracted and attention wanders. There are also likely to be personality differences among staffs that reflect the two basic positions noted above with some staffs feeling that all the intrusive supervision is both inappropriate and unethical. Consistency is very difficult if not impossible to achieve. Therefore, they concluded that treatment is likely to be the safest as well as the most ethical option in the longer term.

Prevalence and Epidemiology

Prevalence. As has already been mentioned, sexual offending has historically been associated with offenders with IDD. Academics writing at the end of the nineteenth century and beginning of the twentieth century set the philosophical and social context for linking sex offending and IDD. Some early hospital studies continued to establish this link. For example, in their classic study of secure hospitals in England, Walker and McCabe (1973) reviewed 331 men with IDD who had committed offences and had been detained under hospital orders to secure provision in England and Wales. They found high rates of fire raising (15 %) and sexual offences (28 %) when compared with other groups in their secure hospital sample. Therefore, with over one-quarter of individuals having been detained for the commission of sexual offences, it would seem that there may well be a link between ISB (and indeed fire raising) and men with IDD. A more recent study has pointed out a serious methodological flaw in drawing conclusions from a study that focuses on one particular setting. Hogue et al. (2006) reviewed a number of characteristics of offenders with IDD across community, medium/low-secure and high-secure settings. They found that rates of arson as the index offence depended on the setting with low rates in the community setting (2.9 %) and higher rates in the medium/low-secure setting (21.4 %). This is a clear example of the fact that the setting in which the data are collected is very likely to influence the results and subsequent conclusions about the population.

One particular study has been very influential in consideration of offenders with mental disorder in general and offenders with IDD in particular. Hodgins (1992) used a census cohort of 15,117 people born in Stockholm in 1953 and still living there in 1963. Those still living in Sweden at the 30-year follow-up period in 1983 were included in the analysis. Intellectual disability was defined as "those who were placed in special classes for intellectually deficient children in high school and were never admitted to a psychiatric ward" (p. 478). She found that men with IDD were overrepresented threefold for any offence and fivefold for violent offences when compared with non-disabled offenders. Woman offenders with IDD were overrepresented 25-fold for violent offences. Around 50 % of the men with IDD had been convicted of an offence and the average number of convictions was 10.

Lindsay and Dernevick (2013) challenged this conclusion, noting that in their clinical experience, none of their colleagues expressed concern that half of the men in their clinics had committed an average of ten crimes. In fact, criminality was not overly mentioned in intellectual disability services. They reanalyzed the data investigating who was likely to have been in the sample of Swedish school children with IDD during the 1960s. After detailed analysis of the Swedish school system at the time and drawing on the writing of both educationalists and those working in the IDD services, they concluded that "the people with intellectual disability in the Hodgins (1992) study were not the generality of people with such difficulties but rather represented a sample biased towards inclusion of those with conduct disorder or similar behavioral problems as children or adolescents as well as their intellectual problems" (p. 155).

In relation to offenders with IDD in various forensic settings, there have been a reasonable number of studies investigating prevalence. Several recent studies suggest that continuing methodological differences still produce varying results. In a variety of settings, differences in prevalence have been reported: probation services (Mason & Murphy, 2002; prevalence—4.8 %), pretrial assessment (Vinkers, 2013; prevalence—4.4 %), appearances at court (Vanny, Levy, Greenberg, & Hayes, 2009; prevalence—10 %), and prison settings (Murphy, Harrold, Carey, & Mulrooney, 2000, prevalence—28.8 %).

Two studies conducted in prison settings illustrate some of the problems. Crocker, Cote, Toupin, and St-Onge (2007) attempted to assess 749 offenders in a pretrial holding center in Montreal. For a number of reasons including refusal to participate, administrative difficulties, and technical problems, they were only able to assess 281 participants with three subscales of a standardized mental ability scale. They reported that 18.9 % were in the probable IDD range with a further 29.9 % in the borderline range. On the other hand, in a study of prisoners in Victoria, Australia, Holland and Persson (2011) found a prevalence rate of less than 1.3 % using the Wechsler Adult Intelligence Scale. In the latter study, all prisoners were assessed routinely by trained forensic psychologists while, in the former study, only around one-third of potential participants were included in the study. In the former study, three subscales of an intelligence test were used while, in the latter, a full WAIS was used for all participants. It is difficult to reconcile these two pieces of work, but it is likely that the difference in assessment methods, comprehensiveness of the sample, and differences in legal systems were all significant contributors to the disparity and results.

There is no doubt that there are a significant number of individuals with IDD in the criminal justice system. In a meta-analysis of studies on individuals with IDD in the prison system, Fazel, Xenitidis, and Powell (2008) noted the methodological differences in the definition of IDD and methods of assessment, and concluded that the evidence suggested that intellectual disability was not overrepresented in prison system, with a prevalence of between 0.5 and 1.5 %. Given the difficulties with different methodological approaches and differences between studies that include problems of definition of the population of criminals with IDD, differences in the study setting, differences in the assessment method for establishing IDD, and difficulties in defining the problem behavior (inappropriate sexual behavior or sexual offending), it is clear that one cannot draw firm conclusions on epidemiology or prevalence. There seems no recent persuasive evidence to alter the conclusion drawn by Lindsay (2002) that there is no strong evidence to support either an increase or a decrease in prevalence for sexual offending in men with IDD. What is certainly clear is that all studies find a significant proportion of individuals with IDD at various points in the criminal justice system.

Epidemiology. There is a great deal of speculation, but little definitive knowledge on the causes of sexual offending in men with IDD. Caparulo (1991), Day (1994), and Langevin and Pope (1993) have listed a number of features in the history of sexual offenders with IDD including behavioral disturbance in school, poor ability to form relationships, poor impulse control, a history of family psychopathology, abuse in childhood, and a history of personal psychopathology. This suggests that these might be epidemiological factors in the development of sex offending, but even a cursory review of them will indicate that they could be factors for any problem in people with IDD including violent offending, personality disorder, self-harm, and a range of other difficulties. Empirical studies do shed some light on epidemiology.

Sexual abuse in childhood has been implicated frequently in the development of sexual offenders (Jespersen, Lalumiere, & Seto, 2009). Lindsay, Steptoe, and Haut (2012) compared 156 sexual offenders with 126 nonsexual offenders and found that 33 % of the sexual offenders and 18 % of the nonsexual offenders had experienced sexual abuse in childhood. This difference was significant suggesting a possible developmental factor, but two-thirds of the sexual offenders did not report abuse in their childhood. These authors reviewed childhood abuse over a period of 1 year and felt that they had fairly robust disclosure of sexual abuse in their cohorts. Therefore, the two-thirds who did not report abuse were unlikely to have had it in their developmental history and it could not contribute to etiology. In addition, 18 % of the men with no history of sexual offending did report sexual abuse in childhood again suggesting that there is not a strong relationship between sexual abuse in childhood and sexual offending in adulthood.

In another review, this time through case files, Lindsay and Carson et al. (2012) compared 131 sexual offenders with IDD against 346 nonsexual offenders with IDD. There was no difference between the groups on history of sexual abuse in childhood with the sexual offenders recording 13 % and the nonsexual offenders 9.8 %. Therefore, while sexual abuse might seem a candidate epidemiological factor, it is not strong empirically. In a regression study predicting the level of security to which sex offenders with IDD might be referred (Carson et al., 2014), sexual abuse did not emerge as a significant predictive factor. In fact, although not strong predictors, history of substance abuse and current aggression contributed more to predicting higher security than sexual abuse in childhood. In the previously reported study comparing sexual offenders and nonsexual offenders, all with IDD (Lindsay, Carson et al., 2012), the most interesting finding was how few differences there were between the groups in developmental and epidemiological factors and yet the patterns of offending were quite distinct. Sex offenders had significantly lower rates of aggression and substance misuse and significantly higher rates of previous sexual offences. While the latter finding might seem axiomatic, Glaser and Deane (1999) found no differences in previous sexual offending when they compared men with IDD detained for violent offences with those detained for sexual offences.

There has also been a considerable amount of work done on factors influencing sexual offending pathways in men with IDD. This research has included social, psychological, and biological variables extensively. Green, Gray, and Willner (2002) studied court appearances and convictions in sex offenders with IDD. They found that those who had committed offences against children were significantly more likely to be reported to the criminal justice system than men who had committed sexual offences against adults. They felt that any group of offenders with IDD would be likely to have an overrepresentation of men who had committed sexual offences against children as a result of this ascertainment bias.

Coming to very different conclusions based more on a biological underpinning, Blanchard et al. (2007) have also found that sex offenders with lower intellectual functioning are more likely to commit offences against young children and male children although the proportion of variance in their studies was not high. Blanchard et al. (2007) compared referrals from a number of different sources in order to test the hypothesis that ascertainment bias would increase the number of offenders with IDD who had assaulted children. They found little difference between the referral sources. What can be said is that there does seem to be a small increase in offenders against children in forensic IDD groups when compared to control groups.

In a reanalysis of data on 5647 sexual offenders and 16,222 nonsexual offenders, Cantor, Blanchard, Robichaud, and Christensen (2005) found a similar effect, but again average IQ for offenders against children while significantly lower than offenders against adults remained in the low average range. Rice, Harris, Lang, and Chaplin (2008) compared 69 sex offenders with IDD and 69 control participants without IDD. They found that the offenders with IDD had a higher rate of pedophilic interest than the control group, but were no more likely than the comparison offenders to exhibit preferences for extremely coercive sex with children or to exhibit deviant adult activity preferences, nor were they more likely to reoffend. This study drew similar conclusions to the previous studies (Blanchard et al., 2007; Cantor et al., 2005) that sex offenders with IDD may suffer from organic perturbation that predisposes certain individuals to aberrant sexual preferences. However, it is subject to the same possible ascertainment bias noted by Green et al. (2002) in that individuals with IDD who offend against children may be prone to a more serious judicial pathway compared to those who offend against adults. This research also begs the question that if organic perturbation is a cause, why does it not feature in all men with such damage.

Langevan and Curnoe (2008) studied 2286 male sex offenders referred to a university hospital and private clinic over a period of 39 years. Across this population, there was no increase in the level of IDD (2.4 %) or borderline intelligence (7.2 %) compared to the proportion expected in the general population. There were also no differences in offence type between those with and without IDD. Summarizing this research, Blanchard et al. (2007) noted the small effect sizes and wrote “the statistical relations of IQ … to pedophilia, although valuable as potential clues to the etiology of this disorder, are far too small to permit these variables to be used as diagnostic indicators” (p. 308). With the population of offenders with IDD, this poses a further problem. The population, almost by definition, is likely to have organic perturbation to some degree. Why then should the organic perturbation be invoked as an explanation for sexual offending when, presumably, all men with IDD are likely to suffer from similar global or specific perturbation? Why should some men commit sexual offences and others do not when organic disturbance will be prevalent across both groups?

Lindsay et al. (2013) conducted a 20-year follow-up of a forensic IDD service incorporating 156 sexual offenders, 126 nonsexual offenders, and 27 women. Although this was a clinical follow-up study, the findings were similar to those of Lindsay and Carson et al. (2012) case review study; sex offenders had significantly lower rates of aggression, substance misuse, and anxiety difficulties. The patterns of offending were also quite distinct with sex offenders showing little violent offending and violent offenders committing almost no sexual offending.

Several authors (Cohen et al., 2002; Nussbaum et al., 2002) have conducted studies in which it appeared that sex offenders were less impulsive than other types of offenders when these personality traits were measured systematically. Both Parry and Lindsay (2003) and Snoyman and Aicken (2011) have found that sex offenders with IDD have lower rates of impulsivity than other groups of offenders with IDD. Although these findings may appear counterintuitive, professionals who work in the field of offenders with IDD have been unsurprised by this result. When they work with sex offenders and other types of offenders, they have noticed that the sex offender group is quieter, less demonstrative, and more self-contained. It may be that we are overly influenced by the very-high-risk individuals who are extremely disinhibited and take up a great deal of staff time, attention, and concern. Poor impulse control is a clearer concept than impulsivity. Carers may remark "he is so impulsive, as soon as you turn your back he will do something." The important point is that the person employed some self-restraint until staffs reduce their level of vigilance. Here they seem to be referring to a lack of longer term self-restraint and the willingness, to engage in something that is viewed as impulsive behavior, to take advantage of any opportunity even if the short-term consequences are likely to be negative. Therefore, poor impulse control and opportunism may provide a setting that allows sex offending and reoffending.

The fact that some men hold attitudes condoning or justifying sexual offences has been invoked as an important etiological factor in sexual offending by several workers in the field over the last 20 years (e.g., Ward, Johnston, & Marshall, 1998). There is some evidence that sex offenders with IDD endorsed a significantly greater number of attitudes that can be considered supportive of or consistent with the perpetration of sexual offences. Lindsay, Whitefield, and Carson (2007) developed the Questionnaire on Attitudes Consistent with Sexual Offences (QACSO) which has a 63-item questionnaire specifically designed for use with sex offenders with IDD. This protocol is designed to measure cognitive distortions commonly expressed by sexual offenders across eight domains: rape and attitudes to women, voyeurism, exhibitionism, stalking, dating abuse, homosexual assault, and offences against children. The QACSO has been standardized on sex offenders with IDD, nonsexual offenders with IDD, non-offenders with IDD, and mainstream men. In the original standardization, sex offenders with IDD endorsed a significantly higher number of cognitive distortions across all subscales in the QACSO when compared to all other groups. Indeed, the average scores for sex offenders with IDD on almost all scales were at least one standard deviation higher than the average scores for the other groups indicating significant differences in the cognitive framework held by sex offenders with IDD when compared to others. This suggests that the individual's attitudes towards potential victims are likely to play a significant role in both the perpetration of an offence and the post-offence justification in these individuals.

In summary, there is not yet a strong body of research indicating that there are factors associated with sexual offending in men with IDD. Research investigating aetiological factors has produced only weak associations between childhood factors, including sexual abuse and childhood behavioral problems, and sexual offending in adulthood. There is more robust evidence regarding differences between adult sexual offenders with IDD and other types of offenders with IDD. Adult sexual offenders have been assessed as being less impulsive, less aggressive, and less anxious than other types of offenders. They have also been found to abuse substances to a lesser extent. The evidence on whether or not sexual offending is featured more frequently in men with IDD remains unclear.

Evidence Base for Treatments

In analyzing the quality of studies on the treatment of offending behavior, reviews have for some time employed the evaluation of evidence supporting particular therapeutic techniques and their use with particular types of offenders. The work has been subsumed under the category "What Works" in the treatment and management of offenders to reduce crime. Sherman et al. (1997) developed a technique for reviewing the evidence in response to a request by the US Congress for an evaluation of the effectiveness of annual grants from the Department of Justice of more than $3 billion. Since then, there has been an accumulation of "What Works" literature in mainstream criminal research.

The Sherman et al. (1997) system considered five levels relating to the quality of the evidence supporting any given intervention in the field of criminal behavior. Level I studies indicated some correlation between the program and measures of recidivism. Interventions would lack a comparison group. At this level, the evidence was not considered sufficiently robust to help assess effectiveness. Level II studies indicated some association between the program and recidivism. However, given the research design, alternative explanations could not be ruled out. Level III studies compared two or more groups, one with the program and one without the program. The study design would allow a reasonable similarity between the two groups. Level IV studies included comparisons between a program group and one or more control groups controlling for extraneous factors. Level V studies included randomized assignment and analysis of comparable program and comparison groups. This level of evidence would also control for attrition, a common problem in offender studies.

The literature on evidence-based corrections has provided guidelines on "What Works," "What Does Not Work," and "What Is Promising." A number of studies supported the findings that effective programs are structured and focused, use multiple treatment components, focus on developing skills including behavioral and cognitive skills, focus on clearly defined overt behavior as opposed to nondirective counseling focusing on insight, self-esteem, or disclosure (e.g., Landenberger & Lipsey, 2005). There should be meaningful contact between the treatment personnel and the participant. Crucially, they should focus on characteristics of the offenders that are associated with criminal activities and can be changed (criminogenic needs: Andrews & Bonta, 1994, 2010).

There have been a number of other innovations to develop evaluation systems in psychological therapy, including the American Psychological Association (APA) and their system for developing empirically supported psychological interventions. Chambless and colleagues (Chambless et al., 1998; Chambless & Ollendick, 2001) have described the way in which treatment for specific diagnostic groups is split into well-established treatments, possibly efficacious treatments, and experimental treatments. Well-established treatments are characterized as those that have at least two good between-group design experiments that would usually be randomized controlled trials (RCTs). These controlled trials should demonstrate the treatment's superiority to psychotherapy placebo or medication or to some other treatment. Alternatively, they may demonstrate that the treatment is of equivalent efficacy to an established treatment. A second way of demonstrating that the treatment has well-established efficacy is through a series of single-case design experiments. These single-case experiments should show good experimental design and may compare the intervention to another treatment. They should also be conducted in a standardized manner with a treatment manual, the characteristics of the sample should be specified, and treatment effects should have been demonstrated by independent research teams.

Probably efficacious treatments have a lower standard of verification with two experiments that should show the treatment to be superior to a waiting list control. Alternatively, one RCT that demonstrates the treatment is superior to psychotherapy placebo or pill placebo, or a smaller series of single-case design experiments meeting well-established treatment criteria would be sufficient. Experimental treatments are those which are not yet tested and do not meet the criteria for either well-established treatments or probably efficacious treatments.

These three categories have been used to establish clinical research support for a number of treatments for specific diagnoses, e.g., exposure treatment for specific phobias, stress inoculation for stress disorder, and systematic desensitization for specific phobia. The system was not without its difficulties and critics. One particular criticism is that it is artificial to force diagnostic categories into such discrete divisions. In addition, critics have suggested that it is similarly artificial to categorize psychological treatments so tightly. This latter point is particularly relevant given one of the criteria for meeting both well-established and probably efficacious categorization is that the treatment should be based on a manual or an equivalent clear description. This is often an artificial distinction in that therapists can be flexible in the way they employ the various tenets of treatment. It is, however, the case that many programs for offence-related issues are manualized (e.g., sex offender treatment programs, reasoning and rehabilitation).

Two other criticisms are particularly important from the point of view of this chapter. The APA task force required that reliable and valid methods for determining outcome were employed. A review of the outcome measures suggests that they were largely self-report assessments such as self-reported anxiety, self-reported depression, and self-reported confidence and self-esteem. With work on offenders, self-reported measures can only be considered proximal and the only evidence of interest from a social policy point of view is whether or not another offence has been committed. From a societal stance, it is of little value to know that an offender reports low levels of anger if he or she continues to commit an equivalent number of violent offences following treatment. Similarly, it is of little value if an offender reports low levels of cognitions related to sexual offending if he or she continues to commit offences at an equivalent rate. Therefore, the most valid outcome measure for offender treatment is the number of future incidents in comparison to the number of incidents prior to the commencement of treatment. It is an exacting standard, but it is the case.

Another relevant criticism has been the establishment of conditions during periods of follow-up. For the APA task force, the follow-up period should be as uncontaminated by other variables as possible. This can be extremely difficult in intellectual disability services when a number of agencies may be involved with individuals in order to help them integrate with society. Following treatment, a housing agency may be involved to help establish residency, or criminal justice agencies may continue to monitor the individual as part of their conditions from court disposal. As we shall see, some of the evaluations of sex offender treatments have been made within the context of forensic intellectual disability services that apply a holistic approach to individuals including psychiatric review, or occupational placement, nursing interventions, community management, criminal justice involvement, and even 24-h supervision as well as the psychological therapy being evaluated. This is clearly important for the evaluation of the particular therapy, but is probably less important from a social policy point of view. If this amalgamation of intervention produces a lowering in the rate of offending, then, if it can be replicated, it is successful.

There are further crucial limitations in applying the APA criteria to offenders with IDD. The Chambless et al. (1998) criteria deemphasize the importance of long-term follow-up focusing, rather, on the efficacy of treatment compared to relevant control conditions. Long-term follow-up is crucial in work with offenders to the extent that a relapse after 15 years has been considered a failure. Cann, Falshaw, and Friendship (2004) conducted a 21-year follow-up study of 419 sexual offenders discharged from prisons in England and Wales. They found that some individuals reoffended 15 years after they had been discharged from custody. Their conclusion, far from indicating the success of treatment with no "relapse" up to 15 years after treatment, was quite to the contrary. They concluded that these individuals were "at risk" in the community for 15 years prior to reoffending. Therefore, treatment with sex offenders is considered with a different yardstick when compared to work with other groups. Any "relapse" no matter how long after treatment it occurs is likely to be considered a treatment failure. Therefore, a behavioral treatment that has a short follow-up, but has been shown to be consistently effective over three or four individual carefully controlled case studies, might be considered as a contribution towards effective treatment in other areas, but in sex offender treatment, the short follow-up is a huge limitation.

Behavioral approaches. Until relatively recently, sexual reorientation and behavioral management approaches have been the most common psychological treatments for the management of sexual offending (Plaud, Plaud, Colstoe, & Orvedal, 2000). Through the 1970s, a number of clinicians presented a series of case studies using behavioral methods to reduce sexual arousal or reorientate sexual preference in men with IDD. This followed mainstream work where around 78 % of studies at the time employed aversion therapy in an attempt to change deviant sexual preference, especially in those interventions for offenders against children (Kelly, 1982).

In one of the few examples in IDD, Rosenthal (1973) described the treatment of a 21-year-old man with mild IDD who had committed offences against children. He was referred for aversion therapy following his third arrest. The painful nature of aversion therapy was explained to the client who subsequently discussed it with his lawyer and probation officer. The description of treatment is disturbing with electric shocks being administered after the presentation of images of girls. The duration and intensity of the shocks increased over the treatment period and did result in rapid increases in response latencies until the client spontaneously reported an inability to obtain deviant sexual images or sexual policies while being presented with the stimulus items. Periodic follow-ups over 32 months suggested that treatment effects were maintained with the absence of pedophilic images and sexual arousal to children. While this case study suggested that it is indeed possible to suppress pedophilic images and sexual arousal to them, the disturbing nature of the treatment would, rightly, discourage any consideration in contemporary program.

Luiselli, Helfen, Pemberton, and Reisman (1977) treated persistent masturbation in an 8-year-old male with IDD. They found that social praise, positive feedback, and token reinforcement for desisting failed to reduce the frequency and they added an overcorrection procedure consisting of arm movements. Masturbation was completely suppressed after 9 days and this was maintained at a 12-month follow-up. Several other studies (Cook, Altman, Shaw, & Blaylock, 1978; Hingsburger et al., 1991) have demonstrated the effectiveness of behavioral approaches using case illustrations. However, the case studies have not been conducted to a standard that would be considered acceptable according to the criteria suggested by Chambless and Ollendick (2001). In addition, the goals of such treatments were essentially restrictive rather than rehabilitative in contrast to subsequent behavioral approaches.

Fyffe et al. (2004) used functional communications training and extinction to treat inappropriate sexual behavior in a 9-year-old boy. The authors wrote that they followed the procedure of Iwata, Dorsey, Slifer, Bauman, and Richman (1994) suggesting that 40 sessions were conducted at a rate of eight per day and resulted in a 90 % reduction in ISB. There was no follow-up assessment. More recently, Dozier, Iwata, and Warsdell (2011) treated a 39-year-old man with a fetish for the feet of women wearing sandals. A functional analysis confirmed that a combination of stimuli (a woman wearing sandals) were required for the ISB response. Response interruption and time-out proved to be an effective treatment for eliminating the behavior. Treatment sessions were conducted 3–5 times per day and the 60-session program could not have lasted more than 4 weeks. Treatment generalized to other women wearing sandals and follow-up was measured at 6 months, with no reported incidents of ISB.

The first significant and influential development in the field of sex offenders with IDD was a comprehensive treatment program aimed at improving social functioning, improving sexual awareness and sexual knowledge, extending relationships, improving coping skills, and reducing inappropriate sexuality (Griffiths, Quinsey, & Hingsburger, 1989). Griffiths et al. took as a starting point the fact that individuals may have restricted social and sexual opportunities, which caused them to develop inappropriate choices. They also noted that previous treatments for individuals with developmental delay had been restrictive rather than rehabilitative. They developed a multifactorial treatment plan designed to increase personal and social skills as well as address issues of sexuality. They also included protective relapse prevention procedures and methods. Their book includes a wealth of information on approaches to treatment and constitutes a detailed treatment manual. In a review of 30 case studies, they recorded no reoffending with a number of successful cases to illustrate their methods.

Around the same time, Haaven, Little, and Petre-Miller (1990) described a similarly wide-ranging approach promoting problem solving, social, and self-regulation skills. Again, they reported no reoffending, but in this case, treatment was conducted in a secure setting and clients had little opportunity to engage in inappropriate sexual behavior.

This last point highlights a significant problem in the evaluation of sex offender treatment for men with ID. In some studies, participants have been monitored 24 h a day and have little opportunity to reoffend. For example, Craig, Stringer, and Moss (2006) reported a treatment study on six sex offenders with IDD. Following a 7-month program incorporating sex education, addressing cognitive distortions, and promoting relapse prevention, they found no significant improvements on proximal measures including the assessment of sexual knowledge. However, they also reported no further incidents of sexual offending during a 12-month follow-up. In the description of individual participants, they noted that all six received 24-h supervision and so, presumably, had little or no opportunity to reoffend.

From the point of view of the considerations noted at the beginning of this chapter this is extremely important. In some studies it may be that self-reports, carer reports, and other proximal measures demonstrate change. However, in the absence of reasonable recordings of behavior in uncontrolled settings, few conclusions can be drawn that would be relevant for social policy. Again, we must note that the criteria outlined by Chambless and Ollendick (2001) must be augmented for this client group.

The most striking aspect of treatment for ISB using behavioral approaches is that after 50 years of extremely effective developments in applied behavior analysis, there appears to be so little research in the development of effective treatments for this particular class of problems. Given the importance of this group of behaviors in terms of social validity, there seems to be little attention paid to it. One explanation might be that a large number of studies have been conducted, but very few have been successful, thus resulting in few publishable reports. Another explanation (and this seems unlikely) is that ISB is more readily tolerated in services. The study by Dozier et al. (2011) was extremely effective and did eliminate ISB, but it was only on one individual and the follow-up was for 6 months only. As I have indicated, inappropriate sexual behavior is evaluated by society using a different yardstick and any recurrence up to 15 years after the intervention has been seen as a treatment failure.

Fyffe et al. (2004) reported reductions of over 90 % in a study on one participant. In terms of social validity, it is hugely unfortunate that this would be considered a treatment failure because inappropriate sexual behavior was still evident. The best examples of the successful use of behavioral approaches for ISB/sexual offending are those of Griffiths et al. (1989) and Haaven et al. (1990) that, although far poorer in terms of experimental integrity, had the advantage of large sample sizes, “real-life” settings, and no reoffending. However, these latter reports included a complex combination of treatment approaches with high levels of escorting and observation of participants and it is difficult to partial out the effects of each treatment component. As I have also mentioned, in terms of social validity or the evaluation by society, this does not matter because the data of interest are whether or not the person has reoffended sexually over years of follow-up.

Case studies using cognitive behavior therapy. In their meta-analysis on the effectiveness of sex offender treatment in mainstream services, Hanson et al. (2002) reported that “current treatments (any treatment currently offered and cognitive behavioral treatment is offered since 1980) were associated with significant reductions in both sexual and general recidivism whereas the older treatments were not” (p. 187). “Older treatments” were predominantly behavioral, employing techniques such as aversion therapy, reorientation of sexual preference through masturbatory reconditioning, and teaching social skills. Current treatments generally employed CBT methods in addressing sexual offending and inappropriate sexual behavior.

In a second major meta-analysis some 10 years later, Långström et al. (2013) reviewed the available controlled trials on sex offender treatment for sexual abusers of children. They found only five controlled trials that fulfilled their scientific criteria and concluded that there was insufficient evidence supporting the benefit of both psychological treatment and pharmacotherapy. They also reported on a single trial on the effectiveness of treatment for children with sexual behavior problems and again, although this trial was of a high quality, concluded that there was insufficient evidence for effectiveness. In fact, Långström et al. (2013) noted the good quality of the study on children who abuse other children. This study (Carpentier, Silovsky, & Chaffin, 2006) compared the effects of treatment for 135 children aged 5–12 randomly allocated to cognitive behavior therapy and play therapy conditions. Treatment lasted only 12 sessions and participants were followed up for 10 years. The study found that those receiving CBT had a significantly lower recidivism rate than those receiving play therapy (2 % vs. 10 % reoffending, respectively). These authors concluded that "after receiving short-term CBT, children's long-term risk for sex offence arrest was … so low that they would be difficult to lower further." However, because it was a single study, Långström et al. (2013) felt that they could not draw firm conclusions about effectiveness.

By the time of the Hanson et al. (2002) review, CBT for sex offenders had developed to a sophisticated degree (Marshall, Anderson, & Fernandez, 1999). This was not the case for sex offenders with IDD where the first report on a cognitive approach was that of O'Conner (1996). She developed a problem-solving intervention for 13 adult male sex offenders. This involved consideration of a range of risky situations in which offenders had to develop safe solutions for both themselves and the potential victims. She reported positive results from the intervention, with most participants having achieved increased community access. However, as noted above, the extent to which this increased community access was supervised is not mentioned in the report.

In a series of case studies, Lindsay, Marshall, Neilson, Quinn, and Smith (1998), Lindsay, Neilson, Morrison, and Smith (1998), Lindsay, Olley, Jack, Morrison, and Smith (1998), and Lindsay, Olley, Baillie, and Smith (1999) reported on the treatment of men with ID who had offended against children, exhibitionists, and stalkers. Treatment was developed on the basis of cognitive interventions in which various forms of denial and mitigation of the offence were challenged over periods of up to 3 years. There were three fairly distinctive aspects of these reports. Firstly, after each session, client attitudes were assessed in relation to their specific offence, e.g., exhibitionism, sexual assault, or offences against children. They were assessed on an early version of the Questionnaire on Attitudes Consistent with Sexual Offences (QA CSO: Broxholme & Lindsay, 2003). This assessment reviews the extent to which participants endorse a range of cognitive distortions consistent with rape and attitudes to women, exhibitionism, voyeurism, dating abuse, offences against men, stalking, and offences against children. Therefore, it was possible to link the content of each session to the impact on specific cognitive distortions. The second fairly distinctive aspect was that all participants lived in the community and had unsupervised access to their usual community routines such as leisure facilities, occupation, transport, shops, entertainment, and so on. The reports did not, therefore, have the drawback of continued close supervision that has been a problem with so many studies in the field. Where an individual is closely supervised, the validity of proximal and behavioral assessments (i.e., incidents of inappropriate sexual behavior) is completely undermined because the individual is likely to have reduced opportunities to offend. A final distinctive feature was the extent of follow-up period. These authors did not publish any of the outcomes until they had data for at least 4 years following referral. Several participants had follow-ups for up to 7 years.

Through the careful, weekly assessment of cognitive distortions, it became clear that some aspects of cognition were easier to change than others. Those based on factual information such as the age of consent changed much more readily than those based on more entrenched opinions such as the view that victims share some of the responsibility. Indeed, some attitudes did not change at all, such as the view that sexual offences are associated with power to a greater degree than they are with sex. Most participants retained the attitude that the purpose of sexual assault was to gain sexual gratification rather than power over the individual. At the time of writing, despite participants having free access to the community, there was only one case of recidivism among offenders against children and none in the exhibitionist offenders. The incident of recidivism in the child's case was relatively minor and the individual was incorporated once again to treatment. There was, however, a series of more severe recidivism incidents in one of the stalking cases.

In three carefully controlled case studies, Singh et al. (2011) evaluated the use of mindfulness-based procedures to control deviant sexual arousal to children. Using a multiple baseline design they demonstrated the effectiveness of mindful observation of thoughts and meditation over 35–40 weeks in controlling sexual urges when compared to participants' own self-control strategies. This was an unusual intervention study since it impacted directly on deviant sexual arousal and was so carefully controlled showing the effectiveness of the treatment procedures in promoting self-regulation of deviant arousal. The study was a pilot evaluation demonstrating feasibility and the authors did evaluate outcomes for 45–52 weeks, which is a significant follow-up period and better than many studies in the field.

These cases provided some basis for optimism in treatment given that they did not suffer from some of the drawbacks in previous cases such as continued supervision and short follow-ups. Therefore, some of the requirements noted by Chambless and Ollendick (2001) such as relatively unpolluted follow-up periods and a reasonable length of follow-up period were fulfilled. However, apart from the study by Singh et al. (2011), the cases did not contain the requirements of adequate evaluation in that there were no control conditions when individuals received other types of treatment or no treatment at all.

Uncontrolled group interventions. Therapists and researchers have begun to develop and report more systematic evaluations of sex offender treatment with this client group. Rose, Jenkins, O'Conner, Jones, and Felce (2002) reported on 16-week group treatment for five men with IDD who had perpetrated sexual abuse. The group treatment employed self-control procedures, consideration of the effect on victims and identifying emotions within oneself in addition to sex education, appropriate assertiveness, and avoiding situations involving risk. Participants were assessed using the QACSO attitude scale, a measure of locus of control, a sexual behavior, and law scale and victim empathy scale. The only significant difference from baseline to posttreatment was more external locus of control after intervention. They reported no reoffending at 1 year, but the follow-up period was contaminated by the fact that participants were generally escorted and monitored.

Rose, Rose, Hawkins, and Anderson (2012) recently reported a treatment study for 12 individuals who completed a community CBT program. All participants had contact with the criminal justice system for at least one sexual offence and were followed up for 12–16 months after the completion of treatment. Participants showed significant improvements on a range of cognitive assessments including the QACSO, a victim empathy scale, and a measure of locus of control. Only one individual reoffended, despite the fact these individuals lived in family and group homes and had unescorted access to the community. While this study is essentially a series of 12 case reports, it possesses a number of validity strengths including relatively uncontaminated and lengthy follow-up periods.

Craig, Stringer, and Sanders (2012) evaluated a program for 14 sex offenders with IDD living in the community. They completed assessments of sexual knowledge and empathy and used the QACSO. Sessions were conducted weekly for 14 months and they found significant improvements in attitudes (QACSO), victim empathy, and sexual knowledge. They followed up all participants for 6 months and six participants for 12 months. All had access to the community and so were able to commit further incidents. No further incidents of ISB were reported.

It should be noted in relation to these case studies that while follow-up periods are uncontaminated by 24-h supervision and continued staff monitoring, it is still the case that these individuals with IDD are likely to be receiving services from a range of statutory bodies. They may continue to attend occupational or educational placements, and are likely to be visited by community learning disability nurses and social workers. Therefore, if professionals in any of these agencies were to note that the client was having difficulty or were to note any other type of deterioration in attitudes, behavior, or routines, they would be likely to report it to multidisciplinary teams for consideration and possible remedial measures. In this way, the follow-up period may have been contaminated to some extent. It is also the case that any incident was more likely to be reported as opposed to only incidents that come to the notice of the police. However, the outcome measures (whether or not the client has reoffended) remain of crucial social significance and validity.

The evaluation of sex offender treatment through group comparison. One of the difficulties in comparing groups of sex offenders for treatment effectiveness is that referring agencies, such as the courts or criminal justice system, are reluctant to allow any delay of sex offender treatment for reasons of public protection. This means that having a waiting list control condition is very difficult. It certainly means that randomized allocation of participants to experimental and no treatment conditions can be impossible. Because of this, there have been a number of studies where researchers have taken advantage of existing comparison groups. One of the first was by Lindsay and Smith (1998) when they compared seven individuals who had been in treatment for 2 or more years with another group of seven in treatment for less than 1 year. The comparison was predicated on probation sentences delivered by the court. Those individuals who had been in treatment for less than a year showed significantly poorer progress and were more likely to reoffend than those treated for 2 or more years. These authors concluded that short treatment periods may be of limited value for this client group.

Keeling, Rose, and Beech (2007) compared 11 special-needs offenders and 11 other mainstream offenders matched on level of risk, sex of victim, offence type, and age. All participants were treated in prison, all released from prison into the community, with the average time since release being 16 months. Participants were assessed using the victim empathy scale, the relationship questionnaire, the emotional loneliness scale, and the social intimacy scale. There were no significant differences between groups on any of these proximal measures, but follow-up was taken at 16 months after release. There were no further recorded convictions for sex offending for any of the special-needs participants.

Lindsay, Michie, Haut, Steptoe, and Moore (2011) conducted a comparison between 15 men with ID who had committed sexual offences against adults and another 15 with IDD who had committed sexual offences against children. All were treated for 36 months using approaches manualized by Lindsay (2009), repeated measures were taken on the QACSO, and records were kept on reoffending for all individuals. There were significant differences between the two groups at baseline with the offenders against adults showing higher scores on the *rape scale* and the offenders against children showing higher scores on the *offences against children scale*. Although there were differences between the groups at baseline, they ceased to exist as treatment progressed and, by the end of the process, both groups endorsed cognitive distortions on the QACSO at a rate consistent with non-offending and nonsexual offending males. Although showing some variation, the trends were close to linear with large effect sizes suggesting that treatment effects continued throughout the 36-month period, reinforcing the need for lengthy periods of sex offender treatment. The follow-up data for offending again showed no difference between the groups. All individuals were followed up for at least 6 years and, of the 30 participants, 7 committed another incident with 3 in one group and 4 in the other. Taken together, this represented a reoffending rate of 23.3 %, which was consistent with rates reported in other studies.

There have been three fairly large-scale reports on the outcome of treatment and management systems for sex offenders with IDD.

Following a program of total deinstitutionalization in Vermont, USA, McGrath, Livingston, and Falk (2007) reviewed the treatment and management regimens of 103 adult sex offenders with IDD. All participants lived in a staffed or private home of between one and three people with paid caregivers. Social and daily living skills were taught to participants and they were encouraged to interact in the community. There were also treatments to promote skill-managing risk. Therefore, the treatment was focused on skill promotion rather than being focused on CBT. In an 11-year follow-up period, with an average of 5.8-year follow-up, they reported 10.7 % reoffending. The 11 individuals who reoffend committed 20 new sexual offences. As a comparison, they reported 195 treated and untreated adult male sexual offenders without IDD who had been followed up for an average period of 5.72 years. These individuals had a prison sentence and 23.1 % were charged with a new sexual offence at some point in the follow-up period. In a further comparison, they reported on 122 treated and untreated male sex offenders who received probation orders and were followed up for 5.24 years, of whom 6.5 % were charged with a new sexual offence.

As with other studies, one of the difficulties in the sex offenders with IDD cohort was that 62.1 % had received 24-h supervision, which presumably limited access to potential victims. However, McGrath et al. (2007) also considered that this level of supervision resulted in a more comprehensive identification of future incidents when compared to the other two cohorts who had been unsupervised. They also reported a considerable amount of harm reduction in that 83 % of the participants were classified as contact sexual offenders while only 45 % of the reoffences were contact offences. The rest were typified by exhibitionism and public masturbation.

Murphy et al. (2010) conducted a treatment study on 46 sex offenders with IDD who were living in community settings. Treatment groups ran over a period of 1 year and assessments included several attitudinal measures. Treatment was manualized and conducted across a number of different settings and services. The detailed manual described methods for dealing with cognitive distortions, offending patterns and routines, deficits in sexual knowledge, poor victim empathy, and inadequate relationship skills in addition to sections guiding therapists through disclosure exercises. They found that sexual knowledge, victim empathy, and cognitive distortions improved significantly following treatment, but that only improvements in sexual knowledge and reduced cognitive distortions maintained at the 6-month follow-up. They also reported that 8.7 % of their sample reoffended after the treatment program. Two incidents were of sexual touching (outside clothing) and the rest were non-contact offences (public masturbation and stalking). Separately, Murphy and Sinclair (2006) have reported that although this study was designed as a treatment-controlled trial, it proved difficult to recruit and retain control participants.

Lindsay, Steele, Smith, Quinn, and Allan (2006) published a similarly comprehensive report. The sample in the community forensic IDD service consisted of 247 consecutive referrals of whom 121 were referred for sexual offending or inappropriate sexual behavior, 105 were referred for other types of offending such as assault or alcohol-related offences, and 21 were women, of whom 5 were referred for sexual offences (prostitution). The sex offender cohorts were significantly older than the other offenders, but there was no significant difference between the groups on IQ. All sex offenders were treated using the CBT and relapse prevention program reported by Lindsay (2009). The follow-up period in the Lindsay and Michie et al. (2006) and Lindsay and Steele et al. (2006) study was up to 13 years and reoffending rates were higher at 23.9 % for the sex offender cohort in comparison to the 10.7 % reoffending reported by McGrath et al. (2007). Lindsay et al. (2013) have reported a further 20-year follow-up of 156 sexual offenders, 126 nonsexual male offenders, and 27 female offenders. All received at least 4-week assessment and appropriate treatment directed at their criminogenic need (deviant sexuality, anger, alcohol-related treatment). All but 15 participants continued to have unrestricted access to the community throughout the follow-up period. Sixteen percent of the sex offender cohort was reported to have committed another incident and for nonsexual male referrals 43 % committed another offence (mostly violent offences). There was a significant difference in reoffending between the sex offender cohort and the non-sex offender cohort, with the former having a significantly lower recidivism rate.

Lindsay et al. (2013) also recorded the number of incidents perpetrated by the reoffenders during the follow-up period. This was possible because the study was conducted in a circumscribed region where incident records were gathered routinely. Six-monthly case reviews were held on each client for as long as any agent dealing with the client wished them to continue. They found that, for reoffenders only, there was a significant reduction in the number of offences committed when comparing figures from 2 years prior to the referral and up to 20 years after referral. In conducting this exercise, they also biased the data against finding a positive result for harm reduction by using a cutoff of 15 offences for any one individual. They argued that some individuals had committed dozens of offences prior to the referral and these participants would have significantly biased the analysis in favor of a harm reduction hypothesis. The highest number of offences committed by an individual after referral was 13. For the sex offender cohort, the 16 % of individuals who had reoffended committed 287 sexual offences prior to referral and 76 after referral. This represented around a 70 % reduction in the number of incidents and significant amount of harm reduction in those individuals who did commit further offences. If one takes into account the majority of individuals who did not reoffend, the reduction in recidivism is over 95 %.

The evaluation of sex offender treatment reports. The reports by McGrath et al. (2007), Murphy et al. (2010), Lindsay and Michie et al. (2006), Lindsay and Steele et al. (2006), and Lindsay et al. (2013) constitute major evaluations of sex offender IDD treatment services. All demonstrated significant treatment effectiveness in the one area that is of paramount importance to social policy, i.e., reoffending incidents. In all three reports that has been shown to be the case both in comparison to other sex offender groups (McGrath et al., 2007) and in comparison to the rate of previous offending (Lindsay, Michie, et al., 2006; Lindsay, Steele, et al., 2006). A further strength in two of the reports (Lindsay et al., 2013; Murphy et al., 2010) is that therapists followed detailed manualized treatment. In addition, three different research groups have conducted these major evaluations. Therefore, some of the criteria outlined by Chambless and Ollendick (2001) have been followed.

However, once again the comparison groups are ones of convenience and are not optimum. There has been no random allocation to treatment condition and there has been no waiting list control. For two of these studies (Lindsay et al., 2013; McGrath et al., 2007), there is no description of behavioral or attitude change following treatment. As has been mentioned previously, the experimental rigor in case studies on sex offender treatment has not reached the required standard for classification as “well-established treatment.” While they fulfil the criteria of lengthy follow-up periods and some are uncontaminated by constant supervision, they do not have alternative treatment conditions or return-to-baseline conditions.

The treatment comparison studies that focus specifically on sex offenders with IDD are all comparisons of convenience. For example, Keeling et al. (2007) compared special-needs offenders to mainstream offenders, Lindsay and Smith (1998) compared sex offenders with IDD treated for 1 vs. 2 years, and Lindsay et al. (2011) compared two types of sex offenders with IDD. While all of these reports recorded treatment effectiveness, the comparison groups are neither no treatment nor an alternative treatment. Only Lindsay and Smith (1998) make a realistic comparison of alternative approaches and, in this case, it was length at time in treatment.

This field cannot be considered to meet the criteria for “well-established treatments.” When one reviews the criteria for “probably efficacious treatments,” one can see that it requires two experiments showing treatment superiority to a waiting list control group or one more experiment meeting well-established criteria, or a small series of single-case design experiments meeting well-established treatment criteria. The treatment reported by Lindsay and Smith (1998) meets criteria for a comparison of alternative treatment approaches, but although there are a large number of additional research reports in this field, they do not meet any of these criteria. Therefore, according to APA criteria (Chambless et al., 1998), this body of work contains only one study showing treatment superiority and, despite the wealth of data showing reductions in reoffending and harm reduction, fulfills only the criterion for experimental treatments.

In relation to the "What Works?" criteria, the studies reach the standard of level II criteria in that they indicate some association between the program and reduced recidivism. The research design does not allow for alternative explanations to be ruled out. However, all of the main studies have carefully recorded recidivism and, in this regard, social validity is of the highest standard. The programs have been structured, focus on developing behavioral and cognitive skills, and focus on clearly defined overt behavior as opposed to nondirective counseling, self-esteem, or insight (see Landenberger & Lipsey, 2005). These programs have focused on characteristics of sex offenders that are associated with recidivism and they have addressed criminogenic need (Andrews & Bonta, 1994, 2010). Therefore, treatment for sex offenders with IDD has had important relevance to the criminal justice system and to society.

Translation of research to practice. From the foregoing review, it is apparent that research on sex offenders with IDD, while giving a clear direction for treatment with delineated programs, has not been definitive in terms of effectiveness. There is, however, a consensus among those who work with the sex offenders in the general that cognitive behavior therapy (CBT) and conducting treatment within the context of the good lives model (GLM) is the preferred approach. GLM is a treatment approach developed by Ward and colleagues (Ward & Stewart, 2003; Ward & Gannon, 2006) that concentrates on the achievement of personal human goods such as occupation, relationships, shelter, sexuality, spirituality, personal development, and personal learning. It is immediately apparent to those of us working in the field of intellectual disabilities that this is an approach based on quality of life (QoL). In fact, the GLM model is very similar to the field of QoL and IDD, and specifically similar to the personality model of Reiss and Havercamp (1997).

The primary goods stated in the GLM model include excellence in work; excellence in play; inner peace; knowledge; friendship; community; happiness; creativity; spirituality; and excellence in agency (self-directedness). Reiss and Havercamp (1997) included equivalent factors in their motivational model of personality such as power/status; tranquility; curiosity; social contact; family; idealism; independence; romance; exercise; and saving. The essential aspect of both of these approaches is that people are motivated to achieve a good QoL and so QoL should be incorporated as an important aspect of treatment.

Lindsay (2005, 2009) has outlined these issues in greater detail and has advocated a treatment model that focuses both on the criminogenic aspects of sexual offending and QoL. For sex offenders, criminogenic factors include attitudes that justify an offence, patterns and behavioral scripts associated with individual offending, impulse control, sexual attraction/sexual deviancy, feelings of sexual entitlement, uses of pornography, victim empathy, inadequate problem solving, issues associated with personal physical and sexual abuse, and knowledge of sexual and interpersonal relationships. QoL factors include the development of pro-social relationships, the quality of personal attachments, engaging in occupational or educational activities, and accepting that a change towards a pro-social lifestyle is an important part of remaining offence free. This dual focus for sex offender treatment has been incorporated into several programs (e.g., Lindsay, 2009; Murphy et al., 2010).

The available research suggests that attitudes that condone or justify ISB or sex offending are extremely important in successful treatment. Detailed disclosure of offences has been considered an important starting point for sex offender treatment in mainstream work and also in treatment for sex offenders with mild IDD. It is often the nature of sexual offences that they are relatively of low frequency in contrast with some behavioral difficulties that may happen at a very high frequency. For example, a sex offence that is perpetrated repeatedly once a week would be considered an extremely high density of incidents. On the other hand, some behavioral disturbances that happened once a week might be considered to be only moderate in frequency. If a man engages in exhibitionism weekly over a period of months this would be considered as a very-high-density series of sexual offences. Six or seven incidents over a period of 2 months would also be considered of high frequency and during disclosure each incident might be reviewed for their commonalities and differences. One of the aspects that would be of interest to therapists during disclosure is the cognitions associated with each incident of indecent exposure. In this way, all of these aspects of sex offender treatment are woven together and therapists should be aware of each facet of treatment and the way in which other facets might be relevant to the particular area being dealt with at the moment. The best way to illustrate this is with a case study.

Case study. When he was referred, Russell was 22 years old and he had committed five incidents of indecent exposure and two of sexual assault in a local park. He was charged and convicted of all seven offences. Assessment revealed that he had a measured IQ of 67 and his adaptive behavior was consistent with this. He lived with his mother and father throughout his childhood. They found it difficult to care for him due to their own personal difficulties and Russell did not have a significant history of behavioral disorder in childhood. He had managed school reasonably well, reporting some bullying and some fighting with other pupils. However, he had never been excluded or expelled, and left school at 17 years of age to commence a special needs course at a local college. When he was at the local college, there was one reported incident when he was found in the female toilets and it was thought that he had been locked in a cubicle for some time. However, he said that he had gone into the female toilets by mistake and when he realized that he was in the wrong place, he locked himself in until he thought that he could leave without alarming any of the females. He left college at 20 years of age and reported that he had one relationship with a female there. He then gained supported employment with the local authority in the cleaning department, but this placement was terminated because he was too slow to keep up with the other employees. In terms of has adaptive behavior, he had been able to use public transport to get to the placement, and used banking facilities with some support from his parents and demonstrated some responsibility in maintaining the placement with reasonable punctuality and motivation.

In terms of assessment, his adaptive behavior and intellectual ability were evaluated first. The primary reason for this assessment was to respond to a request from court on his ability to understand criminal justice procedures. The evaluation concluded that if the procedures were suitably simplified and presented in a straightforward manner, he would be able to understand and participate in the requirements of court. An assessment of intellectual ability was also important to gauge the extent to which an individual can understand the demands of treatment. In this case, Russell was well able to participate in and engage with treatment.

Prior to the commencement of treatment, his attitudes towards sexual offending were assessed using the QACSO. As has been mentioned, the QACSO assesses attitudes in the areas of rape and attitudes to women, exhibitionism, voyeurism, stalking, dating abuse, offences against men, and offences against children. The QACSO also has a social desirability scale consisting of five items that are ostensibly the same or similar to all the other items. The difference in these items is that most of the men in the original standardization, in all of the groups including the three control groups (nonsexual offenders with IDD, non-offenders with IDD, and men from the general population without IDD), endorsed the items. Therefore, if a man consistently does not endorse these five items, it is likely that they are answering in what they consider a socially desirable fashion.

The first area in which research specifically influences practice in an individual case is in the field of assessment. The QACSO was assessed in four standardization groups including sex offenders with IDD and there are norms for each individual section. The responses to items by each individual can then be compared to the average scores for sex offenders with IDD in each section. Russell's scores can be seen in Table 29.1 and his responses were elevated, indicating that he endorsed a number of cognitive distortions consistent with sexual offences, in the areas of rape and attitudes to women, exhibitionism, voyeurism, stalking, and dating abuse at both assessments prior to commencement of treatment. He endorsed fewer items, relative to the standardization groups, in the areas of sexual offences against men and offences against children. This effect has been noted previously with larger numbers of sex offenders with IDD. Lindsay and Michie et al. (2006) studied 54 sex offenders with IDD in three categories: offenders against women, offenders against children, and exhibitionists. They found that offenders against women scored significantly higher on the rape scale and lower on the offences against children scale than offenders against children. These differences had medium to large effect sizes suggesting that it is a reliable effect. These finding are reflected in Russell's responses but the main aspect of the profile is that his scores were either consistent with or in excess of the mean for sex offenders with IDD in the other categories.

His understanding and knowledge of sexuality were also assessed using the Assessment of Sexual Knowledge (ASK: Galea, Butler, Iacono, & Leighton, 2004). His sexual knowledge was reasonable in the sections on parts of the body, puberty, masturbation, adolescent sexual development, and sexual intercourse. His understanding was a good deal poorer in sexual health, sexually transmitted disease, safe sexual practices, legal issues, contraception, menstruation, and interpersonal relationships. Michie, Lindsay, Martin, and Grieve (2006) compared sexual knowledge in groups of sexual offenders and nonsexual offenders (both with IDD) and found that the sexual offenders had a greater level of sexual knowledge. This finding has emerged from other studies (Lockhart, Guerin, Shanahan, & Coyle, 2010; Lunsky, Frijters, Griffiths, Watson, & Williston, 2007) and Lockhart et al. (2010) concluded: "in relation to sexual knowledge, the current study did not uphold the hypothesis that individuals with sexualized challenging behavior would have the lowest levels of sexual knowledge" (p. 27).

All of these studies (Lockhart et al., 2010; Lunsky et al., 2007; Michie et al., 2006) were assessing the counterfeit deviance hypothesis. To recap, the counterfeit deviance hypothesis suggests that men with IDD may commit ISB because of a lack of understanding of appropriate sexuality, appropriate interpersonal relationships, the laws and conventions of society, and sexual knowledge rather than being driven by sexual deviance or a wish to commit sexual offences. All of these authors felt that the fact that sex offenders with IDD had greater levels of sexual knowledge when compared to controls was inconsistent with counterfeit deviance. However, the fact that sex offenders with IDD had greater levels of sexual knowledge compared to other individuals with IDD does not mean that their sexual knowledge is adequate. Indeed, their sexual knowledge remains particularly poor in relation to the general population (Griffiths & Lunsky, 2003; Lindsay et al., 1992). Therefore, while their knowledge of sexuality may be better than others with IDD, it is still significantly poorer resulting in an inadequate understanding of the extent to which it is against the laws of society.

This effect can be seen with Russell in that his understanding of interpersonal relationships, social interaction, and safe sexual practices was particularly inadequate. These gaps in his sexual knowledge were likely to interact with his perception and attitudes towards women that emerged from his responses to the QACSO. His inadequate understanding of interpersonal relationships and appropriate social interaction would combine with attitudes such as "women make too much fuss about sexual assault"; "if a woman is wearing a short skirt she wants men to follow her"; "women like men to stare at their bodies"; and "flashing at a woman is a good way to show her you want to have sex." In this way, there is an interaction between counterfeit deviance and attitudes consistent with sexual offending and the available research contributes to both

Table 29.1 The repeated measures for Russell on the Questionnaire Consistent with Attitudes on Sexual Offending

Scale	Pretreat 1	Pretreat 2	6 months	12 months	18 months	24 months	30 months	36 months	48 months
Rape	9	9	5	2	3	2	2	2	2
Voyeurism	6	7	5	4	4	4	2	2	1
Exhibitionism	5	5	2	2	2	2	2	2	2
Stalking	8	9	4	4	3	0	1	0	0
Dating abuse	6	6	3	3	2	1	1	1	1
Offences against men	1	1	0	0	0	0	0	0	0
Offences against children	2	3	1	0	0	0	0	0	0
Social desirability	5	5	4	3	4	3	3	3	4

Measures were taken on two occasions prior to the comments of treatment and thereafter every 6 months until 3 years after referral and then again 4 years after referral of these clinical areas in a manner that is directly relevant to both assessment and treatment.

Treatment has been outlined in several manuals and generally covers the following areas: offence disclosure and accounts of index incidents; sex education; reviewing offending pathways; dealing with cognitive distortions and attitudes consistent with sexual offending; problem solving in risk situations; understanding the impact of personal physical and sexual abuse; victim awareness and empathy; use of pornography and dealing with sexual fantasy; developing self-regulation; developing appropriate attachments and relationships; satisfying needs to appropriate means (GLM); lifestyle change and preventing relapse; and understanding personal risk.

Sex offender treatment usually lasts 1–2 years and, as can be seen from the preceding description, it is a multicomponent treatment that is difficult to assess in terms of its component methods. Figure 29.1 is the account of personal index incidents described by Russell during the disclosure phase of treatment. The figure illustrates a number of principles described by Lindsay (2009). The first principle is that individuals keep their own notes and accounts of treatment. There is little point in the facilitator writing notes on a flip chart recording information when group members are talking since all of the group members will have limited literacy skills to the extent that they have difficulty reading. It can be seen in the figure that Russell has written or drawn all of his own notes even though his reading and writing are minimal. The figure shows five incidents, all of which were dealt with in court proceedings. Russell pled guilty to all five incidents.

The depiction in the middle of the page with some words around it is crucial in this account. The words are “angry, revenge, sex, unhappy.” The two figures are Russell and his father. He gave an account of arguments with his father during which he was severely chastised for his behavior, his attitude towards his family, and what his father saw as his laziness. After the arguments, Russell said that he felt angry and unhappy and wanted revenge. This emotional arousal was often translated into sexual arousal, and Russell said that he masturbated on occasion in order to try and calm down. This use of sexual activity as a coping mechanism is consistent with the theoretical position outlined by Marshall and Barbaree (1990) in which they proposed that some men use sexual behavior in relation to emotional arousal.

On other occasions, Russell left the house and walked around a local park feeling angry and sexually aroused. He said that he began following women while in the park and masturbating while he was following them. The drawing on the top left of the figure is a representation of Russell following one woman in the park. The drawing on the top right represents another occasion when he followed a woman in the park and approached her while she was near a tree and asked for sex. On this occasion the female told him, in no uncertain terms, to go away which he did. The depiction on the bottom right of the picture shows him following a woman near the clubhouse in the park and the one on the bottom left shows him following a woman and being interrupted by another man. On this latter occasion, the man apprehended him and called police. Russell tried to run away but the man was too strong and held him until the police came. The drawing in the middle of the figure was an occasion when Russell followed a woman along the path in the park and attempted to put his hand up her skirt. He was charged with sexual assault for this incident and was charged with sexual harassment and indecent exposure offences for the other incidents.

The police had been informed about two of the other incidents by the woman involved and had been paying more attention to the local park. They had been monitoring movements and people using the park, but had not noticed Russell in the park at any time. When they were called by the man who had apprehended Russell during one incident of sexual harassment, they interviewed him about the two other reported incidents. When these three incidents were reported on the local radio station, other women came forward to report untoward experiences that they had had in the park. In the end, Russell admitted to all of the incidents with which he was charged. Because of his intellectual disability, his sexual naiveté, his lack of sexual experience and interpersonal relationships, his willingness to attend treatment, and

Fig. 29.1 Russell's disclosure account of index offences

the obvious support from his family, he was given a 3-year probation sentence as court-ordered treatment. It was clear to him that if he did not attend treatment and did not attend his probation sessions, he would receive a custodial sentence.

A number of principles emerge from this account. First, Russell kept all of his own treatment notes. This is important because in other settings, where the facilitator has written the notes for group members, group members may deny that they said certain things and maintain that the facilitator wrote particular details because he misunderstood what the individual had said. Second, because Russell had recorded all this himself, he understood the account and was able to describe each aspect of the drawing.

Third, he also had ownership of the record because he had generated the account. The disclosure account is also depicted in terms that he was able to understand. This understanding continued until the end of treatment and at other stages during treatment when his disclosure accounts were referred to. Ownership of treatment is another important aspect since participants are often reluctant to attend voluntarily and will only come because various agencies have required attendance.

This account has clear links with some theoretical underpinnings for sex offender treatment. The relationship between emotional arousal and inappropriate sexual behavior is clear. This was an aspect that could be dealt with repeatedly through treatment. There are also indications that Russell has an inadequate understanding of appropriate sexual behavior and appropriate interpersonal relationships. This is fairly obvious from the fact that he felt walking around the park and following women is a reasonable response to emotional adversity. This is another aspect that can be dealt with through treatment. There are features in this account that can be used for the self-regulation aspects of treatment. From a treatment point of view, the fact that he was noticed by a member of the public who then reported his behavior to the police could be used in later sessions.

The incidents described in Fig. 29.1 also give a very good description of Russell's pathway to offending. It shows an automatic but active behavioral script of walking around the park that becomes consistent with inappropriate sexual behavior. Subsequent information gathered through treatment made it clear that after arguments with his father he first started to masturbate and then decided that he might walk in the park to look at women while he was masturbating. Therefore, his inappropriate sexual behavior had an active goal of following women while masturbating. At one point this developed into approaching women and asking for social and sexual contact. This is a clear indication of an inadequate understanding of the way in which social and sexual relationships develop suggesting that at least some aspects of his behavior were consistent with counterfeit deviance.

All of these features emerged from his disclosure account and can be used through treatment. One very good example is the use of covert sensitization to promote self-restraint in relation to his ISB. During the group session, Russell was asked to imagine himself following a woman in a local park. At first, he was extremely embarrassed about doing this and was reluctant to engage. However, after encouragement from facilitators and other group members, he was able to do it. Therapists asked him to describe the woman in terms of hair color, what she was wearing, and where she was going. They asked him to imagine himself becoming sexually aroused while he was doing it. Once satisfied that he was able to imagine the situation, the therapists told him to imagine that a man had seen him becoming sexually aroused and following this woman. The man grabbed him, restrained him, swore at him, and called the police. From his behavior during the imaginal session, Russell was obviously uncomfortable with his covert images. In fact, other group members were able to be much more explicit in describing possible consequences for Russell and then a therapist may have been as the facilitator.

Some of the other group members had experience of being in the police station and were able to ask Russell to imagine certain circumstances while he was in the cells. Other group members asked Russell to imagine a more robust and aggressive response from the man who had seen him and apprehended him. While this might seem ethically questionable, it is probably realistic. In any sex offender group, individual members will have acute experiences of vigilante activity in relation to their sexual behavior. Some group members might say quite explicitly "people hate sex offenders," because that is precisely what they had experienced themselves. For some, their family members had been attacked and for others their houses had been spray-painted with words such as "pervert" or "beast." Therefore, these individuals have a much better firsthand experience of the public reaction to inappropriate sexual behavior and sexual offending than facilitators and they are able to use these experiences during covert sensitization sessions.

Russell employed covert sensitization during sessions and also continued to use the technique throughout treatment. He said that he practiced at home and used this technique whenever he felt emotionally aroused in subsequent months and years of treatment. He said that he found the suggestions made by other group members (the more explicit suggestions) most helpful and he understood that other members of the public may not have simply apprehended him and called the police. The other group members had, in fact, implied that he was lucky because the man who had apprehended him had not assaulted him. Other group members had experience of being assaulted and had experience of family members being seriously assaulted as a result of their inappropriate sexual incidents.

The way in which attitudes consistent with sexual offending can be challenged during treatment has been described extensively by Lindsay (2009). In these methods, the inappropriate cognition is elicited from the group member and a group member can then write it down so that it cannot be denied as the session progresses. Through a process of Socratic questioning, the individual himself or herself can be led through inductive reasoning to adopt the opposite, socially acceptable attitude. The facilitator can then employ cognitive dissonance so that the individual challenges his or her own previously stated attitudes with his or her own logical conclusions. This process can produce an irritated or even angry response from group members but, with repeated application, he or she can come to understand that his or her own attitudes are untenable and socially unacceptable.

As can be seen from Table 29.1, Russell's cognitive distortions were stable across the two pretreatment assessments. On the rape scale, he endorsed nine items, on the voyeurism scale he endorsed at least six, on the exhibitionism scale he endorsed five items, on the stalking scale he endorsed at least eight, and on the dating abuse scale he endorsed six. His attitudes on the offences against men and offences against children scales were lower and consistent with nonoffending males. Repeated measures were taken every 6 months and it can be seen that the number of attitudes he endorsed reduced as treatment progressed. At 6 months, although he endorsed fewer items, some of his scores remained consistent with sexual offenders with IDD, but as treatment progressed up to 1 year and 18 months, his attitudes became much more socialized.

It is often suggested that sex offenders simply learn to tell you what you want to hear. In other words, they learn socialized responses and repeat them during assessment. The implication of this is that men still harbor antisocial attitudes towards women and children, but realize that they should not express them. From this point of view, the social desirability scale is interesting. It contains five items that are ostensibly similar to other items, but which are generally endorsed by men who have not committed sex offences or ISB. Since most men endorsed them, if someone answers in what might be considered a socially appropriate fashion, they are likely to be answering to appear socially desirable. It is clear that Russell continued to answer some of these items in a way consistent with nonsexual offenders and this gives greater credence to his other responses.

In fact, his response to treatment was fairly consistent and positive. The principles of QoL/GLM were followed. Russell was accepted into a garden project following 4 months of treatment that he attended twice a week. The facilitators drew up management and observation guidelines for him while he was in the garden project and the occupational therapist associated with the treatment service organized the liaison between treatment services and the occupational placement. The garden project was familiar with referrals from the forensic IDD service and was well organized to accommodate the observation and management requirements reflected in the risk assessment. The day placements are crucial to well-organized forensic IDD services in that they provide positive experiences, skill building, and crucially pro-social interaction for group members. In very practical terms, if Russell were to express an attitude that was consistent with any type of offending, this attitude would be challenged by his peers directly and continually. After 2 years of treatment and day placement, the occupational therapist managed to organize an additional educational placement at the local college comprising of 2 days a week at a special-needs course over 3 years. The special-needs course and the treatment service were used to arrange risk assessment procedures of observing, monitoring, and checking in coordination with guidelines developed and provided through the treatment service. This procedure is very difficult in terms of coordination of services, but are essential if treatment is to conform to the principles of Qol/GLM.

Russell did not reoffend over the period of treatment and 8 years following his referral has not reoffended. It has been seen that his attitudes consistent with offending reduced significantly. His sexual knowledge also increased and assessment of his emotion indicated that he became less anxious as treatment progressed. It was always considered that his reported increase in anxiety was probably related to his court appearance and referral to treatment rather than any basic exaggerated propensity towards anxiety. He also recorded clinical levels of depression at his initial assessment but again this was considered to be reactive and related to his apprehension by the police and subsequent court proceedings rather than any long-lasting chronic depression.

Conclusion

Without research in the field of sex offenders with IDD, it is not overly dramatic to suggest that we would not know what to do with these cases. It would be fairly obvious to provide sex education for sex offenders with IDD, but methods for challenging cognitions, methods for covert sensitization, methods for increasing victim awareness, the importance of establishing and maintaining pro-social relationships, and the way in which we can use information on the experience of childhood abuse would not have been incorporated into treatment.

The research on assessment has also provided a rich range of choices that can be employed in the evaluation of treatment. These include assessments for sexual knowledge, assessments for attitudes consistent with offending, assessments of emotion, as well as the more familiar methods of observation and behavior recording. In fact, observation and behavior recording are not particularly helpful forms of evaluation in behavior that is extremely of high risk, but very low frequency. If a man commits sexual assault at a frequency of around every 3 months, this is almost impossible to observe, but extremely socially important. It is also the case that most sexual offending will not occur under controlled conditions in a treatment service or a service in which there are a number of graduate students working on research projects for their degrees. Therefore, these proximal measures of attitude change and self-regulation are important.

Having made this point, in terms of social validity, the ultimate data of value will be reoffending. The only information of interest to society is whether or not the person has reoffended and whether or not the person is likely to reoffend. Agents of society, such as the police, would be withering if one were to report that a sex offender had more socialized attitudes or better sexual understanding, but they had also committed further sexual offences. Therefore, it is crucial that every forensic IDD service makes careful records of reoffending incidents whether they be sexual, violent, theft, vandalism, fire raising, and so on. If one starts a service for problems related to forensic intellectual and developmental disabilities, it is certain that there will be additional incidents of reoffending and some of them will be sexual. It is important to continue liaison with local agencies, such as criminal justice and police services, so that the overall effectiveness of the service can be appreciated and that any individual instance of reoffending can be placed in this context.

In terms of the research base, there is obviously a great deal of work to be done on the evaluation of sex offender treatment. There are no adequate treatment outcome evaluations. One of the biggest difficulties is the employment of an appropriate control group. Given the social importance of sexual offending, research ethics committees remain reluctant to sanction the random allocation of referred sex offenders to experimental and no treatment control conditions or "treatment as usual" control conditions. The possibility of publicity regarding a group of intentionally untreated sex offenders makes such a decision very difficult to take. Therefore, the existing evaluations are all comparisons of convenience. Therefore, there is a pressing need to continue with innovative and creative research designs that might allow us to compare treated sex offenders against appropriate controls.

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Sleep Disorders

30

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Introduction

Sleep is essential for human survival. Problems with sleep can impact daily functioning and quality of life. According to the Centers for Disease Control and Prevention (2015), over 25 % of the general population in the USA indicated they did not obtain enough sleep. Sleep requirements vary among individuals and typically changes with age. The hours of sleep needed tends to decrease with age. The National Institutes of Health (2015) has recommended daily 16–18 h for newborns, 11–12 for preschoolers, 10 h of sleep for school-aged children, 9–10 h for teenagers, and 7–8 h for adults. Sleep problems were noted to be fairly common in individuals diagnosed with intellectual disabilities. Didden et al. (2014) reported a range of sleep problems from 15 % to 85 % in children and adults with intellectual disabilities.

Many parents and other caregivers consider sleep disturbances to be major concerns in children and adults with intellectual and developmental disabilities. As in the general population, individuals with intellectual and developmental disabilities exhibit different types of sleep disorders. Sleep–wake disorders referenced in the DSM-5 (American Psychiatric Association, 2013) include insomnia, hypersomnia (excessive sleepiness), narcolepsy, breathing-related disorders (e.g., central sleep apnea), circadian rhythm disorders, and parasomnias (e.g., sleepwalking, nightmare disorder, and restless legs syndrome). Insomnia disorder consists of problems with maintaining sleep, difficulty falling asleep (initial insomnia), waking up at night (middle insomnia), and waking up early in the morning and not going back to sleep (late insomnia). Insomnia and other sleep disorders may be associated with behavioral and cognitive difficulties, reduced learning, deficits in performing daily living activities, and increased fatigue, stress, and irritability (Didden et al., 2014; Durand, 2014; Wiggs, 2012). Sleep disorders can impact the entire family. It is important that sleep problems be addressed to help improve the quality of life of individuals and decrease caregiver demands and concerns.

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Prevalence and Factors Associated with Sleep Disorders in Children

Sleep problems are common in children, affecting approximately 25–40 % (Owens, 2007). Sleep problems may be more prevalent because many parents and caregivers do not discuss sleep problems with their pediatrician or family physician (Johnson, 1991) and often are undiagnosed by physicians (Meltzer, Johnson, Crossette, Ramos, & Mindell, 2010). Lack of adequate sleep in the pediatric population has become a major health concern (Matricciani, Olds, Blunden, Rigney, & Williams, 2012).

Sleep problems for children with intellectual and developmental disabilities are more prevalent and problematic than typically developing children (Didden et al., 2014). Common nighttime wakefulness problems for children with autism include latency of sleep onset and night waking difficulties (Weiskop, Richdale, & Mathews, 2005). Children with autism spectrum disorders (ASD) were found to have longer sleep latencies, less overall sleep, a higher number of night wakings, more parasomnias, and more anxiety than typically developing children who also had sleep difficulties (Souders et al., 2009). Wiggs and Stores (2004) found 64 % of children with ASD, 5–16 years old, exhibited sleep disorders via sleep diaries, parent questionnaires, and actigraphs. Disorders were mostly behavioral (i.e., inappropriate sleep related behaviors). Sleep–wake cycles and anxiety disorders were also evident.

Thirumalai, Shubin, and Robinson (2002) found almost half of the children with autism whose parents complained of “frequent nocturnal awakenings” showed REM sleep behavior disorders during polysomnographic lab research. Schreck, Mulick, and Smith (2004) found sleep problems exacerbated symptoms of autism. Parent report of sleep problems of children with autism, ages 5–12, and with fewer hours of sleep per night predicted overall autism scores and social skill deficits. Stereotypic behavior reported during the day predicted less sleep and screaming at night in the bedroom.

Persistent sleep disturbance has harmful effects on child’s learning and behavior. Children’s sleep disorders are associated with maternal ill-health, marital discord, impaired parent–child relations, as well as physical punishment and abuse. Fortunately, successful treatment resolves or at least reduces these negative outcomes (Stores & Wiggs, 2001).

Sleep difficulties may exacerbate symptoms of autism and other developmental disabilities (Hoffman et al., 2005; Schreck et al., 2004). Fewer hours of sleep have been associated with more stereotypical behaviors, night wakings with screaming, and problems interacting with others. Positive correlations have been shown between anxiety, challenging behavior, and sleep problems in children with intellectual and developmental disabilities and/or autism spectrum disorder (ASD; Rzepecka, McKenzie, McClure, & Murphy, 2011).

Children with intellectual and developmental disabilities (IDD) displaying sleep disorders were also reported to have pain, breathing difficulties, and nocturnal seizures (Spruyt & Curfs, 2015). Due to lack of communication by children with IDD to identify problems associated with sleeping, information is commonly obtained from parental reports. Breau and Camfield (2011) evaluated the role of pain in sleep problems in children with IDD. Parents or primary caregivers completed The Children’s Sleep Habits Questionnaire (CSHQ; Owens, Spirito, & McGuinn, 2000) for their children with IDD. The primary sources of pain identified were musculoskeletal and gastrointestinal problems. Children reported to have pain exhibited significantly more overall sleep problems including sleep-disordered breathing, parasomnias, night wakings, and shorter duration of sleep (Breau & Camfield, 2011).

Spruyt and Curfs (2015) conducted a review of 90 published articles addressing sleep problems among children with developmental disabilities. Over 60 % of studies were conducted in the home and included males as participants. A high percentage of studies were focused on sleep quality and involved children with syndromes. Epilepsy and sleep-disordered breathing were correlated with sleep disruptions. The majority of measurement techniques to monitor sleep problems were subjective. Methods of obtaining data included sleep diaries, logs, observations, questionnaires, and some objective measures (e.g., actigraphy, polysomnography). Over half of the studies reported case study or single-case designs and employed multicomponent strategies. Approximately 74.4 % of research articles reviewed utilized behavioral approaches. Almost all of the behavior techniques used with children typically developing have been successfully implemented with individuals with intellectual and developmental disabilities. Spruyt and Curfs (2015) recommended that sleep ecology, sleep hygiene, sleep regularity, and daytime somnolence be addressed to optimize sleep. More objective measures and randomized controlled trials were also recommended. Based on the review of articles addressing sleep problems in children by Spruyt and Curfs (2015), more research appears to have been conducted with children than adults. According to Ram, Seirawan, Kumar, and Clark (2010), the majority of research on sleep problems concerns children and adolescents.

Prevalence and Factors Associated with Sleep Disorders in Adults

Since individuals with intellectual and developmental disabilities are living longer, they will most likely face increasing problems with sleep as they age. According to the DSM-5 (American Psychiatric Association, 2013), insomnia is the most prevalent sleep disorder, and approximately one-third of the adult population reported experiencing symptoms of insomnia. The prevalence of sleep disorders appears to be higher in adults with intellectual and developmental disabilities compared to the general population in some studies (Doran, Harvey, & Horner, 2006; Luiselli, Magee, Sperry, & Parker, 2005; Poindexter & Bihm, 1994), but lower in others (Boyle et al., 2010; Lundqvist, 2013). Reports of sleep disturbances have varied based on the definition of sleep problems, age of participants, residence, and research procedures employed.

In adults with intellectual and developmental disabilities, sleep problems were reported to range from 8.5 % to 34.1 % (van de Wouw, Evenhuis, & Echteld, 2012). van de Wouw et al. (2012) analyzed prevalence of sleep problems based on 17 published articles from January 1990 to August 2011. All of these studies were based on questionnaires filled out by family members or caregivers. Settling problems were reported in 8.5–26.8 % and waking up at night 11–34.1 % of participants in studies evaluated. Other disturbances noted included sleeping during the day, recurrent nightmares, sleepwalking, poor sleep hygiene, sleep–wake irregularities, snoring, and sleep apnea. Of the studies conducted, van de Wouw et al. (2012) rated one study (Boyle et al., 2010) as “high quality.”

Boyle et al. (2010) conducted a 4-week study in the UK with 1023 adults with intellectual and developmental disabilities. They conducted a multivariate analysis of factors associated with four sleep problems. They assessed initial insomnia, broken sleep (waking up for 1 h or more before going back to sleep), early morning wakening, and serious sleep problems with the Psychiatric Assessment Scale for Adults with Developmental Disabilities (PAS-ADD) Checklist (Moss et al., 1998). Of the participants, 8.5 % had initial insomnia, 12 % exhibited broken sleep, 9.9 % experienced early morning awakenings, and 9.2 % reported significant problems in sleeping. Boyle et al. (2010) used a 1-h cutoff in defining broken sleep. The cutoff for broken sleep employed in most studies and the International Classification of Sleep Disorders (ICSD-R) was 30 min (American Academy of Sleep Medicine, 2001). This difference in the cutoff may have reduced the total percentage of individuals reporting problems sleeping.

Variables associated with sleep disorders in adults have included age, behavior problems, breathing-related disorders (e.g., sleep apnea), caffeine consumption, disability level, medical conditions (e.g., seizures), nocturnal urinary incontinence, physical disability, psychiatric disorders, psychoactive medication, residential placement, and sensory impairment (Brylewski & Wiggs, 1998; Didden & Sigafoos, 2001).

Trouble sleeping has also been linked to autism and genetic disorders, such as Angelman syndrome, Down syndrome, fragile X syndrome, Prader–Willi syndrome, and Smith–Magenis syndrome (Didden et al., 2014; Wiggs, 2012).

van de Wouw et al. (2012) recently conducted a systematic review of the published research addressing sleep problems with adults with intellectual and developmental disabilities. Factors associated with sleep disturbances included behavior problems, visual impairment, respiratory disease, psychiatric disorders, and prescription of psychoactive medication (antiepileptic, antidepressant, and/or psychotropic). Inadequate information was available to assess the relationship of age, dementia, gender, and level of disability with sleep problems (van de Wouw et al., 2012). Luiselli et al. (2005) also reported that age, gender, and level of disability did not correlate with sleep problems. Brylewski and Wiggs (1998) indicated older people had more daytime somnolence and snored more. Women were noted to sleep longer and had difficulty preparing for bed. Deb, Hare, and Prior (2007) reported adults with Down syndrome and dementia wandered at night, woke up early in the morning, napped during the day, and some did not sleep at night. Conflicting evidence was gleaned on the correlation between adults with autism spectrum disorder and sleep (van de Wouw et al., 2012). Total caffeine intake did not appear to be associated with sleep disturbances (van de Wouw et al., 2012). However, consumption of four or more cups of coffee or tea after 6 pm was linked to delay of sleep onset and decreased sleep duration (Brylewski & Wiggs, 1998).

van de Wouw, Evenhuis, and Echteld (2013) conducted a sleep study with over 500 adults with intellectual and developmental disabilities. For at least 7 days, participants wore the Actiwatch to monitor movement, sleep onset, time spent sleeping, waking up at night, latency to arise, and sleep efficiency. In older adults, disruptions in sleep may be impacted by psychiatric and medical conditions such as chronic pain, gastrointestinal disorders, pulmonary disease, and cardiovascular disease. A greater duration of time in bed was associated with being older, lower level of intellectual disability, residence in a central facility, having a wheelchair for mobility, being female, and depressive symptoms. The latency of sleep onset was longer in adults with Down syndrome and shorter for those with higher body mass index. Sleep onset latency was longer in those with Down syndrome and dementia. Duration of total sleep was longer in adults with epilepsy, females, and those prescribed antipsychotics. Waking after falling asleep was longer for participants who were older, had vision impairments, and lower body mass index. For adults with visual impairment, sleep efficiency was lower. Sleep efficiency was higher for those with epilepsy, higher body mass index, and participants taking antipsychotics. A shorter latency to arise was reported in participants with epilepsy, and longer latencies were noted with a moderate intellectual disability. Of the participants, 72.1 % had at least one problem sleeping, and three or more problems were reported by 12.3 %. For participants having two problems, 32.2 % had both a total sleep time of less than 6 h and a "wake after sleep onset" of more than 90 min.

Boyle et al. (2010) conducted a multivariate analysis of factors associated with four sleep problems (i.e., initial insomnia, broken sleep, early morning wakening, and serious sleep problems). Psychotropic medication and psychiatric disorders were correlated with all four sleep problems. Behavior problems were linked with early morning wakening, broken sleep, and significant sleep problems. Individuals diagnosed with severe/profound intellectual disability and those with digestive and respiratory disorders were more likely to have issues with initial insomnia, broken sleep, and significant sleep problems. Epilepsy, prescription of antiepileptic mediations, and use of analgesics were correlated with broken sleep. Visual impairments were associated with initial insomnia.

Lenjavi, Ahuja, Touchette, and Sandman (2010) evaluated the relationship between aberrant behavior and sleep patterns at night. They monitored sleep (i.e., in 15 min intervals) and behavior data for 20 adult female residents. Approximately 95 % of participants were prescribed psychotropic medication. For 4 months, nighttime sleep was observed every 15 min from 10:45 pm to 6:15 am and daytime behavior data collected from 6:15 am to 10:45 pm. A sleep efficiency index was determined by dividing the total time sleeping by the total duration of time in the bed multiplied by 100. Problem behaviors mainly consisted of aggression toward self, others, and property, and screaming. A relationship between sleep disturbances and severe behavior problems was shown to exist.

Lundqvist (2013) gathered information in Sweden on 915 adults with intellectual and developmental disabilities using the Behavior Problems Inventory (Rojahn, Matson, Lott, Esbensen, & Smalls, 2001). Based on the information collected, 12 % were noted to have sleep problems, the mean length of sleep was 7.9 h, and behavior problems were correlated with sleep duration and disturbances. Adults reported to display behavior problems averaged about 20–30 min less in sleep duration per night.

Assessment of Sleep Problems

In the general population, sleep problems in adults are assessed by self-reports. Research with adults with intellectual and developmental disabilities do not typically employ self-reports, so it is difficult to compare the rate of sleep problems to the general population. Studies with adults with intellectual disabilities reviewed by van de Wouw et al. (2012) were reported to use the following assessments of sleep: actigraphy (monitors motor movements), EEG, interviews (parent and therapist), medical history, questionnaires, sleep dairy, polysomnography (a multiparametric test conducted in a sleep study), and observations of sleep. Behavioral observations of sleep were recorded in set time intervals during the night. Several different types of questionnaires were used to assess sleep problems. For example, Maas et al. (2010) used the Epworth Sleepiness Scale (Johns, 1991) and Sleep Apnea subscale for the Sleep Disorders Questionnaire (Douglass et al., 1994). Brylewski and Wiggs (1998) used a modified version of the Sleep Questionnaire used with children and adolescents developed by Simonds and Parraga (1982). Maas et al. (2011) pointed out the importance of administering standardized sleep disorder assessments as psychometric properties of some questionnaires for individuals with intellectual disabilities may be unknown.

To assess sleep disorders, Gunning and Espie (2003) used a questionnaire based on the ICSD-R (American Academy of Sleep Medicine, 2001), interviewed caregivers and some clients, and gathered medical history and other pertinent information prior to treatment. Sleep diaries were utilized to obtain information on quality and pattern of sleep. Daytime attention, concentration, and tiredness were measured by a visual analogue scale from 0 to 10. Data collected varied based on client behavior. The selection of treatment components was based on the assessed sleep problems. For a client who was evaluated to display inadequate sleep hygiene and consumed a high amount of caffeine, sleep hygiene strategies were implemented to help reduce the number of caffeinated drinks and improve sleep onset latency. In addition, stimulus control and relaxation using mental imagery were employed to decrease latency to sleep onset.

People with intellectual and developmental disabilities residing in group settings tend to spend more time in bed. Individuals with profound or severe intellectual disability were reported by Espie et al. (1998) to be in bed 42 % of the time per day (24-h period). Reducing the time spent lying in bed and not sleeping would improve sleep efficiency. Hylkema and Vlaskamp (2009) used a sleep hygiene checklist, a survey of daytime activities, a sleep diary, and Actiwatch to measure arm movement. Based on the duration of sleep and time spend in bed, a sleep efficiency index was determined. Based on the data collected, sleep efficiency, hours of sleep, sleep latency, rising latency, and time in bed were calculated to evaluate sleep disturbances.

Studies addressing sleep disturbances in adults with intellectual disabilities tend to describe the sleep problem requiring intervention and not the treatment of the motivating variables impacting the sleep disorder. As with any behavior problem, it is important to assess the function of the maintaining variables. O'Reilly (1995) conducted a functional analysis (Iwata, Dorsey, Slifer, Bauman, & Richman, 1982/1994) on aggression. The attention and demand conditions were run during sleep deprivation and more sleep periods (i.e., more than 5 h of sleep the night before). Aggression was reported to occur more during the demand condition when sleep deprived. A multicomponent behavior intervention program was effectively employed to decrease aggression. Didden, Curfs, van Driel, and de Moor (2002) conducted a functional behavior assessment of sleep problems displayed by children and young adults, and determined sleep problems were shaped and maintained by parent attention. For four participants, they effectively employed extinction procedures by withdrawing reinforcement for disruptive behaviors interfering with sleep.

A functional behavior assessment can be conducted to determine the function of the sleep disorder in order to develop an effective treatment strategy. If sleep problems are reinforced by caregiver attention, access to preferred reinforcers such as watching television or playing video games, extinction procedures involving withdrawal of attention and tangibles can be employed. If disruptive behaviors serve as a means to escape going to bed, escape-extinction techniques can be utilized.

Jin, Hanley, and Beaulieu (2013) conducted a functional behavior assessment for sleep problems with children. They administered the Sleep Assessment and Treatment Tool (SATT, Jin et al., 2013) which is a functional behavior assessment interview consisting of open-ended questions regarding history of sleep problems displayed, current sleep schedule, bedtime routines, sleep dependencies, behaviors that interfere with sleep, desired behavioral outcomes after treatment, and sleep goals. During the interview with the parent, information about specific sleep problems was addressed. The SATT included problems with noncompliance with nighttime routine, behaviors interfering with sleep, delayed sleep onset, night awakenings, and early awakenings. Jin et al. (2013) monitored sleep onset delay, sleep-interfering behaviors, and duration of night waking with infrared nighttime video and sleep diaries recorded by parents. Percentages of sleep estimates during goal hours were also calculated. Effective treatment packages contained interventions based on the function of behavior interfering with sleep.

Evidence-Based Interventions for Adults

Interventions to treat sleep disorders with adults with intellectual and developmental disabilities are often not based on a functional analysis of behavior, do not employ well-controlled experimental designs, and lack interobserver agreement. Of the studies reviewed by van de Wouw et al. (2012), most were case studies, and some evidence supported interventions employed to improve sleep in adults with intellectual and developmental disabilities. The main interventions reported included behavior therapy (multicomponent), cognitive behavior therapy, light therapy, and melatonin. Of the articles evaluated by van de Wouw et al. (2012), two employed multiple subjects (Gunning & Espie, 2003; Hylkema & Vlaskamp, 2009). Gunning and Espie (2003) had nine participants and used a multiple-baseline design across subjects. Effective intervention components included cognitive behavior therapy, extinction, light therapy, optimal scheduling, relaxation, stimulus control, sleep hygiene, and behavior management to decrease nighttime challenging behavior and "nocturnal obsessional rituals." The treatment component selected was based on the sleep problems assessed. Hylkema and Vlaskamp (2009) had 34 participants. They implemented sleep scheduling based on age, changed daytime routines, and increased physical activities during the day. Sleep efficiency improved with less time spent in bed and more time sleeping while in the bed.

Multiple behavior therapy components have been used to treat sleep disorders in adults with intellectual and developmental disabilities. Response prevention techniques including better sleep hygiene, scheduling optimal sleep time, and stimulus control strategies to promote nighttime sleeping have been utilized (van de Wouw et al., 2012). Relaxation techniques can be used to address insomnia related to problems relaxing. To address delay sleep phase syndrome in two adults, Gunning and Espie (2003) used a modified progressive muscle relaxation technique. Use of the relaxation program decreased sleep onset latency, and treatment effects were maintained up to 50 weeks based on follow-up.

Gunning and Espie (2003) used sleep hygiene, sleep scheduling, and stimulus control as effective interventions to improve sleep. Sleep hygiene can be used effectively to address lifestyle factors and bedtime routines that interfere with sleep. It involves increasing physical activities during the day, reducing rigorous activities prior to bedtime and nighttime. Environmental enhancement, alterations in diet, and reduction in caffeine intake prior to bedtime may be recommended. It is important to decrease environmental distractions to sleep such as bright lights or loud noise, ensure approximate temperature, comfortable bed, scheduled regular sleep times, and set bedtime routines and practices. Improvements in sleep hygiene are worth trying as a preventive measure. It is important to assess individual behavioral needs prior to intervention. For example, an older adult who frequently gets up at night to use the restroom may find a night light helpful to see at night and to safely navigate going to the restroom without falling.

Optimal sleep scheduling involves consolidating sleep by adjusting the time in the bed to the estimated sleep duration. It is used to help improve sleep efficiency and to reduce daytime napping, insomnia, and sleep–wake cycle problems. Daytime somnolence and time spent not sleeping in bed are decreased. The time spent in bed is gradually increased to an optimal level in which sleep occurs. Times for sleeping at night and waking in the morning are set and specified. Hylkema and Vlaskamp (2009) effectively used sleep scheduling corresponding to the participant's age in 15 cases.

Stimulus control involves increases in cues associated with sleeping only in the bed, reducing sleeping outside the bed, decreasing cues to remain awake in bed, and promotes stimuli being associated with staying awake outside the bed. A "15-min rule" can be used, in that, if within 15 min of going to bed the person is not asleep, then it is best to get out of bed and return when sleepy. Stimulus control techniques are used to address insomnia and lying in bed awake for long durations of time (Gunning & Espie, 2003).

Cognitive behavior therapy has been used to address issues that interfere with sleep. Therapy services can be provided to the client or to their caregivers to help with sleep. Bradshaw (1991) used cognitive behavior therapy to help change a nightmare that interfered with sleep to a positive ending. Gunning and Espie (2003) employed cognitive techniques to help parents cope with their adult daughter's seizure disorder as part of the treatment to improve their daughter's sleep. Willner (2004) used cognitive therapy with an adult who reported having a recurring nightmare. The nightmare was rescripted and followed by rehearsal with the ending changed. The cognitive therapy procedure used to change the details about the nightmare was shown to be effective, and improvement in sleep was reported during the follow-up 6 and 12 months later.

Light therapy involves exposure to bright lights to facilitate the endogenous melatonin cycle controlling the "body clock." Commercial light boxes and natural sunlight can be used. During the summer, ambient daylight can be adequate. Light therapy can be used with circadian rhythm disorders, sleep–wake cycle disturbances, or with sleepiness in the morning and being alert late in the evening. Short and Carpenter (1998) used light therapy to reducing excessive daytime sleepiness and to improve the nighttime sleep pattern with an adult male with visual impairment and profound level of intellectual disability. Light therapy was applied at a set time in the morning by taking him outside. For adults prescribed psychotropic medications that are photosensitizing such as antipsychotics, light therapy may not be the best intervention. Light therapy can be combined with other techniques. Gunning and Espie (2003) combined light therapy to stimulus control and sleep hygiene to help address morning sleepiness and to reduce sleep onset latency in an adult female with intellectual disability and delayed sleep phase syndrome.

Melatonin, which is secreted by the pineal gland, plays a role in sleep control. In response to darkness, melatonin increases while production and release are suppressed in response to light. Synthetic endogenous melatonin is typically taken an hour prior to bedtime and is available in tablet, liquid, and capsule form with sustained and immediate release. Most studies are small and do not involve randomized controls; however, Braam, Didden, Smits, and Curfs (2008) conducted a study with 51 children and adults with intellectual and developmental disabilities using a randomized placebo-controlled design. Melatonin treatment was reported to be successful in decreasing chronic insomnia and associated circadian rhythm sleep disorders. Potential adverse side effects should be monitored when taking melatonin.

Didden et al. (2014) reviewed articles using children and adults as participants and published in English from 1980 to 2013. Studies were included if the focus of treatment was on sleep disorders with nonpharmacological interventions except for use of melatonin or valerian; sleep problem behaviors were measured by actigraphy, direct observations, or rating scales; and experimental designs employed control or within-subject designs. Of these studies, sleep procedures were evaluated to be effective if three independent research teams demonstrated treatment success with at least nine individuals with intellectual disabilities. Melatonin and behavioral strategies of extinction and bedtime fading were shown to be effective. Sleep restriction, valerian, and behavioral strategies including graduated extinction, relaxation, and differential reinforcement were reported to “lack sufficient evidence.” Based on this review, there is a lack of evidenced-based intervention to address sleep disorders in individuals with intellectual and developmental disabilities.

Evidence-Based Interventions for Children

Cortesi, Giannotti, Ivanenko, and Johnson (2010) suggested that melatonin may be effective in decreasing sleep onset latency and waking after sleep onset, as well as increasing total sleep time, in children with ASD. Andersen, Kaczmarska, McGrew, and Malow (2008) found melatonin therapy to be effective in treating sleep onset insomnia and sleep maintenance insomnia in many children with ASD. However, the authors reported a need for more controlled studies on the efficacy and safety of melatonin. Braam et al.’s (2009) meta-analysis supported the efficacy of melatonin as an intervention in treating sleep problems in individuals with intellectual and developmental disability. Similarly, Rossignol and Frye (2011) conducted a meta-analysis of melatonin usage for sleep problems in children with ASD. They suggested that melatonin may be a promising treatment, but further controlled research was warranted.

Wiggs and Stores (2001) reported a behavioral program that included a functional assessment of the sleep problem, tailored with a choice of extinction, graduated extinction, stimulus control, and positive reinforcement, and reduced settling and waking problems in an experimental group of 15 children compared to a control group of another 15 children with severe intellectual disabilities. Social validity measures were different for mothers and fathers as well as objective and subjective data on the children’s sleep over time.

Extinction was found to be the only behavioral technique that provided sufficient treatment efficacy to be effective in children with autism that evidenced sleep problems (Schreck, 2001). Bedtime routines, stimulus fading, and faded bedtimes were considered promising, but lacking sufficient empirical support. Similarly, Mindell, Kuhn, Lewin, Meltzer, and Sadeh (2006) reported extinction to be the most efficacious in their review for typically developing children. Caution, however, should be exercised before using extinction because parents have a difficult time carrying out this procedure during response bursts (Rickert & Johnson, 1988).

Graduated extinction, or the Ferber (2006) technique, seems promising as a method to reduce bedtime tantrums as well as night wakings for children with intellectual and developmental disabilities (Durand, Gernert-Dott, & Mapstone, 2001; Wiggs & Stores, 2001). The Ferber technique differs from typical extinction methods in that a gradual delay, often in 5-min intervals, occurs before parents or caregivers check on their children to make sure they are not sick or hurt. Then the caregiver leaves the bedroom, no longer attending to the child, and subsequent intervals for checking are increased in 5-min intervals. This is designed to encourage "self-soothing" by the child; the key to its efficacy is that the parents or caregivers repeatedly enter the child's bedroom and no longer reinforce crying episodes by parental attention (with or without other reinforcers such as food). Recall, however, that Schreck (2001), Didden and Sigafoos (2001), and Mindell et al. (2006) considered graduated extinction promising, but not the most efficacious.

Circadian rhythm management (CRM), which involves keeping regular daily schedules for significant events such as meals, bedtimes, wake times, and naps, has been effective for children with intellectual and developmental disabilities (Lancioni, O'Reilly, & Basili, 1999). CRM is often coupled with sleep restriction/bedtime fading in which the bedtime is delayed until the child falls asleep without assistance. Subsequently, bedtimes are gradually moved earlier over many nights to a more appropriate time. For example, Piazza, Hagopian, Hughes, and Fisher (1998) systematically delayed the bedtime for an 8-year-old child with developmental delay while maintaining a regular schedule during waking hours. Durand and Christodulu (2004) found sleep restriction effective for bedtime struggles and night wakings for two 4-year-old girls with developmental disability. DeLeon, Fisher, and Marhefka (2004) used bedtime fading to stabilize sleep schedules after scheduled awakenings were implemented to reduce self-injurious behavior in a 4-year-old boy. In their review of behavioral interventions, Vriend, Corkum, Moon, and Smith (2011) found CRM and bedtime fading to be promising as recommended treatment for sleep problems, but more research is needed compared to extinction and scheduled awakenings.

Scheduled awakenings with typically developing children were shown to be effective in several studies based on a review conducted by Mindell (1999). Scheduled awakenings involve waking the child up at a set time prior to an "anticipated event" such as a spontaneous awakening (e.g., due to a night terror). With scheduled awakenings, the child is typically consoled and resettles, and this procedure is faded out. Johnson and Lerner (1985) showed parental adherence to implementing this procedure impacted treatment effectiveness. Durand (2002) successfully employed scheduled awakenings to address sleep terrors in children with ASD.

Positive bedtime routines (PBR) is an effective procedure for typically developing children (Adams & Rickert, 1989) as well as a promising technique for children with developmental delay (Vriend et al., 2011). During PBR parents and caregivers proceed through four to six activities with the child on a consistent basis every night at bedtime. Each activity is followed by praise, and this sets the occasion for the next behavioral interaction in the chain such as bath time, brushing teeth, reading a story, hugs and kisses, and then lights out when the parents/caregivers leave the bedroom. Often PBR is coupled with bedtime fading/sleep restriction (Cristodulu & Durand, 2004). Weiskop et al. (2005) coupled PBR with extinction to reduce bedtime disturbances and night wakings. Although effective in typically developing children, Vriend et al. (2011) considered PRB to be promising rather than efficacious in their review of behavioral techniques for children with ASD.

Moon, Corkum, and Smith (2011) used a successful multicomponent behavior program including a handbook for parents to reduce sleep onset latency in children with ASD. The handbook included information on sleep problems, sleep physiology, sleep hygiene, bedtime routines, positive reinforcement, and faded bedtime with response cost. A set wake time was established, and a bedtime was set for 30 min after the child normally fell asleep to increase the likelihood of the child falling asleep with the new bedtime. Response cost consisted of the child being removed from bed and engaged in "low intensity activity (e.g., reading)" if not asleep within 20 min of the new bedtime. The child went back to bed in 20 min, and the procedure continued until the child was asleep. When the child successfully fell asleep for a couple of nights at the set bedtime, the bedtime was moved up by 20 min until the desired bedtime was obtained. A sticker chart was used to reward positive sleep behavior.

Piazza and Fisher (1991) effectively used a faded bedtime with response cost procedure to treat sleep problems for children with intellectual disabilities. They used a multiple-baseline design and collected sleep data on a 30-min momentary time-sampling procedure. Baseline data were collected to determine the bedtime at which sleep was most likely (e.g., subtracted 30 min from average baseline sleep onset time). Bedtime was faded by 30 min dependent of the previous night sleep onset latency. If sleep did not occur within 15 min of bedtime, the child was removed from the bed for an hour and kept awake and then returned to the bed. Based on a 1-year follow-up with two of the children, percentage of intervals with appropriate sleep remained high and frequency of night wakings was low.

Of the combined strategies utilized to address sleep disorders, sleep hygiene is typically identified as the "first line of treatment" (Jan et al., 2008). Spruyt and Curfs (2015) advocated for sleep hygiene, sleep ecology, and sleep regularity to be addressed with children with developmental disabilities. According to Jan et al. (2008), sleep hygiene can be separated into different categories including environmental, sleep practices, scheduling, and physiologic.

Environmental factors that can affect sleep include noise, lighting, temperature, comfort, and safety. Some children may wake up to a small change in noise or alteration in environmental stimuli. White-noise machines may be helpful to mask changes in sounds. Since high-contrast objects and bright colors may stimulate alertness, these may need to be avoided in the bedroom. Ideally the bedroom should be dark, but children who express fear of darkness and wander about and bump into things at night may benefit from a night light. Bright lights should be avoided for children with visual impairment. Spruyt and Curfs (2015) described "sleep ecology" as creating an environmental space for sleeping that enhances effective and continuous sleep. A comfortable bed with preferred bedding may help promote sleep. Some children with ASD show a preference for weighted blankets (Gringras et al., 2014). Sleep position with the head of the bed elevated can be important especially if the child suffers from esophageal reflux. Physical activity is encouraged during the day and not before bedtime.

Sleep-promoting practices focused on improving sleep onset include calming activities prior to bedtime. Planned bedtime routines are best if they are calming, relaxing, positive, and conducive to sleep. Regular routines may include calm bath, small snack, favorite blanket, quiet music, gentle rocking, and bedtime story. Regular sleep and wake times should be scheduled with children. Sleep scheduling needs to be consistent with less than an hour variation between week and weekend wake-up and bedtimes. Structure meals, activities, and set daily routines help circadian rhythms by acting as time cues or "zeitgebers" (Jan et al., 2008). Physiologic factors to enhance sleep include providing a light snack, limiting caffeinated beverages, and avoiding strenuous physical exercise before bedtime; however, empirical research has not been conducted to prove these factors are correlated with sleep disorders with children. For parents or caregivers who have difficulty sleeping because they frequently get up to check on their children, a webcam may be helpful. To cope with lack of sleep, parents may co-sleep with children to reduce sleep deprivation, but this practice may be underreported due to the negative stigma associated with it. Since sleep problems can affect the entire family, the caregivers' and parents' needs should be considered (Jan et al., 2008).

Although empirical evidence may not support the use of some interventions to treat sleep disorders, nonevidenced-based treatment may still be employed. Anecdotal reports may impact strategies utilized, and preferences for some treatments may affect what is attempted to correct sleep disturbances. Gringras et al. (2014) evaluated a weighted-blanket intervention used to address sleep problems in children and adolescents with ASD. They used a randomized, placebo-controlled crossover design and actigraphy to assess total sleep time. Despite no empirical evidence that the weighted blanket improved total sleep duration over the control blanket, parents and children both preferred the weighted blanket.

Finally, white noise seems to be an easy, yet satisfactory, procedure for parents and caregivers to implement (Johnson, 1991). Often continuous monotonous sound (approximations to white noise such as fans or air cleaners) decreases physiological arousal and sets the occasion and maintains sleep. Moreover, the continuous white noise masks other sounds that might awaken children in the residence. Knight and Johnson (2014) used a package of CRM, PBR, and continuous white noise throughout the night to decrease both bedtime struggles and night wakings in three young children with ASD. Whether or not white noise would be effective for children with ID or other developmental delays is not well researched, but considering the ease for parents and caregivers, it is worth researching.

Implementation of behavior intervention techniques addressing sleep problems mainly falls on the parents and caregivers. Most studies do not describe conducting a social validity measure to determine caregiver satisfaction with treatment procedures to address sleep problems. It would seem logical that parents and caregivers would implement procedures easy to administer with good results. Jin et al. (2013) and Knight and Johnson (2014) administered a social validity measure. Parents reported their children's sleep improved and indicated they were highly satisfied with treatment procedures employed. Evidence-based practices are more likely to be implemented if they are easy to administer, functional, provide effective results to improve behavior, and are rated favorably by parents and caregivers.

Conclusion

Sleep disorders have been reported to be a problem with children and adults with intellectual and developmental disabilities. Sleep disturbances not only impact the behavior of the child or adult but may also place a burden on the parents or caregiver. Interventions for children have been studied more compared to adults. The majority of research with adults has been with case studies. Various factors have been associated with sleep disorders in adults such as prescription of psychotropic medication, challenging behavior problems, respiratory disease, psychiatric disorders, and visual impairment. Based on reviews conducted, melatonin, bedtime fading, and extinction were the only strategies reported to be evidence-based treatments of sleep disorders for individuals with intellectual disabilities. Clearly, more research is needed to provide effective evidenced-based interventions to address sleep disorders displayed by persons with intellectual disabilities.

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Communication

31

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Introduction

Enhancing the communication skills of individuals with intellectual disabilities is a major intervention priority. Brown and Percy (2007) noted that provision of formal intervention to address communication deficits, and other impairments of adaptive behavior functioning, has been "particularly important to people with intellectual and developmental disabilities" (p. 342). In line with this comment, Sigafoos, Drasgow, and Schlosser (2003) argued that many individuals with intellectual and related developmental disabilities are likely to require explicit, and often intensive, intervention if they are to develop effective communication skills.

Parents also prioritize communication intervention for their children with intellectual and other developmental disabilities. Radstaake et al. (2014), for example, surveyed 77 parents of children with Angelman syndrome, a genetic condition associated with severe intellectual disability. Parents rated the extent to which providing the child with intervention to develop various skills (e.g., communication, self-care, vocational, and social skills) was a priority. Parents ranked communication skills (e.g., teaching the child to express wants and needs, labeling objects, and greeting people by name) among their top intervention priorities. Parents have expressed similar priorities for their children with autism spectrum disorder (Pituch et al., 2011), cri-du-chat syndrome (Pituch, Green, Didden, Whittle, et al.,

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2010), and Prader-Willi syndrome (Pituch, Green, Didden, Lang, et al., 2010), all of which are associated with intellectual disability.

The priority given to communication skills and communication intervention is not surprising given that communication-related deficits are common among people with intellectual disabilities (Schlosser, Sigafoos, Rothschild, Burke, & Palace, 2007). Without effective intervention, many individuals with intellectual disabilities would most likely continue to present with significant communication deficits and would thus be limited in the ability to interact effectively with others. Snell et al. (2010) noted: "The ability to communicate effectively with others is essential for good quality of life" (p. 365). Thus, without effective communication intervention, many individuals with intellectual disabilities could have a diminished quality of life. Sigafoos, O'Reilly, and Lancioni (2010) argued that intervention for individuals with intellectual disabilities should aim to improve the person's overall quality of life. For many individuals with intellectual disabilities, effective communication intervention will be critical to achieving this aim.

Fortunately, a considerable amount of research has focused on addressing the communication needs of individuals with intellectual disabilities. This research has led to a number of empirically supported procedures for assessing communication deficits, improving speech and language functioning, and teaching new communication skills. Empirically supported, in this context, refers to approaches and procedures that have been demonstrated to be effective across at least three high-quality research studies involving persons with intellectual disabilities (Chambless & Hollon, 1998; Schlosser, 2003). High quality is assigned to studies that have used recognized research designs (e.g., control group or single-case experimental designs) and included evidence of reliable data collection and procedural fidelity (Johnson & McMaster, 2013). The use of empirically supported procedures is an essential part of evidence-based practice (Chambless & Hollon, 1998; Schlosser, 2003; Schlosser & Sigafoos, 2008; Sigafoos et al., 2003).

The aim of this chapter is to advance evidence-based practice by providing an overview of empirically supported procedures for the assessment and treatment of communication deficits/disorders in people with intellectual disability. In the next section, we review a number of relevant epidemiological issues, specifically the prevalence and nature of the communication problems experienced by people with intellectual disabilities. This overview of epidemiological issues is intended to highlight key findings regarding the nature and prevalence of communication disorders among individuals with intellectual disabilities. This overview will set the stage for our subsequent review of empirically supported assessment and intervention procedures. The final section of the chapter provides guidelines for translating research evidence to practice.

Epidemiology

Types of Communication Impairment

Schlosser et al. (2007) delineated a range of speech, language, and communication impairments that are commonly associated with intellectual disability. In this context, speech refers to a learned system of oral communication that requires "coordinated use of voice, articulation, and language skills" (Schlosser et al., 2007, p. 384). Language, in contrast, refers to the systematic code through which one communicates. Communication is a more general term that refers to the sending and receiving of messages. Communication can involve vocalizations, spoken language, or use of nonvocal and non-speech modes, such as use of formal and informal gestures, manual signs, exchanging picture cards, and pointing to symbols/objects (Schindler, Ruoppolo, & Barillari, 2010). For the purpose of this chapter, the terms communication delay, disorder, or impairment will be used to cover the range of speech and language problems associated with intellectual disability, unless we are describing a specific type of speech or language disorder.

Speech disorders include articulation problems, poor voice quality, dysfluencies (e.g., stuttering and cluttering), and inadequate speech production (e.g., failing to initiate speech). Language impairments include delays and deficiencies in the receptive (i.e., the understanding of speech) and expressive domains (e.g., limited vocabulary size, improper use of words, age-inappropriate grammar; Schlosser et al., 2007). Communication impairment can range from delayed development of early communication (e.g., joint attention) to severe communication impairment. The latter term refers to a situation where the person has not developed any appreciable amount of speech or language and presents with no formal or appropriate mode of communication. In the absence of an appropriate alternative to speech, individuals often rely on idiosyncratic gestures, facial expressions, vocalizations, and body movements to communicate (Bartl-Pokorny et al., 2013; Brady, Marquis, Fleming, & McLean, 2004; Calandrella & Wilcox, 2000; Didden et al., 2009, 2010; Marschik, Bartl-Pokorny, Sigafoos, et al., 2014; Marschik, Bartl-Pokorny, Tager-Flushberg, et al., 2014; Sigafoos, Woodyatt, Keen, et al., 2000; Sigafoos, Woodyatt, Tucker, Roberts-Pennell, & Pittendreigh, 2000). This can be a problem because these types of [prelinguistic] communication behaviors are often difficult for others to interpret (Sigafoos, Arthur-Kelly, & Butterfield, 2006). Reliance on such behaviors may be appropriate for young children, but after the child reaches school age, continued reliance on prelinguistic behavior could be socially stigmatizing and would seem likely to impede educational progress. The difficulty of interpreting such prelinguistic acts has also been linked to an increased risk of communication breakdowns (failure to communicate), which can in turn socially isolate the individual and provoke problem behavior, such as tantrums, aggression, and self-injury (Brady & Halle, 2002; Brady, Steeples, & Fleming, 2005; Sigafoos et al., 2004).

Etiology

The types of speech, language, and communication disorders delineated by Schlosser et al. (2007) can arise from various causes, including hearing impairment, oral-motor deformities, oral-motor muscular problems, and neurological deficits. For some individuals, communication problems may arise from environmental factors, such as relative impoverishment, environmental deprivation, limited exposure to appropriate speech or language models, and/or extinction or punishment of communicative attempts (Puckering & Rutter, 1987). However, in many cases no etiology can be identified. Instead, the delays and deficiencies could be seen as comorbid to the general cognitive/learning impairments that define and characterize intellectual disability.

Prevalence

An important area of epidemiology research aims to estimate the prevalence of the various types of speech and language disorders associated with intellectual disabilities. Information of this type can be useful for diagnosis, prognosis, searching for etiology, and intervention planning (Enderby & Philipp, 1986; Marschik, Einspieler, Sigafoos, Enzinger, & Bölte, 2014). To these ends, several studies have provided data on the prevalence of communication disorders among individuals with intellectual disabilities (e.g., Enderby & Philipp, 1986; McQueen, Spence, Garner, Pereira, & Winsor, 1987; Pinborough-Zimmerman, Satterfield, Miller, Hossain, & McMahon, 2007). Enderby and Philipp (1986), for example, searched several literature sources with the aim of identifying the prevalence of communication disorders among various populations, including individuals with intellectual disability. Their literature search included a systematic review of Medlars and Index Medicus, as well as reviews of major speech therapy texts and census surveys. The results suggested that approximately 50 % of children with intellectual disability ($IQ < 70$) were estimated to have severe speech/language impairment. *Severe* in this context meant that the child had difficulty in making himself/herself understood by unfamiliar listeners. This estimate must be interpreted with caution, however, because the review did not consider literature on preschool or adult populations. In addition, the severity of intellectual disability in the literature reviewed ranged from mild to severe. The inclusion of this wide severity range could have resulted in a skewed prevalence figure because, as noted later, there are differences in the nature and prevalence of communication disorders for individuals with mild/moderate versus severe/profound intellectual disability. Still, this estimate suggests that a significant percentage of school-aged children with intellectual disability will likely require assessment and intervention to address their associated (and often severe) communication impairments.

In another relevant study, McQueen et al. (1987) focused on 7- to 10-year-old children with IQs less than 55. From a cohort of 307 such children, the authors found that 65 % had severe communication impairment (i.e., limited or no intelligible speech). The 65 % figure reported by McQueen et al. (1987) made communication impairment among the top three associated disorders. The other most commonly associated conditions were behavior disorder and epilepsy.

Pinborough-Zimmerman et al. (2007) provided another prevalence estimate on communication impairment for a cohort of 26,315 children. The children were living in Utah and all had been born in 1994. The children were 8 years of age when surveyed. Criteria for having a communication disorder were derived from special education classifications and diagnostic codes from the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD09-CM; World Health Organization, 1997). Diagnoses, by qualified professionals, included (a) developmental speech and language disorder, (b) expressive language disorder, and (c) mixed receptive-expressive language disorder. The findings revealed that 1667 children met the criteria for communication disorder, making for an overall prevalence of 6.3 %. Significantly more boys than girls (8:1) had communication disorder. Of these 1667 children, 4 % also had intellectual disability (IQ of 70 or less) and another 3.7 % had autism spectrum disorder. These findings suggest that a substantial proportion of the population with a communication disorder will be comprised of individuals with intellectual disability and/or autism spectrum disorder. This finding is consistent with studies showing significant correlations between speech/language skills and severity of intellectual disability and autism symptomatology (Lang, Regester, Rispoli, Pimentel, & Carmargo, 2010). That is, speech/language impairment increases with severity of intellectual disability/autism (Law, Boyle, Harris, Harkness, & Nye, 2000; Matson, Kozlowski, & Matson, 2012).

Overall, the studies by Enderby and Philipp (1986), McQueen et al. (1987), and Pinborough-Zimmerman et al. (2007) suggest that communication impairment is prevalent among individuals with intellectual disabilities. However, varying prevalence estimates have been reported across studies. The differing prevalence estimates are likely due to differences in the size and composition of the samples studied. In addition, the varied findings could suggest that the prevalence, type, and severity of comorbid communication disorder vary in relation to severity and etiology of the primary disability.

Communication Impairment in Relation to Severity of Intellectual Disability

Mild and moderate intellectual disability. With respect to severity of intellectual disability, Sigafoos, O'Reilly, and Green (2007) described the general communication profiles and impairments of individuals with mild and moderate intellectual disability. They noted that such individuals would be expected to develop sufficient speech and language to meet their everyday communication needs, although their language development is often significantly delayed and there may be speech disorders (e.g., articulation and/or fluency problems). Common areas of delay include (a) slower emergence of multi-word utterances, (b) persistence of immature grammatical forms, and (c) problems in learning conversational turn taking. Generally, children with mild and moderate intellectual disability achieve speech and language developmental milestones at a later age than their typically developing peers and their trajectory of achievement will be lower and less consistent.

In terms of prevalence of communication disorders among individuals with mild and moderate intellectual disability, David et al. (2013)

surveyed a 1997 birth cohort of 15,100 children to identify 9- to 13-year-old children with mild intellectual disability (IQs from 46 to 77). The survey was undertaken in Isère County, France. They found 267 such children for an overall prevalence of 1.8 %. Assessments were conducted on 68 % of these children ($n=181$). Among these 181 children, 54 % presented with comorbid speech impairment. In addition, a significant percentage of parents (47–49 %) reported that the child had shown delayed language development. The delays included a later mean age of speech acquisition (after age 2) and slower acquisition of word combinations. For this later skill, the average age for this sample was 30 months, whereas for typically developing children this milestone occurs at about 16–24 months. The authors argued that the data point to significantly delayed language development warranting early intervention. They also noted that language development should be routinely assessed because language delays could be a warning sign for intellectual disability.

In addition to delayed language development during the early years, individuals with mild and moderate intellectual disabilities can also present with communication disorders that persist throughout the life-span. Coppens-Hofman et al. (2013), for example, provided data on the prevalence of speech dysfluencies among 28 adults with mild-to-moderate intellectual disability. The adults were nominated by caregivers to have poor speech intelligibility. The sample included 16 men and 12 women from 18 to 40 years, and with IQs in the 40–70 range. They reported that 22 cases (75 %) presented with "clinically significant dysfluencies" (p. 484). Interestingly, the reported dysfluencies were mainly due to cluttering (i.e., abnormally rapid rate/irregularity that reduces intelligibility) or cluttering and stuttering, rather than from stuttering alone (i.e., interrupted flow of speech due to repetition and prolongation of words). The authors argued that these data suggest a pattern of dysfluency specific to this population. However, this conclusion should be interpreted with caution due to the relatively small sample size ($n=28$). Still, the data suggest the need for effective interventions to address cluttering, given that cluttering appears to be a source of poor speech intelligibility among adults with mild and moderate intellectual disabilities.

Severe and profound intellectual disability. As would be expected, communication abilities of individuals with severe and profound intellectual disability ($IQ<50$) are generally more seriously deficient than for individuals with mild and moderate intellectual disabilities. Sigafoos et al. (2007) noted that nearly all individuals with severe and profound intellectual disability could be expected to present with severe communication impairment, meaning the person would have considerable difficulty in communicating with others and understanding the speech of others due to limited expressive and receptive speech/language development. Indeed, speech is often completely absent or so limited that it cannot meet the person's everyday communication needs. Indeed, individuals with severe-to-profound intellectual disability often have considerable difficulty in expressing even their most basic wants and needs (Matas, Mathy-Laikko, Beukelman, & Legresley, 1985). This expectation is consistent with the results of the prevalence studies reviewed previously (i.e., Coppens-Hofman et al., 2013, Enderby & Philipp, 1986; McQueen et al., 1987; Pinborough-Zimmerman et al., 2007).

Belva, Matson, Sipes, and Bamburg (2012) investigated the communication deficits found among 204 individuals with profound intellectual disability. The sample consisted of 106 males and 98 females from 27 to 85 years of age (mean age of 52 years). All participants were living in state residential facilities. Participants' expressive, receptive, and written languages skills were assessed using a standardized measure (i.e., Vineland Adaptive Behavior Scales; Sparrow, Cicchetti, & Balla, 2005). The results indicated significant deficits across the three domains of communication functioning that are assessed by the Vineland (i.e., receptive, expressive, and written). This finding suggests that individuals with severe/profound intellectual disabilities will most likely require comprehensive (and multi-domain) communication intervention. However, deficits were greater in the written and expressive domains compared to the receptive domain, suggesting that the former two domains might be of higher priority for intervention.

Communication Impairment in Relation to Etiology of Intellectual Disability

In relation to etiology of intellectual disability, there is some evidence to suggest the presence of syndrome-specific communicative profiles. For example, Duker, van Driel, and van de Bercken (2002) examined the communication skills of individuals with Angelman syndrome, Down syndrome, and pervasive development disorder to determine if these conditions were associated with distinct communication profiles. The study involved 26 individuals with Angelman syndrome, 26 individuals with Down syndrome, and 25 individuals with pervasive development disorder. The 77 participants ranged from 3.2 to 52.2 years of age. Communication skills were assessed using the Verbal Behavior Assessment Scale (VerBAS; Duker et al., 2002), which includes 15 items related to functional (expressive) communication skills, such as requesting, naming, and rejecting. The VerBAS is unique in that it considers speech, as well as alternative modes of communication (e.g., gestures and picture-based systems). The results suggested that there were distinct communication profiles for the three syndromes. Specifically, Angelman syndrome was associated with better requesting/rejecting skills relative to naming skills. Down syndrome, in contrast, was associated with relatively better naming and imitation compared to requesting/rejecting. The communication profile associated with pervasive development disorder was similar to Down syndrome.

Consistent with the findings of Duker et al. (2002), Martin, Losh, Estigarribia, Sideris, and Roberts (2013) compared the language skills of boys with fragile X versus Down syndrome. They found differing communication profiles across these two groups. Specifically, boys with fragile X syndrome scored higher on the syntactic and pragmatic aspects of language than boys with Down syndrome. In a similar vein, Marschik and colleagues provided data suggesting that Rett syndrome and fragile X syndrome are associated with distinct and unique communication profiles (Bartl-Pokorny et al., 2013; Marschik, Bartl-Pokorny, Sigafoos, et al., 2014; Marschik, Bartl-Pokorny, Tager-Flushberg, et al., 2014). Autism has also been associated with specific types of communication deficits (Matson et al., 2012). This evidence must be interpreted with caution, however, because the data also point to a considerable amount of within-syndrome variability (Duker et al., 2002; Marschik, Bartl-Pokorny, Sigafoos, et al., 2014; Marschik, Bartl-Pokorny, Tager-Flushberg, et al., 2014; Martin et al., 2013). Still, the results of these studies suggest that genetic/biological factors will likely interact with aspects of the person's language learning environment to influence the nature and severity of communication impairment (Abbeduto & Boudreau, 2004; Abbeduto, Evans, & Dolan, 2001). Thus, the etiology of intellectual disability has implications for communication intervention. For example, children with Down syndrome might be in greater need for intervention to develop syntactic and pragmatic aspects of language compared to children with fragile X syndrome.

Summary of Epidemiological Issues

In summary, our review of epidemiological evidence suggests that comorbid (and often severe) communication impairments are prevalent among individuals with intellectual disabilities. While overall prevalence is high, it is important to note that the prevalence and nature of associated (comorbid) communication impairment vary with the severity and etiology of intellectual disability. Overall, the speech and language development among persons with intellectual disabilities can be characterized as slower and lower as noted by MacLean, Miller, and Bartsch (2001). That is, compared to typically developing peers, individuals with intellectual disabilities tend to reach speech and language milestones later and achieve a lower overall level of communication proficiency (Martin et al., 2013).

With respect to the need for communication intervention, the data suggest that a majority of individuals with intellectual disabilities are likely to experience speech, language, and/or communication problems of sufficient magnitude to warrant formal assessment and intervention. Further, because individuals with intellectual disabilities often present with a range of speech, language, and communication impairments, a range of communication assessments and interventions are likely to be indicated. Schlosser and Sigafoos (2008) argued that communication intervention is more likely to be successful when the procedures implemented are based on the best available evidence of what works, that is when interventionists use empirically supported procedures and follow an evidence-based practice model (Schlosser, 2003). To facilitate evidence-based practice, the next section provides a brief overview of three empirically supported assessment approaches. This is followed by a review of research evidence for a range of intervention approaches that have been used in the treatment of communication impairment in persons with intellectual disabilities.

Communication Assessment

Assessment of communication skills and deficits is integral to evidence-based communication intervention (Cole, Dale, & Thai, 1996; Matson, 2004, 2007). Reliable and valid assessment data provide objective evidence for decision making, such as deciding whether there is a need for intervention and, if so, what specific type of intervention might be indicated. Two specific aims of communication assessment include (a) documenting the person's current level of communicative functioning, and (b) identifying the nature and severity of any presenting speech, language, and communication delays/impairments. A comprehensive assessment should aim to document existing prelinguistic behavior, receptive language skills, expressive speech, literacy/written communication abilities, and a range of related abilities, such as vision, hearing, and motor skills (American Speech-Language-Hearing Association, 2005; Cole et al., 1996; Dowden & Cook, 2012).

Data from a reliable and valid assessment of communication can be useful for several purposes, including (a) screening, (b) diagnosis, (c) classification, (d) intervention planning, and (e) evaluation of interventions (American Speech-Language-Hearing Association, 2005). With respect to screening, the aim of assessment is to determine whether there are any speech and language delays or problems that might be indicators of a possible developmental delay/disability. If so, the person can be referred for more a comprehensive assessment to either rule out or confirm a diagnosis. When a diagnosis is made (e.g., intellectual disability, autism spectrum disorder), assessment data can be helpful for classification purposes (e.g., Does the person have a mild or severe intellectual disability?). At the intervention planning stage, assessment data are used to set intervention priorities and identify a starting point for intervention. After this, regular and repeatable assessments are necessary to monitor/evaluate intervention effects (Schroeder & Reese, 2007). For this latter purpose, the assessment targets will be the specific communication skills that the intervention is aiming to improve and/or the specific communication impairments that the intervention is aiming to address.

A number of measures and approaches have been developed to assess the communicative functioning of individuals with intellectual disabilities. Because a range of assessment measures and approaches have been reviewed elsewhere (American Speech-Language-Hearing Association, 2005; Brown & Percy, 2007; Carr, O'Reilly, Noonan Walsh, & McEvoy, 2007; Cole et al., 1996; Dowden & Cook, 2012; Matson, 2004, 2007), this section provides only a brief overview of three measures that have been used to assess communication functioning of individuals with intellectual disabilities. These measures exemplify three common types of assessment approaches, that is, (a) general measures of adaptive behavior functioning, (b) communication-specific measures, and (c) non-standardized assessments of prelinguistic communication. Each approach has strengths and limitations, but collectively these types of assessments provide useful data related to a person's communication strengths and deficits. Information of this type provides the objective information for intervention planning.

Vineland Adaptive Behavior Scales

The Vineland Adaptive Behavior Scales (Vineland-II; Sparrow et al., 2005) is a widely used measure for assessing general adaptive behavior functioning. The Vineland is relevant for communication assessment because it includes a communication domain with three subdomains that assess receptive, expressive, and written communication skills. The receptive subdomain includes 20 items covering development from less than 1 year of age (e.g., Turns eyes and head toward sound.) to 3+ years (e.g., Points to at least five minor body parts when asked.). The expressive subdomain contains 54 items covering development from less than 1 year of age (e.g., babbles, smiles when smiled at) to 7+ years (e.g., Says own telephone number when asked.). The written subdomain includes 25 items from 3 years (Identifies one or more alphabet letters.) to 9+ years (Reads and understands material of at least ninth-grade level.). Results are translated into age equivalence scores. The Vineland will reveal areas where expected communication skills are absent/delayed or beginning to emerge, both of which are useful for intervention planning. One potential limitation of the Vineland is that the age ranges covered are often rather wide (e.g., less than 1 year to over 9 years). This means that there are relatively few items for some age levels, which could hinder the identification of specific strengths and skill deficits, particularly in early childhood. This is understandable because the Vineland is a comprehensive assessment of adaptive behavior functioning and thus covers numerous domains in addition to communication (e.g., daily living skills, socialization skills, motor skills, and maladaptive behavior). Supplementing the Vineland with an additional, communication-specific measure could help to offset this potential limitation.

Receptive-Expressive Emergent Language Test

One communication-specific assessment instrument that could be used to supplement a more general assessment of adaptive behavior functioning is the second edition of the Receptive-Expressive Emergent Language Test (REEL-2; Bzoch & League, 1991). The REEL-2 is intended to assess a person's level of receptive and expressive language development as well as identify specific receptive and expressive language skills that are either present, emerging, or absent from the person's communicative repertoire. The instrument has a receptive and expressive subscale, with 66 items each. These items reference communication milestones from birth to 36 months of age, so the REEL-2 is suited to assessing early communication skills and development. For each item, informants indicate if the person's performance/skill is typical of the person, emerging or partly exhibited, or never observed. Ratings are converted into age equivalency scores, which can be used to compare a person's communication development to that of typically developing infants and young children.

Sigafoos and Pennell (1995) used the REEL-2 to assess 16 preschool children with varying diagnoses (e.g., autism, Down syndrome, developmental delay). The sample consisted of 11 boys and 5 girls ranging from 33 to 55 months of age (mean age = 45.8 months). Parents and teachers independently rated the 132 items for each child and the resulting scores were compared to assess parent-teacher agreement. The results showed no significant differences between parent and teacher ratings on the expressive subscale items, but significant differences on the receptive subscale. Overall agreement was 31 % and 56 % for the receptive and expressive subscales, respectively. The results suggested that receptive language skills are more difficult to reliably assess than expressive skills and that assessment results might vary across informants and settings (i.e., home versus school). These findings should be interpreted with caution, however, because the study had a relatively small and diagnostically heterogeneous sample. Still, there were numerous instances for each child where parents and teachers agreed that a skill was either absent or emerging, which would seem most important for intervention planning. In such cases, a logical starting point for intervention would be to teach absent skills and strengthen emerging skills.

Inventory of Potential Communicative Acts

A potential limitation of standardized measures, such as the REEL-2, is that they tend to reference only the major milestones of [typical] communication development. This could be a problem for individuals with severe communication impairment. Such individuals often present with atypical, idiosyncratic, and prelinguistic behaviors that may not be referenced in standardized measures. Identifying such behaviors is important however, because they could be developed into an effective means of communication with intervention (Sigafoos et al., 2006; Wetherby, Warren, & Reichle, 1998). Undertaking an assessment to identify any such potential communication acts would therefore seem important. Such an assessment would be considered especially important when standardized assessment data indicate that the person has limited communication skills and is functioning at a level commensurate with the early, prelinguistic/pre-intentional stage of communication development (Reichle, Beukelman, & Light, 2002; Stephenson & Linfoot, 1996).

To this end, Sigafoos, Woodyatt, and Keen et al. (2000) developed the Inventory of Potential Communicative Acts (IPCA). The IPCA is a structured interview protocol for use with informants who are familiar with the person. Informants are asked to describe any behaviors that the person uses for communicative purposes. A range of behaviors (e.g., vocalizations, body movement, facial expression, visual orienting, breathing pattern, problem behavior, and sign/gestures) and functions (e.g., attention seeking, rejecting/protesting, requesting, commenting, and social convention) are considered. To assess skills related to requesting an object, for example, informants are asked to describe how the person indicates that he/she wants something, such as a toy or snack.

Several studies have used the IPCA to gather descriptive information on the communicative forms and functions of individuals with intellectual and other developmental disabilities (Bartl-Pokorny et al., 2013; Didden et al., 2009; Keen, Woodyatt, & Sigafoos, 2002; Marschik, Bartl-Pokorny, Sigafoos, et al., 2014; Marschik, Bartl-Pokorny, Tager-Flushberg, et al., 2014; Sigafoos, Woodyatt, Keen, et al. (2000); Sigafoos, Woodyatt, Tucker, et al., 2000; Tait, Sigafoos, Woodyatt, O'Reilly, & Lancioni, 2004). The studies have focused on individuals with severe/profound disability and severe communication impairment and results have consistently shown that such individuals are reported by informants and/or have been directly observed to use varying (and often idiosyncratic) forms to accomplish a number of basic communicative functions, such as requesting, commenting, and recruiting attention. In addition, results suggest that the IPCA is valid for intervention planning.

Tait et al. (2004), for example, used the IPCA to identify existing forms and their associated communication functions in six children with developmental and physical disabilities. The assessment data were used to select emerging communicative behaviors. For example, one child reportedly made whining-like vocalizations to request help in reaching preferred items. Another child was reported to make choices by attempting to touch the preferred option. Intervention then focused on replacing these reportedly existing forms with more formal communication forms (e.g., teaching the first child to sign HELP and teaching the second child to touch graphic symbols representing choice options to indicate a selection). Prior to intervention, the children were observed to use prelinguistic forms in contexts that suggested that these forms were communicative. The intervention was largely successful in that the participants learned to accomplish these same communicative functions with the new forms. The fact that the intervention was successful suggests that the IPCA also has good predictive validity for intervention planning. Keen, Sigafoos, and Woodyatt (2001) reported similar findings in a study that similarly linked IPCA results to intervention. In that study, a number of idiosyncratic communicative acts identified by an initial IPCA assessment (e.g., staring/looking as a greeting/hello response) were successfully replaced by teaching children more conventional forms (e.g., waving to say hello).

Summary of Assessment Issues

Comprehensive assessment of communication skills and deficits is a vital component of evidence-based practice in communication interventions for individuals with intellectual disabilities. Various types of assessment approaches have been developed, including standardized measures of adaptive behavior functioning and communication-specific measures. Assessment data are needed to document communication skills and deficits so that intervention targets can be selected.

After treatment priorities have been identified and the starting point for intervention determined, the next step is to identify empirically supported (evidence-based) treatments. For example, if an assessment revealed that the person was able to produce speechlike sounds and some single words, but did not imitate speech, one might decide to search for high-quality intervention studies that reported success in developing imitative speech with persons with similar characteristics. The next section of this chapter reviews the research evidence for a range of communication interventions that have been used to enhance the communication skills of individuals with intellectual disabilities.

Evidence-Based Treatments: Review of Research

Schroeder and Reese (2007) noted that the first systematic attempts to enhance communication functioning of individuals with intellectual and other developmental disabilities began in the 1950s. By the 1970s, the research had led to several empirically supported interventions (Guess, Sailor, Rutherford, & Baer, 1968; Lovaas, 1977). The procedures evaluated in these pioneering studies were largely based on principles of applied behavior analysis (ABA) and generally implemented within a structured, discrete-trial training format. Specifically, the therapist would initiate opportunities for communication learning, by, for example, holding up an object (ball) and asking *What is this*? If a correct response did not occur within 3–5 s, then the therapist would provide a response prompt (e.g., *Say ball*.). Prompts were faded systematically and correct responses reinforced. Variations on this general approach were successfully applied to teach individuals to label objects (*What is this?*), identify objects (*Point to the* ____ .), make requests (*I want the* ___ .), and perform a range of generative language skills, such as correct use of singular/plural forms and prepositions, and constructing sentences. Most of these early intervention efforts were focused on the developing speech-based communication. One problem with this focus was that many individuals with intellectual disabilities presented with little or no speech and little or no ability to imitate speech. With these individuals, the initial intervention target was to develop speech via imitation training.

Imitation Training

Imitation training has been widely used to successfully develop speech in individuals with intellectual and other developmental disabilities (Guess et al., 1968; Harris, 1975, Lovaas, 1977; Lovaas, Koegel, Simmons, & Long, 1973; Sloane, Johnston, & Harris, 1968). Imitation training is based on modeling, shaping, and differential reinforcement (Duker, Didden, & Sigafoos, 2004). A classic study in this area is that of Lovaas, Berberich, Perloff, and Schaeffer (1966). These researchers developed an intervention protocol for teaching imitative speech that involved a four-step process. The first step aimed to increase the frequency of vocalizations by reinforcing any and all vocalizations made by the person. Reinforcers included food, drinks, and social reinforcers, such as hugs and tickling. After the participant was engaging in more frequent vocalizations, the next step was to introduce an imitative model for speech (i.e., discriminative stimulus) and shift to a differential reinforcement schedule. For this step, the therapist would model a word or speechlike sound (*ball* or *ba*) and reinforcement was delivered only if the participant vocalized shortly after the model. Once the participant had learned to make vocalizations in response to the therapist's discriminative stimulus, the shaping process began. For this third step, reinforcement was now given only when the participant's vocalizations began to more closely sound like the model provided by the therapist. For example, if the therapist said *papa*, the participant would initially be reinforced for any vocalization, but later in training reinforcement was only provided for vocalizations that more closely matched the model (e.g., *pa*, *papa*). The final step was to introduce new words for imitation and thus build up the person's vocabulary.

Although this type of imitative training procedure can be viewed as empirically supported for teaching speech, not all recipients of intervention appear to be able to acquire speech in this manner. In an effort to enhance the effectiveness of imitation training for participants who fail to respond to this treatment, a number of variations and refinements to the procedure have been evaluated in intervention research. For example, investigators have studied whether initial acquisition of generalized motor imitation (i.e., teaching children to imitate the motor actions of another person, such as clapping hands, raising arms, and pointing) would generalize to the imitation of speech (Garcia, Baer, & Firestone, 1971). The results of these studies suggest that while generalized motor imitation can be taught to individuals with intellectual disabilities, this training does not necessarily influence the acquisition of imitative speech.

However, Ross and Greer (2003) evaluated an approach that involved providing generalized motor imitation training (e.g., clapping hands) immediately prior to presenting opportunities to imitate the therapist's spoken model (e.g., *cookie*). This study involved five, 5- to 7-year-old children with autism and intellectual disability. The children reportedly did not have spontaneous speech and did not imitate speech. The authors reported that with the motor-vocal sequence in place, the five participating children began to vocalize. Ross and Greer (2003) suggested that the success of this intervention could have stemmed, in part, from a behavioral momentum effect. That is, performing the initial motor responses increased the probability that the children would then also imitate a spoken model. The increase in speech might also relate to the fact that vocal responses were reinforced as requests; that is, the child received a cookie for saying *cookie*.

Stimulus-Stimulus Pairing

Stimulus-stimulus pairing is another approach for inducing vocalizations. This procedure is based on the logic of conditioned reinforcement. Specifically, the procedure involves pairing reinforcement with a prior vocal model. The intent is to eventually establish the child's own vocalization as an effective type of conditioned (automatic) reinforcement. The steps of the procedure are as follows: First, the therapist must gain the child's attention (e.g., *Look at me*.). Second, the therapist makes a simple speechlike sound several times in quick succession (e.g., *ba*, *ba*, *ba*). Third, while preforming Step 2, the therapist also gives the child a highly preferred object, such a cookie or raisin. By pairing the first stimulus (i.e., *ba*, *ba*, *ba*) with the second stimulus (i.e., cookie or raisin), the child's tendency to vocalize should increase due to the mechanism of conditioned reinforcement. That is, the child's own vocalizations will be automatically reinforcing.

Three studies have reported success in increasing the vocalizations of children with autism with this technique (Miguel, Carr, & Michael, 2002; Sundberg, Michael, Partington, & Sundberg, 1996; Yoon & Bennett, 2000). Despite the reported success, the procedure and its evidence base have some potential limitations. First, the conditioning process has required up to 400 stimulus-stimulus pairings to increase the children's vocalizations. Second, the number of studies and participants to date has been modest. And third, the procedure has yet to be evaluated as a treatment for individuals with intellectual disabilities and severe communication impairment. Although promising, more positive outcomes from additional research would be necessary before the procedure could be considered empirically supported. Further, the efficiency (i.e., the time required to achieve treatment gains) could also be questioned.

Dysfluency Treatments

Despite the high prevalence of dysfluent speech among individuals with intellectual disabilities (Coppens-Hofman et al., 2013), the few available treatment studies are uncontrolled case reports (Bray, 2001; Bray, Haselwood, & Crookson, 1995; Cooper, 1986; Harasym & Langevin, 2012; Preus, 1990; Stansfield, Collier, & King, 2011). Stansfield et al. (2011), for example, described the treatment of atypical stuttering in a 23-year-old man (Participant 1) and a 44-year-old woman (Participant 2) with mild/moderate intellectual disabilities. The man's stuttering was characterized by (a) restricted speech output, (b) low volume, (c) rapid speech, (d) initial sound repetition, (e) 2 % stammer count, and (f) up to 0.5-s stammer duration. The woman had more severe stuttering, characterized by (a) whole word repetition, (b) initial sound repetition, (c) prolongations, (d) 50 % stammer count, and (e) up to 30-s stammer duration. A group treatment approach was implemented, during which Talking Mats technology was used to "facilitate discussion of feelings and provide a vocabulary for discussion of cognitive, emotional and behavioural coping strategies and safety behaviours" (p. 25). Talking Mats is an augmentative communication device with graphic symbols to represent words and phrases (Ferm, Sahlin, Sundin, & Hartelius, 2010). The participants also received individual therapy, such as encouraging longer utterances (Participant 1) and modeling prolonged speech (Participant 2). The authors reported that group therapy was associated with social gains, but fluency improved only for the male participant, who had less severe stuttering. Overall, this study provided inconclusive evidence due to lack of experimental controls, small sample, and multiple treatment components that varied across the two participants.

In another case report, Harasym and Langevin (2012) provided treatment to an 8-year-old girl with Down syndrome. Her stuttering impairment was considered profound and characterized by part-word repetitions, silent and audible prolongations, and multisyllabic stuttering on words. Treatment involved fluency shaping and parent-delivered contingencies. Fluency shaping involved practicing fluent speech while utterance length and complexity systematically increased. Contingencies included praise for fluent speech and requiring correction of stuttered speech. Speech fluency improved significantly at a 4-month follow-up. Self-esteem and school participation also improved. The authors concluded: "… fluency shaping with parental contingencies may be a viable treatment approach to reduce stuttering in children with Down syndrome" (p. 253). This conclusion must be viewed as tentative, however, because the study was an open trial involving a single participant.

Still, Harasym and Langevin's (2012) conclusion is consistent with the results of numerous well-controlled experimental studies on the treatment of stuttering in people without intellectual disabilities (Jones et al., 2005; Lewis, Onslow, Packman, Jones, & Simpson, 2008; Onslow, Jones, O'Brian, Packman, & Menzies, 2012). These studies have demonstrated consistently positive effects from behaviorally based treatments that include fluency shaping and parental contingencies. An obvious direction for future research would be to evaluate the effectiveness of such treatments in larger scale experimental trials that include persons with intellectual disabilities. Until such studies occur, clinical practice can be guided by existing case studies and general treatment recommendations (e.g., Bray, 2001; Bray et al., 1995; Cooper, 1986; Costello Ingham, 2003; Harasym & Langevin, 2012; Langevin & Kully, 2003; Onslow et al., 2012; Preus, 1990; Stansfield et al., 2011).

Cues-Pause-Point

Some individuals with intellectual disabilities engage in frequent echolalia. Echolalia refers to repeating the words or phrases spoken by another person. For example, when asked a question, the person might simply repeat the question. McMorrow and Foxx (1986) developed the cues-pause-point procedure to address echolalic responding in people with intellectual disabilities. The procedure aims to shift stimulus control from the therapist's speech to a nonverbal stimulus.

For example, when shown a picture of an apple and asked *What is this?*, the aim is to teach the person to say *Apple*, rather than simply repeating the question.

The procedure involves five steps. First, the therapist delivers a pause prompt to induce the participant to remain silent and refrain from a verbal response. This is done by holding up a finger and saying *No* or *Shhh*. Next, the therapist points to the nonverbal stimulus (e.g., a picture of an apple). While doing this, the therapist asks *What is this?* The nonverbal stimulus is then covered and the pause prompt is delivered again to prevent impulsive and echolalic responding. After a pause, the therapist uncovers the picture and points to it. This is intended to serve as the cue for the participant to label the picture. Correct labeling responses are reinforced and a verbal model is delivered if necessary (e.g., *Say apple*.).

Several studies have successfully used this procedure to replace echolalia with functional labeling responses (Al-Dawaideh, 2014; Foxx, McMorrow, Faw, Kyle, & Bittle, 1987; McMorrow & Foxx, 1986; McMorrow, Foxx, Faw, & Bittle, 1987; Valentino, Shillingsburg, Conine, & Powell, 2012). In light of the positive outcomes from these studies, the procedure can be classified as empirically supported for use with individuals with intellectual and related developmental disabilities. The procedure is indicated for people who present with echolalia, but also have the vocabulary for the objects to be labeled in their speech repertoire.

Milieu Therapy

Milieu therapy is a naturalistic teaching approach characterized by (a) providing instruction in the natural environment, (b) arranging the natural environment to create the need for communication, such as placing preferred items out of reach, (c) waiting for the person to initiate communication, such as by looking at or reaching for a preferred item, (d) using mand/model/prompting (e.g., *Say*____ . *Say I want* ____ .), and (e) natural reinforcement (i.e., giving the person the preferred item when he/she says *I want* ____ .).

Milieu therapy can be distinguished from discrete-trial training, which is generally a more structured approach where the teacher/therapist initiates learning trials. With discrete-trial training, for example, the teacher might initiate an opportunity for object labeling by holding up an object and asking *What is this*? However, both milieu therapy and discrete-trial training are based on principles of ABA and make use of various prompting, shaping, fading, and reinforcement tactics (Duker et al., 2004). Milieu therapy is part of a more general class of naturalistic teaching approaches that include variations that have been referred to as (a) incidental teaching, (b) the natural language paradigm, (c) enhanced milieu teaching, and (c) pivotal response treatment (Mancil, 2009; Verschuur, Didden, Lang, Sigafoos, & Huskens, 2014).

Mancil (2009) reviewed eight studies that evaluated the use of milieu therapy for developing communication skills in children with developmental disabilities. The eight studies included a total of 34 participants. All of the children were diagnosed with autism, but based on available mental age scores, the majority also probably had intellectual disability. Specifically, mean chronological age was 7.3 years (range = 2.9–15.8 years), whereas mean mental age (available for all but ten children) was 3.9 years (range = 2.7–6.2 years). Prior to therapy, the children were described as having either (a) limited speech ($n = 16$), (b) echolalic speech ($n = 7$), (c) extensive speech ($n = 5$), or (d) no speech ($n = 6$). The therapy goals included (a) teaching the children to make requests (e.g., for help, a break, and/or preferred snacks), (b) increasing mean length of utterance, (c) object labeling, (d) preposition use (e.g., on/under), and (e) social commenting (e.g., *I like you*.). The procedures generally involved the following tactics. First, the teacher/therapist waited for a child to initiate interaction by showing interest, such as by looking at a toy. Then, the teacher/therapist would gain the child's attention and provide a relevant model (e.g., *Want toy?*). If the child responded to this prompt with the target response (e.g., *Want,* or *Want toy,* or *I want toy.*), the teacher/therapist would verbally acknowledge and repeat the child's response (*Yes, you want toy*.). The teacher/

therapist would also provide the requested toy (i.e., natural reinforcement). However, if the child did not produce the target response after a predetermined time delay interval (e.g., 3–5 s), then the teacher/therapist would deliver a mand-model prompt (e.g., *Say I want toy*.). Overall these tactics appeared to be effective in that all 34 children showed increases in target responses. In addition, the newly acquired skills generalized across settings and people and were also maintained over time. Because these studies all used proper experimental designs (i.e., single-case multiple-baseline designs), the certainty of evidence for a positive intervention effect is reasonably high. However, the Mancil (2009) review was limited to eight studies.

In a more comprehensive review, Verschuur et al. (2014) identified 43 studies that evaluated milieu therapy/natural language teaching techniques. Studies specifically referencing the use of pivotal response training, pivotal response treatment, or the natural language paradigm were sought. Studies were included only if they made use of the following procedures: (a) waiting for the person to initiate, (b) getting the person's attention, (c) providing a relevant model/cue, and (d) use of natural reinforcement. The 43 studies included a total of 420 participants, ranging from 1 to 12 years of age (mean age = 4 years, 7 months). Most children were diagnosed with autism spectrum disorders, but 43 % (n = 181) had a more specific diagnosis of autism/autistic disorder, which is generally considered the most severe condition within the autism spectrum. Only one child had an intellectual disability diagnosis, but given that intellectual disability is estimated to occur in up to 75 % of individuals with autism/autistic disorder (Lord & Rutter, 1994; Matson, Wilkins, & Ancona, 2008), it would seem likely that many of these 181 children also had intellectual disability.

Of the 43 studies, 35 included dependent variables that referenced child behaviors, including numerous communication skills (e.g., increasing spontaneous speech, reducing and replacing echolalic and inappropriate speech, functional verbal communication, social communication, and receptive language). Of these 35 studies, 15 (42.9 %) reported positive outcomes (i.e., all participants/treatment groups showed improvement) and 20 (57.1 %) reported mixed effects (i.e., some, but not all, participants or behaviors that received intervention showed improvement). None of the studies reported negative effects (i.e., no participants/treatment groups showed improvement). However, Verschuur et al. (2014) argued that these encouraging outcomes should be interpreted with caution because roughly 56.4 % had methodological limitations that render their data inconclusive. Still, the remaining 43.6 % of studies were methodologically strong and thus provided conclusive evidence to support the efficacy of this approach for increasing a range of communication skills.

Based on the reviews by Mancil (2009) and Verschuur et al. (2014) there are sufficient data to support the use of milieu therapy as a communication intervention for children with autism spectrum disorder. Because many children with autism spectrum disorder are also likely to have intellectual disability, the approach is justifiable for use with this latter population. However, there would seem to be a need for research to evaluate how the approach could be modified for use with adults. In addition, most of the participants in the studies had some level of speech development, albeit often limited. In light of this, additional research is needed with individuals who have no spoken language (i.e., severe communication impairment). Severe communication impairment is generally found among those with severe/profound intellectual disability and such individuals might be expected to show low rates of initiation (Reichle, York, & Sigafoos, 1991), which could reduce the effectiveness of milieu therapy.

Functional Communication Training

A significant percentage of individuals with intellectual disabilities present with severe problem behavior, such as aggression, self-injury, property destruction, stereotyped movements, bizarre/inappropriate verbalizations, and extreme tantrums (Lang, Sigafoos, et al., 2013). In many cases, the frequency, severity, and persistence of such behaviors are of sufficient concern to warrant intervention. Data suggest that problem behaviors often serve a communicative function, for example, recruiting attention, gaining access to preferred objects, and/or escaping from non-preferred activities (Durand, 1990). For such cases, functional communication training (FCT) has been indicated (Sigafoos, O'Reilly, & Lancioni, 2009). FCT aims to replace problem behavior by teaching the person more appropriate communicative forms (e.g., speech, manual signs) that serve the same function or purpose as the problem behavior.

FCT is a two-stage intervention. The first stage involves undertaking assessments to identify the function or purpose of problem behavior. This is known as functional assessment or functional behavioral assessment. A variety of protocols have been developed for this purpose (Iwata, Dorsey, Slifer, Bauman, & Richman, 1982; Matson, 2012; Rispoli, Ninci, Neely, & Zaini, 2014). The gold standard is the experimental-functional analysis methodology developed by Iwata et al. (1982/1994). With this methodology, the frequency of problem behavior is assessed under several conditions, for example, attention, demand, and tangible conditions. For the attention condition, problem behavior is recorded when the person is being ignored by an adult. Instances of problem behavior are followed by attention (e.g., adult would briefly look at, touch, and/or talk to the person). High rates of problem behavior in this condition suggest that problem behavior is occasioned by a non-attending adult and maintained by the reinforcing effects of attention. For the demand condition, the person is prompted to work on a task, but the task is briefly removed following instances of problem behavior. High rates of problem behavior in this condition suggest that it is occasioned by task demands and maintained by escape from the task. For the tangible condition, the person is required to wait before accessing preferred stimuli, such as snacks or toys. Instances of problem behavior are followed by access to the preferred stimuli. High rates of problem behavior in this condition suggest that problem behavior is occasioned by the presence of preferred stimuli and maintained by access to those stimuli. Other conditions, such as an alone condition to test if the behavior is automatically reinforced by the resulting sensory stimulation, have also been included in such assessments.

Numerous functional assessment studies provide supporting evidence that the problem behaviors of persons with intellectual disabilities often represent learned behavior maintained by attention, escape, access to tangible, and/or sensory stimulation (Iwata et al., 1994). When behavior is shown to be maintained by attention, escape, and/or access to tangibles, there can be value in interpreting the behavior as communication related to (a) recruiting attention, (b) rejecting non-preferred activities, and (c) requesting access to preferred stimuli, respectively (Durand, 1990). When behavior is maintained by sensory stimulation, it is not technically communicative, although there might still be value in using an FCT approach aimed at teaching the person to request alternative forms of sensory stimulation.

When the function or purpose of problem behavior has been identified via a functional assessment, the next in an FCT intervention is to teach a new communication response that will serve the same function or purpose. For example, if a child's aggressive acts (e.g., hitting the teacher) are maintained by teacher attention, then the child might be taught to recruit attention using some appropriate form of communication, such as by saying *Come here please* (Lang, Davenport et al., 2013). Alternatively, if an adolescent had tantrums to avoid tasks that were too difficult, then he/she might be taught to request help with the task. Similarly, when problem behavior is maintained by access to preferred objects, then a logical replacement would be to teach the person to request preferred objects using an acceptable mode of communication, such as spoken words, manual signs, or a picture-exchange system.

With FCT, the procedures used for teaching the new communication skills generally involve the same types of instructional procedures used in milieu therapy. First, the therapist waits for, or creates, opportunities for teaching. For example, when problem behavior is maintained by access to preferred objects, the therapist could create opportunities by making preferred objects available, but asking the person to wait. Alternatively, if problem behavior is maintained by attention, then the therapist could create opportunities by briefly ignoring the person. Second, when an opportunity arises or is created, the therapist prompts the new communication response and reinforces this with the same consequence that maintains problem behavior. Third, response prompts are systematically faded.

A considerable amount of research supports the use of FCT in the treatment of problem behavior in individuals with intellectual disabilities. This research data has been summarized and appraised in a number of systematic/meta-analytic reviews (Didden, Duker, & Korzilius, 1997; Didden, Korzilius, Van Oorsouw, & Sturmey, 2006; Kurtz, Boelter, Jarmolowicz, Chin, & Hagopian, 2011; Mancil, 2006; Mirenda, 1997) and narrative reviews (Didden et al., 2012; Sigafoos et al., 2009). Kurtz et al. (2011), for example, identified 28 studies that evaluated the use of FCT for individuals with intellectual disabilities. A total of 80 individuals participated in these 28 studies. The participants included mainly children up to 12 years of age (75 %), but also adolescents and adults. Behaviors targeted for reduction in these 28 studies included self-injury, aggression, and destructive behavior. These studies were mainly of high quality and reported generally positive outcomes. Indeed, Didden et al. (2012) noted that there were over 100 studies on FCT "… with almost entirely positive findings" (p. 134). After 2012, new studies have also reported positive effects of FCT for individuals with intellectual disabilities (Chezan, Drasgow, & Martin, 2014; Lang, Davenport, et al., 2013; Radstaake et al., 2013; Radstaake, Didden, Oliver, Allen, & Curfs, 2012).

Based on extensive supporting evidence, FCT can be classified as an effective, empirically supported intervention. Kurtz et al. (2011) concluded that FCT meets the criteria for a well-established treatment based on criteria for empirically supported treatments developed by the American Psychological Association (Kratochwill & Stoiber, 2002; Task Force, 1995). However, it is important to note that FCT studies have included varying treatment components and the presence/absence of certain components does appear to influence outcomes from an FCT intervention. Specifically, better outcomes accrue by ensuring that the new communication response is more frequently and consistently followed by the same reinforcing consequences that maintain the person's problem behavior. In addition, the new communication response must be made more efficient than the existing problem behavior. Efficiency in this context means that the new response is easy (requires less energy, time, or skill) for the person to use and is reinforced more consistently than problem behavior (Horner & Day, 1991). FCT is also more effective when the problem behavior is no longer reinforced (extinction) and punished (Hagopian, Fisher, Sullivan, Acquisto, & LeBlanc, 1998).

Manual Signs and Gestures

Numerous studies, accumulating since the 1970s, have focused on enabling individuals with intellectual disabilities to communicate using manual signs and gestures (Bryen, Goldman, & Quinlisk-Gill, 1988; Duker, 1988, Duker, Dortmans, & Lodder, 1993; Duker, Hensgens, & Vanderbosch, 1995; Duker & Michielsen, 1983; Duker & Morsink, 1984; Duker & Remington, 1991; Duker & van Lent, 1991; Faw, Reid, Schepis, Fitzgerald, & Welty, 1981; Hall & Sundberg, 1987; Hobson & Duncan, 1979; Horner & Budd, 1985; Kiernan, 1977; Reichle, Rogers, & Barrett, 1984). Manual signs and gestures provide an alternative mode of communication for individuals with little or no speech, provided that the person has sufficient motor skills to produce signs and gestures.

Intervention to establish manual signing and communicative gestures typically involves teaching the individual to produce specific signs or gestures for specific communicative functions, such as requesting preferred stimuli or labeling objects. Functional communication via signs and gestures has been successfully taught using milieu and discrete-trial approaches that have incorporated well-established instructional procedures (e.g., response prompting, prompt fading, and reinforcement). These instructional procedures have been developed through behaviorally oriented intervention research and derived from basic principles of ABA (Duker, 1988; Duker et al., 2004; Goldstein, 2002; Reichle et al., 1991). For example, the therapist might first wait for, or create, opportunities for communication by, for example, offering a preferred item or presenting an object and asking *What is this*? After this, the therapist waits for the correct sign or gesture while looking expectantly at the person. If a correct sign or gesture does not occur within a reasonable period of time (e.g., 3–10 s), then response prompts are delivered to evoke the sign/gesture (e.g., modeling the correct sign or physically assisting the person to produce the correct sign). Correct sign production is reinforced and response prompts are systematically faded.

Reichle et al. (1984), for example, provided intervention to an adolescent girl with severe intellectual disability. The initial part of the intervention focused on teaching the manual sign WANT. This sign was taught as a general request for preferred objects. To teach the WANT sign, the therapist offered a number of highly preferred stimuli. In the presence of the preferred stimuli, the girl was prompted to produce the WANT sign using physical assistance (i.e., gently moving her hands and arms to make the sign). Once the WANT sign had been produced, the girl was allowed to select one of the offered stimuli. This consequence was intended to function as natural reinforcement for producing the sign. Over the course of intervention, the therapist systematically faded the prompt by using less and less physical assistance. With this intervention, the girl reached acquisition (80 % correct) after 25 training sessions. Similarly positive results have been reported for most participants receiving this type of intervention (Bryen et al., 1988; Duker, 1988, Duker et al., 1993, 1995; Duker & Michielsen, 1983; Duker & Morsink, 1984; Duker & Remington, 1991; Duker & van Lent, 1991; Faw et al., 1981; Hall & Sundberg, 1987; Hobson & Duncan, 1979; Horner & Budd, 1985; Kiernan, 1977). Most studies have reported positive outcomes when signs or gestures were taught using milieu therapy or discrete-trial training procedures. These procedures have also been successful in teaching manual sign and gestures to individuals with autism spectrum disorder (Goldstein, 2002; Wendt, 2009). In addition, manual signs and gestures have been successful taught as replacements for problem behavior within FCT interventions (Kurtz et al., 2011; Mancil, 2006; Mirenda, 1997).

Millar, Light, and Schlosser (2006) offered an additional important conclusion regarding the effects of manual sign/gesture communication training for individuals with developmental disabilities. They reviewed studies evaluating whether intervention to teach manual signs impacted speech development. From a total of 15 participants, 13 participants showed collateral increases in spoken language with intervention. Millar et al. (2006) concluded that intervention to establish manual signing does not hinder speech. In fact, this intervention appeared to have facilitated speech development in some cases. In a narrative review, Johnston and Cosbey (2012) also concluded that simultaneous prompting of manual signs with speech input from the therapist appears to promote receptive and expressive language gains for some people.

In summary, the evidence base includes a large number of high-quality studies with sufficiently positive outcomes to support the use of such interventions with individuals with intellectual and other developmental disabilities. This conclusion holds for individuals with severe-to-profound intellectual disabilities and severe communication impairment. Using milieu and discrete-trial training procedures, such individuals have been successfully taught to use manual signs and gestures for a variety of functional communication purposes (i.e., to make requests and label objects). Individuals can also be taught receptive understanding of signs/gestures (Duker, van Deursen, de Wit, & Palmen, 1997). Furthermore, simultaneous use of manual signs and speech has been shown to facilitate spoken language in some cases.

The Picture Exchange Communication System

Picture exchange communication system (PECS) is a manualized intervention protocol that has been widely used as a communication intervention for individuals with developmental disabilities; mainly children with autism spectrum disorder (Bondy & Frost, 2009). It is primarily intended as an alternative to speech for individuals who present with severe communication impairment. PECS makes use of pictures or line drawings that the person is taught to give to a communicative partner as a way of communicating. Handing over a picture of a *BALL*, for example, might be interpreted as being equivalent to saying *I want the ball please*.

The PECS protocol (Frost & Bondy, 2002) outlines six intervention phases. In Phase I, participants are taught to request a preferred object by handing over a corresponding picture card. To teach this initial exchange, the therapist initiates communication opportunities by offering a single preferred object. A second therapist stands behind the participant and prompts the person to select the corresponding picture card and hand it to the first therapist. After this picture exchange occurs, the person is given the preferred object. Over successive opportunities, the second therapist uses less and less physical assistance until the person independently exchanges the picture card when offered the preferred object. The instructional procedures in this phase involve (a) creating opportunities for communication by offering a preferred object, (b) response prompting and prompt fading, and (c) natural reinforcement. Phase II aims to develop persistence in making the picture exchange response. This is done by introducing various obstacles, such as having the listener move away from the person, introducing new communicative partners, and moving the picture card to various locations, so that the person has to first find the picture and then approach the listener to complete the exchange. Again, response prompting, prompt fading, and natural reinforcement are used to develop these skills. In Phase III, additional picture cards, representing additional preferred stimuli, are introduced. Discrimination training and error correction procedures are used to teach the person to match pictures to their corresponding real items. For example, after exchanging the picture for *APPLE*, the correct follow-up response is to then select the real apple. Phase IV focuses on moving from single-picture to multi-picture responses. For example, a participant might be taught to combine *I WANT+BALL* to request a ball using a backward chaining procedure (Duker et al., 2004). In Phases V and VI, the person is taught to respond to questions (e.g., *What do you want? What do you see?* and *What do you hear?*).

Several reviews have examined the literature on PECS (Flippin, Reszka, & Watson, 2010; Ganz, Davis, Lund, Goodwyn, & Simpson, 2012; Ganz, Simpson, & Lund, 2012; Preston & Carter, 2009; Tincani & Devis, 2011). Preston and Carter (2009), for example, identified 27 studies that used PECS as a communication intervention. The 27 studies provided PECS intervention to 394 participants from 20 months to 40 years of age. Most (83 %) were diagnosed with autism spectrum disorder. Intervention outcomes were summarized for four classes of dependent variables: (a) acquisition of picture exchange responses, (b) speech and vocalizations, (c) social behavior, and (d) problem behavior. With respect to the first dependent variable, the overall outcomes were positive. Indeed, all but two participants were reported to have acquired the initial exchange response associated with Phase I of the PECS protocol. And most participants who advanced to subsequent phases made progress in these phases. From the few studies that included measures of speech and vocalizations, the results were mixed. Some studies reported no effect on speech/vocalization, whereas others reported improved speech intelligibility or increased vocalizations/words. Some studies reported positive outcomes with respect to improved social communication and reduction of problem behavior, although there were relatively few studies that assessed these outcomes. The authors concluded that the data are suggestive of PECS' effectiveness, but that positive results from randomized controlled trials would be required before PECS could be classified as a well-established intervention.

Flippin et al. (2010) reviewed 11 studies involving children (<18 years) with autism spectrum disorder. The results showed that PECS was effective in promoting acquisition of the targeted exchange-based communication skills, but speech gains were judged to be absent or small. The authors concluded that PECS was promising. This conclusion is consistent with other reviews (Ganz, Davis et al., 2012; Ganz, Simpson et al., 2012).

In commenting on the PECS literature, Wendt and Boesch (2010) noted that "the effectiveness of PECS has primarily been demonstrated for the picture exchange and requesting portion of the protocol; empirical support is still needed to document the effects on speech, social skills as well as challenging behavior" (p. 59). However, PECS is arguably intended primarily as an alternative mode of functional communication for individuals who present with little or no speech (Bondy & Frost, 2009). In line with this indication, studies have reported consistently positive effects with respect to acquisition of the skills targeted in Phases I and II. PECS is also promising as an intervention for teaching skills associated with subsequent phases, but it is important to note that there are fewer studies that have progressed to these later phases. With respect to the effects on speech/vocalizations, social skills, and problem behavior, the evidence is mixed. PECS does not appear to hinder speech/vocalizations or social skill development, nor does it appear to exacerbate problem behavior. For some participants, PECS intervention has been associated with improvements in these areas. However, because of design limitations, it has been difficult to attribute any such improvements to PECS intervention alone.

In summary, there are sufficient data to classify that PECS has an empirically supported protocol for teaching individuals to request preferred objects by exchanging pictures. It is also promising for teaching persistence, picture discrimination, multi-response requesting, and question answering. Its effects on speech, social skills, and problem behavior have been mixed.

Speech-Generating Devices

Speech-generating devices (SGDs) or voice-output communication aids (VOCAs) represent another option that has been used as an alternative to speech for individuals with intellectual disabilities and severe communication impairment. SGDs usually have communication symbols (e.g., letters, words, line drawings, or photographs) that produce corresponding digitized or synthesized speech output. Numerous SGDs are commercially available. Three commonly used devices are shown in Fig. 31.1.

Rispoli, Franco, van der Meer, Lang, and Camargo (2010) reviewed 35 studies aimed at teaching SGD use to individuals with developmental disabilities. These 35 studies involved 86 participants, 70 % of who had intellectual disabilities. Participants ranged from 1 to 42 years of age, but most were school-aged children (mean age = 12.9 years). Across these 35 studies, 17 different types of SGDs were used. The targeted communication skills included requesting preferred stimuli, naming/commenting, answering questions, and social communication (e.g., greetings, and saying please and thank you). Three main intervention approaches were employed across these 35 studies, specifically (a) discrete-trial training, (b) milieu therapy, and (c) a combination of discrete-trial and milieu therapy. Eighty-six percent of these 35 studies reported positive outcomes (i.e., the participants learned the targeted SGD-based communication skills).

In another relevant review, Lancioni, Sigafoos, O'Reilly, and Singh (2013) summarized 54 studies that evaluated the use of SGDs in communication interventions for individuals with severe/profound intellectual disabilities and comorbid physical and/or sensory impairments. There were 149 participants across these 54 studies. Participants received intervention aimed at teaching them to use SGDs to (a) request access to preferred stimuli (23 studies), (b) reject non-preferred objects (three studies), (c) recruit social interaction/initiate conversation (22 studies), and (d) reduce problem behavior via SGD-based functional communication training (six studies). The intervention procedures used in these studies were generally based on discrete-trial and milieu therapy. Consistent with the findings summarized by Rispoli et al. (2010), the 54 studies reported positive outcomes overall.

Similarly positive outcomes were found in a review of 11 studies, in which 15 adults with intel-

Fig. 31.1 The *upper photograph* shows a BIGmack switch, which is a single-message plate switch that produces digitized (recorded) speech. The *middle photograph* shows a TechTalk with eight panels and eight levels allowing for up to 64 digitized messages. The *bottom photograph* is an iPad®-based SGD. Tapping screen icons produces synthesized speech output

lectual disabilities received SGD-based communication intervention (Sutherland, Sigafoos, Schlosser, O'Reilly, & Lancioni, 2010). The targeted communication skills were mainly requesting access to preferred stimuli and responding to questions. Again, the teaching approaches were based on ABA and delivered through a combination of discrete-trial and milieu therapy approaches. Overall results were again largely positive.

The results of these three systematic reviews support the use of SGDs as an evidence-based intervention for individuals with intellectual disabilities. The literature demonstrates that well-established instructional procedures can be successfully applied to teach individuals with intellectual disabilities to use SGDs for communication purposes. The largely positive outcomes are encouraging because the participants in these studies have been individuals with severe/profound intellectual disability, severe communication impairment, and often comorbid physical and sensory impairments. However, the evidence base is limited because most studies focused on only teaching individuals to use SGDs to request preferred objects. Still, there is sufficient evidence to recommend SGDs as a viable communication option for individuals with intellectual disabilities and severe communication impairment. As with the other interventions reviewed in this section, effective application of well-established instructional procedures appears critical to ensuring intervention success.

Translation of Research to Practice

A basic premise of evidence-based practice is that clinical interventions should be based, in part, on the best available evidence of what works (Carter & Wheldall, 2008). Evidence-based practice therefore requires effective translation of research into clinical applications. Researchers have frequently recommended a four-step process to facilitate clinical application of research evidence (Costello Ingham, 2003; Sackett, Straus, Richardson, Rosenberg, & Hayes, 2000; Schlosser & Raghavendra, 2003). These steps are the following: (a) construct a clinical question, (b) locate relevant studies, (c) appraise the evidence, and (d) apply the evidence and evaluate the application.

Step 1: Construct a Clinical Question

The first step in translating research evidence to practice is to construct a clinical question relevant to a specific referral. A well-constructed question will facilitate the search for relevant treatment studies. For example, a clinician might ask the following: What is the most effective treatment for a 7-year-old girl with Angelman syndrome who presents with no speech, expressive language age of 1.5 years, and severe problem behavior?

Step 2: Locate Relevant Studies

The second step in translating research evidence to practice is to locate studies relevant to the clinical question. Schlosser, Raghavendra, and Sigafoos (2013) recommended that clinicians adopt a hierarchical approach to locating research evidence. For example, a clinician might first turn to meta-analyses, then systematic reviews, and finally individual studies. The logic of this approach is that meta-analyses and systematic reviews provide a higher level of evidence than individual studies. In practice, meta-analyses and systematic reviews can give an overall estimate of treatment effect sizes—thus helping clinicians find effective treatments—whereas individual studies provide details on how to implement effective treatments.

Electronic databases, such as Linguistics and Language Behavior Abstracts (LLBA), MEDLINE, PsycINFO, and PubMed, can be searched to identify meta-analyses, systematic reviews, and relevant individual studies. For example, a PsycINFO search of treatments for problem behavior in person intellectual disabilities returned two meta-analyses (Didden et al., 1997, 2006), both of which identified FCT as having the highest effect size among the range of treatments for problem behavior in people with intellectual disabilities. A follow-up search on the use of FCT and Angelman syndrome returned two treatment studies (Radstaake et al., 2012, 2013). Both of these studies reported positive effects (i.e., increased communication and reduced challenging behavior) across a total of seven children with Angelman syndrome, severe communication impairment, and severe problem behavior. In light of this, there is sufficient empirical evidence to justify the use of FCT for the clinical situation described in Step 1.

Step 3: Appraise the Evidence

The third step in translating research evidence to practice is to appraise the evidence that has been located. A clinician must decide whether the treatment has sufficient evidence to justify its use in clinical practice. Clinicians should only apply treatments that meet the criteria for being effective. To make such determinations, clinicians can turn to existing guidelines (e.g., Chambless & Hollon, 1998; Kratochwill & Stoiber, 2002; Schlosser, 2003; Task Force, 1995). Chambless and Hollon (1998), for example, argued that *effective treatments* are those that have yielded consistently positive effects in at least two independent randomized control trials, or in at least three single-case experimental studies. The classification of *possibly effective* is reserved for treatments that have produced positive effects in a fewer number of studies or for treatments which have not yet been tested by independent research teams. If neither of these criteria is met, the treatment lacks sufficient evidence for clinical practice.

Step 4: Apply and Evaluate

The final step in translating research evidence to practice is to apply the evidence and evaluate its effectiveness for each individual. For this, the treatment protocol could be based on one or more exemplary studies identified at Step 2. Exemplary studies will provide the detail necessary to replicate the treatment. Clinicians must also ensure that they have the competencies to implement the treatment with fidelity. Stakeholders need to be consulted to ensure that the treatment plan is acceptable.

Often treatments need to be modified to suit the individual's unique circumstances. As noted by Linscheid (1999), modifying treatments to suit the individual's unique circumstances requires a thorough understanding of the mechanisms that underlie effective treatment. With FCT, for example, it is important to ensure that the new communication skill matches the function of the person's existing problem behavior and that the new skills are more efficient than the person's existing problem behavior. The specifics of a published study may thus need to be modified to ensure that these basic principles hold when applying FCT with new cases.

Even the best treatments do not always produce positive outcomes in all cases. Objective data must therefore be collected on the individual's response to treatment so as to determine if that treatment is producing sufficient improvement for that person. Such data should be collected and reviewed regularly. When the data show insufficient progress, the treatment protocol should be modified in light of an analysis of the underlying cause(s) for the lack of success.

Summary

Communication impairment is prevalent among individuals with intellectual disabilities and enhancing the communication functioning of individuals with intellectual disabilities is a major intervention priority. An evidence-based practice approach to intervention includes gathering reliable and valid assessment data. Communication assessment aims to (a) document the person's current level of communicative functioning, (b) identify the nature and severity of any presenting speech, language, and communication delays/impairments, (c) document existing prelinguistic behavior, and (d) assess related abilities, such as vision, hearing, and motor skills. Assessment data is used to determine the need for intervention, and, if so, the specific types of interventions, that might be indicated.

Once treatment priorities have been identified and the starting point for intervention determined, the next steps are to identify, implement, and evaluate empirically supported (evidence-based) treatments. A range of empirically supported treatments for enhancing the communication functioning of individuals with intellectual disabilities have been developed as a result of numerous interventions studies. Clinician should identify and implement interventions that have been demonstrated to be effective in a number of high-quality research studies involving persons with intellectual disabilities. A four-step process has been recommended to translating the best available research evidence to practice. These steps are (a) construct a clinical question, (b) locate relevant studies, (c) appraise the evidence, and (d) apply the evidence and evaluate the application. Effective translation of research to practice requires the ability to appraise research data and the clinical expertise to apply that evidence to the individual case.

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Vocational Training

32

John Kregel and Meg Sander

Introduction

Persons with intellectual and developmental disabilities often require individualized vocational skill training and supports to achieve the ultimate goal of obtaining competitive, community-based employment. Numerous public agencies and private organizations or businesses provide important vocational services. State Vocational Rehabilitation agencies (SVRAs) and public schools, sometimes in conjunction, are often the primary public agencies to provide vocational skill training. Those who qualify for special education and related services under the Individuals with Disabilities Education Act ("IDEA") must, no later than age 16, be provided transition services that may include the acquisition of vocational skills. SVRAs offer eligible individuals vocational rehabilitation ("VR") services, including supported employment and job placement, through an Individual Plan for Employment (Rehabilitation Act of 1973, as amended). A 2012 Government Accountability Office (GAO) report suggested that with numerous vocational skill-related services available, individuals with disabilities may have difficulty navigating programs, and service providers may have difficulty coordinating services across different programs. Timely implementation of appropriate vocational services and supports is essential to maximizing the employment potential of individuals with disabilities.

This chapter discusses the work supports and services available to qualified individuals with disabilities. We discuss the participation of individuals with intellectual and developmental disabilities in the workforce, and the often-unnecessary obstacles to work that some individuals encounter. The most relevant federal laws, their purposes, and their work-related provisions are introduced, as are the agencies that provide services pursuant to those laws. The efficacy of specific vocational interventions, particularly supported employment, is described. Several research-backed vocational skill programs are described to provide the reader with real-life examples of successful vocational programs. Finally, employer practices and preferences that lead to the employment of individuals with disabilities are discussed.

Epidemiology of the Behavior

Individuals with disabilities continue to be underrepresented in the competitive workforce. This is particularly true for individuals with intellectual and developmental disabilities (Carter, Austin, &

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Trainor, 2011; Simonsen & Neubert, 2013). Department of Labor (DoL) (n.d.) statistics suggest that in the 2010–2012 period, on average, less than one-third (32.0 %) of working-age people with disabilities were employed as compared to over two-thirds (72.7 %) of people without disabilities. US DoL (2015) statistics also suggest that in 2014, 33 % of workers with a disability were employed part time, compared with 18 % of non-disabled workers. Similarly, US DoL (2012) found that in 2012, half of the individuals with disabilities who were not employed reported at least one barrier to employment, and the two most common barriers were their own disability (80.5 %) and lack of education or training (14.1 %).

Medicaid-funded supported employment. Since 2000, the number of individuals with intellectual/developmental disabilities receiving community living services through Medicaid has more than doubled and the number of persons receiving family support services has risen by nearly half. However, the number of individuals receiving supported employment services has remained flat since 2000 at approximately 100,000 individuals per year (Braddock et al., 2013). During a period where the research evidence documenting the efficacy of supported employment rapidly increased, Medicaid-funded opportunities for community-integrated employment for individuals with intellectual/developmental disabilities has stayed at a low level. During this same period, SVRAs eliminated sheltered or facility-based employment as an appropriate employment outcome for individuals receiving VR services (Wehman, Revell, & Brooke, 2003). From an expenditure perspective, supported employment accounts for less than 1 % of all Medicaid funding for individuals with intellectual disabilities.

While the number of individuals participating in supported employment has remained flat over the past 15 years, the number of persons with intellectual disabilities served in non-vocational day activity programs has increased to approximately 490,000 in 2013 (Braddock et al., 2013). Many individuals express a clear desire for competitive integrated employment, but service and expenditure data indicate that Medicaid-funded community service has not changed the balance between supported employment and non-vocational day options over the past 15 years.

Vocational rehabilitation services. Butterworth, Migliore, Sulewski, and Zalewska (2014), using data from the Rehabilitation Services Administration 911 data, examined the service participation and employment outcomes of VR clients with intellectual disabilities between 2004 and 2012. Among VR clients aged 16–21, individuals with intellectual disabilities accounted for approximately 15 % of all closed cases. Of these individuals, only about 30 % were successfully employed at the time of case closure. Employment outcomes were poor, with weekly earnings of approximately $200 and 24 h worked per week.

In comparison to the 16–21 age group, VR clients with intellectual disabilities aged 22–30 made up a smaller percentage of case closures (10 % versus 15 %), but were more likely to be employed at the time of closure (35 % versus 30 %). Significantly, the authors found that the employment outcomes for the two groups were virtually identical in terms of mean weekly earnings and hours worked per week.

In summary, individuals with intellectual disabilities represented a small percentage of VR case closures over the 8-year time period, only one-third were working at the time of closure, and earnings averaged about $200 per week, reflecting a mean hourly wage of $8.00 per hour.

Results of national surveys. Siperstein, Parker, and Drascher (2013), in collaboration with the Gallup Poll organization, conducted a telephone survey of over 1000 parents or caregivers of adults with intellectual disabilities 21 years of age or older. Fewer than half of respondents were in the labor force (i.e., currently employed or looking for work). Results indicated an employment rate of 34 % for the adults in the sample. This rate included 18 % in competitive employment, 13 % in a sheltered setting, and 3 % self-employed. The unemployment rate was 21 %, indicating that one in five individuals with intellectual disabilities were in the labor market and looking for work. Finally, over half (56 %) of respondents were out of the labor force, not employed and not seeking employment.

Stoddard (2014) analyzed data from the US Census Bureau's American Community Survey and found that the employment rate for persons with cognitive disabilities was 23.7 %. This total was significantly lower than employment rates for individuals with vision or hearing impairments, but much larger than the rates for individuals with significant limitations in self-care and independent living skills. The relationship between self-care skills and paid employment is examined further in the next section.

Youth Characteristics and Work Experience

Individual characteristics are associated with improved or reduced post-secondary vocational outcomes for youth with disabilities. Carter et al. (2011) examined skill factors associated with paid employment for high school students with disabilities. Their research revealed that students who communicated with others well and were independent in self-care were three times as likely to have paid work as students who had difficulty with communication or self-care. Additionally, the ability to travel outside the home independently was strongly associated with paid work, and more work experience resulted in an increased ability to navigate.

Carter et al. (2011) also examined family factors associated with paid work experiences during secondary school. Their research revealed the positive impact of high parental expectations. Students whose parents had self-support expectations had significantly increased odds of having paid work compared to students whose parents did not expect them to become self-supporting. Their research revealed that both a parent with at least some college experience and students with regular household chores were associated with increased odds of paid work.

Work Expectations and Activities Among SSA Beneficiaries

Many unemployed individuals with intellectual disabilities express a strong desire to work. For example, Butterworth et al. (2014), in their study of 9938 individuals served by state Intellectual and Developmental Disabilities agencies, found that 46 % of unemployed individuals expressed a desire for integrated employment. These individuals should be the focus of vocational training and job placement services, although most are currently unable to access the services and supports that they need.

Similarly, while many SSA beneficiaries have serious, chronic health conditions that limit their ability to participate in the work force, millions of beneficiaries whose conditions have stabilized or improved view themselves as able to work now or in the intermediate future. Livermore (2009), using data from the National Beneficiary Survey (NBS), found that 40 % of all unemployed SSA beneficiaries expressed employment goals or aspirations or who have engaged in employment rated activities in the 12 months prior to the NBS interview. This section describes the extent to which these individuals are able to establish and pursue vocational goals.

Challenges Faced by Individuals with Intellectual Disabilities

Seeking to Obtain Employment or Return to Work

Individuals with intellectual disabilities who attempt to enter into competitive, integrated employment face multiple challenges, including (1) low expectations on the part of employers, service providers, and family members; (2) employment discrimination; and (3) lack of access to the services and supports they need to succeed in their employment efforts. Researchers and policy makers have consistently documented these challenges (Kregel, 2009;

O'Mara & Kregel, 2005). These challenges are identified and described below.

Low expectations on the part of service providers. Many unemployed individuals with intellectual disabilities served by state Intellectual and Developmental Disabilities agencies who express a desire to work have not had the opportunity to establish employment goals. Butterworth et al. (2012) found that 72 % of unemployed individuals who expressed a desire for community-integrated employment did not have an employment goal in their Individualized Service Plans. Likewise, the majority of Social Security beneficiaries who express a desire to work do not have a specific employment service goal in their work incentive counseling plans. While many individuals express a desire to work, they are not receiving services that will support their employment aspirations.

Fear of losing federal benefits. Many individuals with intellectual disabilities receive federal cash benefits such as Supplemental Security Income, SSA Title II benefits, or Food Stamps. These individuals frequently receive inaccurate and incomplete information on the effect of employment and earnings on their cash benefits. Service providers such as special education teachers, vocational rehabilitation and workforce counselors, intellectual and developmental disabilities service coordinators, and peers and family members often warn individuals that employment may directly lead to loss of benefits (O'Mara & Kregel, 2005). As a result, individuals often make employment decisions and career choices based on totally inaccurate or incomplete information. This leads them to unnecessarily choose not to work or to restrict their work hours and earnings.

Fear of losing Medicaid. In addition to concerns about losing federal cash payments, individuals frequently cite fear of losing health care coverage as a major obstacle to employment (NCD, 2005). Medicaid provides access to the health care supports needed by individuals with individuals with disabilities with long-term medical needs. In addition to basic physician services, Medicaid also provides access to community services such as housing, employment services, personnel assistant services, and many other supports. Unfortunately, individuals are often told that working at a specific level will lead to termination of Medicaid benefits by service providers and family members unaware of benefit provisions that enable individuals to work for protracted periods of time without threatening their health care coverage in any way. Misinformation on the effects of earnings on benefits and health care is a widespread problem that impacts the pursuit of employment for individuals with intellectual disabilities.

Employer and community attitudes. Individuals with intellectual disabilities continue to face discrimination and poor attitudes as they attempt to access employment opportunities in their communities. Just as service providers continue to hold misconceptions about the effects of employment on federal benefits and health care coverage, many employers still base their hiring practices on misconceptions regarding the potential contribution of individuals with intellectual and developmental disabilities to the work force, such as the following: employees with intellectual disabilities experience high rates of absenteeism; employees with intellectual disabilities require expensive accommodations; employees with intellectual disabilities will cause my workers' compensation premiums to rise; employees with intellectual disabilities will cause my health insurance premiums to skyrocket; or if we hire employees with intellectual disabilities we won't be able to fire them if it doesn't work out.

For example, in 2008 the US Department of Labor, The Office of Disability Employment Policy (ODEP), conducted a study with employers representing a variety of industries and company sizes, for-profit and not-for-profit, in 13 major metropolitan areas of the USA (Domzal, Houtenville, & Sharma, 2008). Among the companies responding, approximately 19 % reported employing individuals with disabilities, while 13.6 % reported actively recruiting people with disabilities. One of the hiring challenges cited by 72.6 % of the employers was that a person with a disability could not effectively perform the work. Other major challenges cited were health care costs, worker compensation costs, and fear of litigation.

Lack of jobs in the local community. In many communities across the county, the availability of jobs in the local economy is somewhat limited. However, with the right combination of services, individuals with intellectual disabilities can access and succeed in prolonged employment (Griffin, Hammis, & Geary, 2007). Supported and customized employment approaches (Wehman, Inge, Revell, & Brooke, 2007) make use of job creation, job restructuring, self-employment, and other strategies to assist individuals with disabilities to obtain employment in situations where few jobs exist in the local workforce. The labor force pressures facing individuals with intellectual disabilities are significant, but services and supports are available that can assist them to become successfully employed even in communities with depressed labor markets.

Lack of education and training. The inability of many individuals with disabilities to access and benefit from additional education and/or training has hindered their ability to maximize their earnings and employment outcomes. Individuals face barriers when attempting to access post-secondary education (Getzel & Wehman, 2005). Efforts to promote access to one-stop career centers by people with significant work limitations have achieved mixed success. While lack of education and training may not completely eliminate access to employment for persons with intellectual disabilities, it too frequently results in individuals being chronically underemployed, working at wage levels that do not allow them to achieve their employment goals and achieve economic self-sufficiency.

Lack of job placement and employment supports. In many communities, the supply of high-quality job placement and long-term employment support service is inadequate to meet the demand for these services by individuals with intellectual disabilities. Despite recent improvements in clinical job placement services, including public agency partnerships with private businesses, employer-driven job placement programs (Habeck, Hunt, Rachel, Kregel, & Chan, 2010), and increased use of newly available technologies, the lack of high-quality job placement and employment support services continues to hamper the ability of individuals with intellectual disabilities to access and maintain employment.

Lack of necessary personal supports. Many individuals are able to obtain employment and enter the workforce; yet the lack of other needed supports often negatively affects their ability to retain employment for long periods of time (NCD, 2005). Lack of access to personal assistance services and specialized transportation may reduce their ability to maintain their attendance at work, forcing them to reduce their hours or resign their positions. Resources for many of these support needs are readily available in local communities if individuals are made aware of their existence and able to access them.

Summary. Individuals with disabilities have consistently reported a number of major challenges as they pursue the vocational goals and seek to access and maintain employment. Many of these challenges require improvements to the delivery of employment supports and coordination of support services. Other challenges, such as addressing the attitudes of employers and community service providers, and misconceptions regarding the effects of employment on benefit receipt and access to Medicaid create a difficult environment in which to successfully implement the evidence-based and best practices described below.

Federal Laws Address Employment of People with Disabilities

Congress has demonstrated a serious interest in the employment of individuals with disabilities. A number of federal laws address work, work preparation, and work supports. Several of the more significant laws and the relevant congressional purposes justifying the laws are below.

Law	Congressional purposes
The Rehabilitation Act of 1973	(1) To empower individuals with disabilities to maximize employment, economic self-sufficiency, independence, and inclusion and integration into society, through- (A) Statewide workforce development systems defined in section 3102 of this title that include, as integral components, comprehensive and coordinated state-of-the-art programs of vocational rehabilitation; (B) Independent living centers and services; (C) Research; (D) Training; (E) Demonstration projects; and (F) The guarantee of equal opportunity; (2) To maximize opportunities for individuals with disabilities, including individuals with significant disabilities, for competitive integrated employment; (3) To ensure that the Federal Government plays a leadership role in promoting the employment of individuals with disabilities, especially individuals with significant disabilities, and in assisting states and providers of services in fulfilling the aspirations of such individuals with disabilities for meaningful and gainful employment and independent living; (4) To increase employment opportunities and employment outcomes for individuals with disabilities, including through encouraging meaningful input by employers and vocational rehabilitation service providers on successful and prospective employment and placement strategies; and (5) To ensure, to the greatest extent possible, that youth with disabilities and students with disabilities who are transitioning from receipt of special education services under the Individuals with Disabilities Education Act (20 U.S.C. 1400 et seq.) and receipt of services under section 794 of this title have opportunities for postsecondary success
Individuals with Disabilities Education Act (2004)	(1)(A) To ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living; (B) To ensure that the rights of children with disabilities and parents of such children are protected; and (C) To assist states, localities, educational service agencies, and federal agencies to provide for the education of all children with disabilities; (2) To assist states in the implementation of a statewide, comprehensive, coordinated, multidisciplinary, interagency system of early intervention services for infants and toddlers with disabilities and their families; (3) To ensure that educators and parents have the necessary tools to improve educational results for children with disabilities by supporting system improvement activities; coordinated research and personnel preparation; coordinated technical assistance, dissemination, and support; and technology development and media services; and (4) To assess, and ensure the effectiveness of, efforts to educate children with disabilities

Law	Congressional purposes
Workforce Innovations and Opportunity Act (2014)	(1) To increase, for individuals in the United States, particularly those individuals with barriers to employment, access to and opportunities for the employment, education, training, and support services they need to succeed in the labor market (2) To support the alignment of workforce investment, education, and economic development systems in support of a comprehensive, accessible, and high-quality workforce development system in the United States (3) To improve the quality and labor market relevance of workforce investment, education, and economic development efforts to provide America's workers with the skills and credentials necessary to secure and advance in employment with family-sustaining wages and to provide America's employers with the skilled workers the employers need to succeed in a global economy (4) To promote improvement in the structure of and delivery of services through the US workforce development system to better address the employment and skill needs of workers, jobseekers, and employers (5) To increase the prosperity of workers and employers in the United States, the economic growth of communities, regions, and states, and the global competitiveness of the United States (6) For purposes of subtitle A and B of title I, to provide workforce investment activities, through statewide and local workforce development systems, that increase the employment, retention, and earnings of participants, and increase attainment of recognized postsecondary credentials by participants, and as a result, improve the quality of the workforce, reduce welfare dependency, increase economic self-sufficiency, meet the skill requirements of employers, and enhance the productivity and competitiveness of the nation

Employment Environments and Work Supports

Individuals with disabilities may work in any of several types of employment environments, including sheltered workshops and competitive employment. While approaches to employment should be individualized, research suggests that some types of employment (e.g., supported employment) are generally more effective than others (e.g., sheltered workshops).

Sheltered Workshops

Some individuals with disabilities work in segregated environments for less than minimum wage. The Fair Labor Standards Act of 1938, as amended ("FLSA"), authorizes the DoL, in certain circumstances, to allow employers to pay individuals with disabilities' subminimum wage. The FLSA justifies the subminimum wage as necessary to "prevent curtailment of employment opportunities for individuals with disabilities." The reduced wages are permitted in certain circumstances for individuals who are "… impaired by age, physical or mental deficiency, or injury …." Subminimum wage work often occurs in so-called sheltered workshops. Sheltered workshops are segregated environments where all or most employees have disabilities and engage in noncompetitive work for subminimum wage. Subminimum wage arrangements are losing their political support, and future legislation will likely discourage such arrangements.

Sheltered workshops are a controversial, if not disfavored, vocational option for individuals with disabilities (e.g., Armsby, 2015; Cimera, Wehman, West, & Burgess, 2012; Gill, 2005; Nicholas, Attridge, Zwaigenbaum, & Clarke, 2015). Cimera et al. (2012) suggested that "individuals with [autism spectrum disorders] achieve better vocational outcomes if they do not participate in sheltered workshops prior to enrolling in supported employment."

Supported Employment

Supported employment is an extensively research-based employment intervention for individuals with disabilities, including mental illness, autism, intellectual disabilities, traumatic brain injury, and developmental delay (Dowler & Walls, 2014; Wehman, Chan, Ditchman, & Kang, 2014; Wehman, Kregel, et al., 2003; West, Targett, Wehman, Cifu, & Davis, 2015). Wehman and Kregel et al. (2003) and Wehman and Revell et al. (2003) defined supported employment as "paid work occurring in integrated settings, with the provision of ongoing support services." Decades of substantial evidence demonstrates that supported employment has consistently better outcomes than traditional VR approaches, even for individuals with severe disabilities (e.g., Wehman et al., 1991; Wehman, Kregel, Revell, & West, 1990). In addition, Wehman and Kregel et al. (2003) and Wehman and Revell et al. (2003) demonstrated that supported employment is a cost-effective intervention.

Characteristics of supported employment. "Supported employment concentrates all the components of vocational intervention—training, counseling, and support—at the job site while the person is actively employed" (Wehman et al., 1991). The overarching goal of supported employment is for an individual to achieve competitive employment at a competitive wage (at least minimum wage) in a job that is open to the general public (not reserved for individuals with disabilities) in a socially integrated, community-based setting. "Essential elements of supported employment services have been pay for real work, integration in the workplace with nondisabled coworkers, long-term ongoing supportive services to facilitate job retention, placement of individuals with severe handicapping conditions, and interagency cooperation and funding of these services" (Wehman, Kregel et al., 2003; see also Wehman, Revel et al., 2003). Supported employment uses an assess-place-train approach that quickly results in paid, competitive, community employment for individuals with disabilities. Individuals are supported into employment and during employment, including facilitating the job search, applying for a job, the job interview, and liaison support between the employee, co-workers, and supervisors (Nicholas et al., 2015). Supported employment can be implemented in a wide variety of service sectors, including food service, retail, hospitality, agriculture, and hospitals (Nicholas et al., 2015; Project Search, 2011–2012).

Perhaps the most well-defined and researched method of supported employment is Individual Placement and Support ("IPS") (Drake, Bond, & Rapp, 2006). IPS uses a vocational specialist (job coach) to effectuate supported employment (Wehman, Kregel et al., 2003; Wehman, Revell et al., 2003). According to Dowler and Walls (2014), the six tenets of the IPS model are "(1) commitment to competitive employment; (2) eligibility based solely on client choice; (3) rapid job search; (4) well-integrated treatment and employment teams; (5) attention to client preference in job search; and (6) individualized employment support."

The Department of Labor promotes supported employment. The US Department of Labor promotes supported employment with its "Employment First" initiative, which the US DoL considers a critical priority. Employment First is "a framework for systems change that is centered on the premise that *all* citizens, including individuals with significant disabilities, are capable of full participation in integrated employment and community life" (US DoL, n.d.). The US DoL urged publicly financed systems (such as SVRAs) to "… align policies, service delivery practices, and reimbursement structures to commit to integrated employment as the priority option with respect to the use of publicly-financed day and employment services for youth and adults with significant disabilities" (US DoL, n.d.).

Federal law and supported employment. Supported employment was introduced in the late 1970s through university-based demonstration programs and by 1990 was incorporated into federal legislation to become an integral part of the VR program (Wehman et al., 1991). The Workforce Innovations and Opportunity Act (WIOA, 2014) supersedes the Workforce Investment Act of 1998 and amends the Adult Education and Family Literacy Act, the Wagner-

Peyser Act, and the Rehabilitation Act of 1973. As noted above, WIOA amends the Rehabilitation Act of 1973 and promotes supported employment, and revises or re-codifies the following pertinent definitions:

1. *Supported employment*: The term "supported employment" means competitive integrated employment, including customized employment, or employment in an integrated work setting in which individuals are working on a short-term basis toward competitive integrated employment that is individualized and customized consistent with the strengths, abilities, interests, and informed choice of the individuals involved, for individuals with the most significant disabilities—for whom competitive integrated employment has not historically occurred; or for whom competitive integrated employment has been interrupted or intermittent as a result of a significant disability; and who, because of the nature and severity of their disability, need intensive supported employment services and extended services after the transition described in [sections 1–13 of the Wagner-Peyser Act (29 U.S.C. 49 et seq.)] in order to perform the work involved.
2. *Supported employment services*. The term "supported employment services" means ongoing support services, including customized employment, needed to support and maintain an individual with a most significant disability in supported employment, that—(a) are provided singly or in combination and are organized and made available in such a way as to assist an eligible individual to achieve competitive integrated employment; (b) are based on a determination of the needs of an eligible individual, as specified in an individualized plan for employment; and (c) are provided by the designated state unit for a period of not more than 24 months, except that period may be extended, if necessary, in order to achieve the employment outcome identified in the individualized plan for employment.
3. *Customized employment*. The term "customized employment" means competitive integrated employment, for an individual with a significant disability, that is based on an individualized determination of the strengths, needs, and interests of the individual with a significant disability, is designed to meet the specific abilities of the individual with a significant disability and the business needs of the employer, and is carried out through flexible strategies, such as—(a) job exploration by the individual; (b) working with an employer to facilitate placement, including—(1) customizing a job description based on current employer needs or on previously unidentified and unmet employer needs; (2) developing a set of job duties, a work schedule and job arrangement, and specifics of supervision (including performance evaluation and review), and determining a job location; (3) representation by a professional chosen by the individual, or self-representation of the individual, in working with an employer to facilitate placement; and (4) providing services and supports at the job location.

Increasingly, federal laws combine to propose proven work supports, including supported employment, and encourage seamless transitions from school to competitive employment.

Current obstacles to supported employment. Although supported employment is arguably the most successful vocational intervention for individuals with intellectual and other disabilities, it is not always successful for every person. West et al. (2015) conducted a retrospective study of the reasons for separation from supported employment. The primary reason that an individual separates from supported employment is employer-initiated termination. Employer-initiated termination may be due to employee work performance, attendance and punctuality, conflicts with the supervisor or other co-workers, and other social and behavioral issues. Individuals may choose to separate from employment for medical reasons (whether pre-existing or new), for economic reasons (reduced hours, layoff, closure), a move, and transportation difficulties. Some individuals chose to separate from supported employment for positive reasons, such as further education, seeking a new job, or career advancement.

Project SEARCH

Project SEARCH High School Transition Model. The Project SEARCH High School Transition Model of school-to-employment transition for youth with significant disabilities has received numerous accolades and has been widely adopted by employers in an effort to hire and retain individuals with disabilities. In addition, educational and workforce development agencies have supported the model as a means of providing work-based learning opportunities leading to employment for youth with disabilities. The model is unique in that business needs act as the impetus for employing youth with disabilities versus the responsibilities of local education and rehabilitation agencies to provide teaching and learning experiences for transition age youth. In providing demand-side employment services, rehabilitation professionals and workforce development specialists provide services directly to employers and transition-aged interns to address the employers' needs for qualified employees. This model has been applied to industries including hospitals, universities, large banking central offices, and government centers. Analysis of the components of the model reveals that it includes all five of the categories of practice from the Taxonomy for Transition and meets the National Standards and Quality Indicators (Test, 2012).

Project SEARCH interns use independent means of transportation (public or private transportation, not a school bus) to arrive directly at the business. The work day includes approximately 1.5 h of Employability Skills curriculum and 5 h at their internship (including lunch and travel time to the internship sites).

Project SEARCH has high school and adult programs. Project SEARCH high school internships are typically for individuals between the ages of 18 and 22, though individuals in the 23–30 age range can be included if funding is available to support participants that are beyond school eligibility. High school student interns should be finished with their high school credit requirements for graduation, certification, or completion. Adult programs typically target young adults aged 30 and under; however, consideration of adults older than 30 could be an individual site decision.

Project SEARCH Critical Core Model

Project SEARCH training and placement program is a work-based learning model for high school transition that was developed at Cincinnati Children's Hospital Medical Center. It is designed for students with cognitive or other development disabilities. The program differs from traditional work-based learning models in the (1) degree of integration of employer, educational agency, and SVRA resources; (2) the intensity and duration (700 h) of supervised work experience; and (3) delivery of customized job placement, job coaching, and ongoing support services provided entirely in the participating business.

Program Components

Business-driven training and employment program. The host business is responsible for leading the development of the policies and procedures that guide the program, such as Human Resource policies, risk management (health and safety) procedures, quality standards and quality assurances, internship and placement supervision procedures, and other necessary policies, as well as committing the staff time of a program liaison for the classroom program component.

Support agency collaboration. The local school district, state VR agency, and local Community Rehabilitation Program (CRP) all commit resources to the program. The local school district assists with student recruitment and staffing of the classroom-based component of the program. The state VR agency is responsible for assessing all project participants to determine eligibility of DRS services providing funding to a local CRP to provide job coaching services. The local CRP assigns site-based job coaches to provide training and support to students throughout the internship and placement phases of the program.

Student/family decision making. The student and his or her family receive the support necessary to make decisions related to program participation, selection of internship sites within the host company, pursuing employment, accepting a position, and the amount and type of ongoing support services received.

Student-specific assessment activities. Initial assessments occur through record reviews, observations, and interviews conducted prior to the student's enrollment. Situational assessments are conducted during the first 4 weeks of the site-based program, with assessments continuing throughout the course of the internships.

Structured sequence of worksite rotations. Over the course of the 9-month training program, students participate in a sequence of unpaid site-based student internships, viewed as analogous to the clinical rotations that are part of every medical school curriculum or the apprenticeships in other career-technical programs. Potential student worksites are identified through a continuous collaborative process involving by Project SEARCH staff and specific worksite supervisors. Students who complete the entire 9-month program receive over 700 h of customized, supervised work experience.

Classroom-based instruction. Students participate in 6 h each week in classroom-based instruction that focuses on a Project SEARCH curriculum that focuses on the functional employment and independent living skills that maximize the student's ability to benefit from the training and placement program. Skills in this curriculum include identifying job strengths, preferences and interests, communicating with supervisors and co-workers, behaving professionally, communicating with customers, accepting correction, asking for and taking a break, calling in sick, late, or requesting time off, preparing a resume, sitting for a job interview, managing personal finances for everyday expenses, and other such important life skills.

On-site systematic instruction. Evidence-based systematic instruction strategies are used during the worksite internships and placement activities. Specific strategies include job and task analysis, reinforcement, prompting, visual and/auditory supports, maintenance, and fading strategies.

Behavior specialist on-site support. A behavior specialist (either a positive behavior support facilitator or a board-certified behavior analyst) provides on-site support weekly and as needed. The behavior specialist observes students on internship sites and in the classroom to complete functional behavior assessment, design behavior intervention plans, design individualized instructional strategies, and provide consultation to on-site Project SEARCH staff as well as business mentors.

Intensive staff training. The on-site job coaches must demonstrate a wide array of sophisticated skills. Staff members complete an initial 80-h training program that covers the characteristics of young adults with disabilities, student and family communication, student assessment, program planning, job analysis, systematic instruction, data collection, and other content. After the initial training, the job coach will be observed and provided feedback daily during the initial 9 weeks of program implementation and at least twice weekly thereafter.

Student-specific job placement. Job placement can occur at any time during the program, but usually takes place within the last few months. Once a placement opportunity is identified, the teacher or job coach performs a job site analysis that forms the basis of subsequent training. Upon hiring, the student's status changes to employee with all the associated responsibilities, wages, and fringe benefits. Project staff will continue to provide ongoing support services for the remainder of the year to enable to participant to learn the job, perform the job to the satisfaction of the employer, and adjust to the new situation. For these students not hired by the training site businesses, DRS will provide job placement and support as necessary to enable the students to obtain and maintain employment.

Ongoing support services. Upon completion, participants who have been previously determined eligible for VR services will continue to receive ongoing support funded by DRS through a local supported employment vendor. The amount and type of services will be based on the support needs of the individual student and be provided as specified by the DRS—Supported Employment provider vendor agreement.

Student and business feedback. Student and employer satisfaction is assessed during all phases of the program. Student satisfaction is assessed during the internship, classroom instruction, and placement phases of the program. Internship supervisors and host company administrators will provide regular feedback on student performance and Project SEARCH staff support throughout the program.

Evidence base for Project SEARCH. Research demonstrates the efficacy of Project SEARCH. Schall et al. (2015) found that Project SEARCH participants with autism spectrum disorder required fewer hours of intervention, achieved a mean higher wage, and had a higher retention rate than their peers who received only supported employment.

Job Placement

Job placement services are simply services that attempt to place individuals with disabilities in jobs for which they are well suited. Job matches are typically developed based on formal and informal assessments by a job placement agency. SVRAs offer job placement services. An individual must meet eligibility criteria to qualify for SVRA services, but even eligible individuals are not guaranteed services. An individual may be placed on a services waiting list, during which time they receive no services or supports. A referral for SVRA services can come from the individual or another person, including family, school, and health care providers.

Marriott Bridges from School to Work

Marriott Bridges from School to Work ("Bridges") is a national job placement program that was founded in 1989 by the Marriott Foundation for People with Disabilities. The program's identified priority is working with youth aged 17–22 who have documentation of disability through the SVRA, an IEP, or medical professional; who are US citizens; and—most importantly—who have a genuine commitment to employment success. The program is non-categorical, meaning that it does not focus on a particular disability.

Bridges relies on strong partnerships. Bridges partners with other service provides, such as public schools, VR, local workforce agencies to identify potentially eligible youth. Typically, program participation begins in a student's last year of high school, though out-of-school youth may also participate. At the outset, participants are administered customized employment assessments and are offered work-readiness workshops. During this time, Bridges staff and the participants get to know one another. These activities occur in the context of vocational planning and goal setting. The best possible job matches are suggested, the appropriate supports are provided, and customized staff intervention is provided for each participant. Bridges partners with over "4500 employers, large and small, and across diverse industries." Typically, Bridges program participation is 15–24 months.

Evidence base. Bridges reports that of the more than 4500 employers, large and small, and across diverse industries that have partnered with Bridges from School to Work to meet their hiring needs nearly 40 % have made multiple hires through the program and partners generally report consistent satisfaction with the program. Since its inception, Bridges has placed more than 2700 students in internships with over 900 employers. Moreover, "87 % of the young people who complete an internship with Bridges receive an offer of ongoing employment." (R. Marriott, interview with Cooper, C. and Donovan, M., n.d.). Hemmeter, Donovan, Cobb, and Asbury (2015) demonstrated a correlation between Bridges participation and higher employment rates, higher earning capacity, and less SSI and/or DI participation than their peers who were on SSI at age 17.

Transition Services

Research repeatedly spotlights the difficulty encountered by students as they transition from secondary to post-secondary life, particularly employment. Planning for the transition from school to work begins in high school (by age 16) for all students, and can begin earlier for other students or by individual state mandate. Despite this focus on transition, research (e.g., Carter et al., 2011) demonstrates that early work experiences elude many youth with severe disabilities.

Individualized education program. Eligible students with disabilities are provided special education and related services in accordance with the IDEA. The IDEA requires that each eligible student has an Individualized Education Program, which sets forth the individualized academic and functional goals, accommodations, services, and educational environment of a student with a disability. The IEP is reviewed and revised at least annually by a multidisciplinary team that includes the student's special education teacher and parents. The IDEA requires that "not later than the first IEP to be in effect when the child turns 16, or younger if determined appropriate by the IEP Team, and updated annually, thereafter, the IEP must include transition goals and services." If transition will be discussed by the IEP team, the student must be invited to participate in the IEP meeting. Self-determination and self-advocacy by the student are important aspects of transition IEP development. If the student does not attend the IEP team meeting, the public school must take other steps to ensure that the IEP team considers the child's preferences and interests (IDEA, 2004).

The foundation of IEP transition goals and services is age-appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills. Transition goals must be appropriate for the student in light of the results of transition assessments, the student's preferences, and all other relevant information. The student's transition services must be designed to assist the student in reaching those goals. Transition services include the student's courses of study and any additional services related solely to transition.

IEP transition services and supported employment. The IDEA specifically provides that transition services may include supported employment. Transition services are defined as "a coordinated set of activities for a child with a disability that [are] designed to be within a results oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation …" 20 U.S.C. 1401(34). Transition services are "based on the individual child's needs, taking into account the child's strengths, preferences, and interests; and includes—(1) instruction; (2) related services; (3) community experiences; (4) the development of employment and other post-school adult living objectives; and (5) if appropriate, acquisition of daily living skills and provision of a functional vocational evaluation. Transition services for children with disabilities may be special education, if provided as specially designed instruction, or a related service, if required to assist a child with a disability to benefit from special education" 34 CFR 300.43.

Interagency linkages. IDEA promotes interagency linkages between public schools and employment support agencies, such as vocational rehabilitation, and the Rehabilitation Act of 1973 contains supporting language. Though interagency linkages are encouraged where appropriate, the public school remains ultimately responsible for transition services. If another agency fails to provide the transition services described in the IEP, the public school must "reconvene the IEP Team to identify alternative strategies to meet the transition objectives for the child set out in the IEP" (IDEA, 2004) 34 C.F.R. 300.324(c)(1).

The IDEA's transition requirements do not relieve any other public agency of their "responsibility to provide or pay for any transition service that the agency would otherwise provide to children with disabilities who meet the eligibility criteria of that agency" (IDEA, 2004) 34 C.F.R. 300.324(c)(2). Currently, only 4–14 % (depending on the state) of transition-age youth with disabilities even apply for SVRA services (Honeycut, Thompkins, Bardos, & Stern, 2015).

Comprehensive Transition Models

Comprehensive transition models are designed to provide a detailed framework of transition principles, programs, practices, and services that can guide effective transition planning. The purpose of such a model is to facilitate the delivery of evidence-based practices in programs designed for youth with disabilities. The use of the model assists transition practitioners in assuring that transition-aged students with intellectual disabilities have access to evidence-based practice in the development of their individualized programs.

The taxonomy for transition programming—One of the most widely referenced, comprehensive, conceptual frameworks for the design and delivery of transition services is The Taxonomy for Transition Programming (Kohler, 1996; Kohler & Field, 2003; Test, 2012). This taxonomy includes the identification, organization, and rating of numerous transition practices derived from the research literature, evaluation studies, and model transition project. Kohler's conceptual framework for transition programming consists of five categories of practice. They are (1) student-focused planning, (2) student development, (3) interagency and interdisciplinary collaboration, (4) family involvement, and (5) program structure and attributes. These categories are comprised of several clusters, each with numerous transition practices. The taxonomy provides a rating for each practice in order of importance in transition planning and programming.

National Alliance for Secondary Education and Transition: National Standards and Quality Indicators (2005). More recent efforts have also affirmed the significance of Kohler's Taxonomy for Transition Programming as a conceptual model for transition service delivery. Commencing in November 2003, the National Alliance for Secondary Education and Transition (NASET), composed of more than 40 national organizations and individuals representing general education, special education, career and technical education, youth development, post-secondary education, workforce development, and families, worked to develop benchmarks that reflect quality secondary education and transition services for all students. These efforts resulted in the development of national standards and quality indicators based on findings of current research in the areas of effective schooling, career preparatory experiences, youth development and youth leadership, and family involvement.

Guideposts for Success (2nd Ed.; National Collaborative on Workforce and Disability/Youth [NCWD], 2006) was developed through funding from the Office of Disability Employment Policy (ODEP), based on an extensive review of research, demonstration projects, and effective practices covering a wide range of programs and services, including youth development, quality education, and workforce development programs. Five categories represent the *Guideposts for Success*: (1) school-based preparatory experiences, (2) career preparation and work-based learning experiences, (3) youth development and leadership, (4) connecting activities, and (5) family involvement and supports. The purpose of the guideposts and corresponding activities is to provide a framework for families, state and local policy makers, youth service professionals, and youth as they make the transition into adult life. The NCWD/Youth indicated that all of their work is research based and has participated in the development of the NASET *National Standards and Quality Indicators* (2005). Therefore, empirical evidence that supports the development of each category is the same used by NASET.

The similarities between these transition models are striking. All of them speak to the need for student development and self-determination, youth leadership, interagency collaboration and connections, family involvement and support, and transition program development and implementation. They are designed for students with all types of disabilities, including transition-age youth with ASD. While these models have formed the basis for a variety of promising practices (Landmark, Song, & Dalun, 2010), few randomized controlled trials have been conducted to empirically validate these models. One key exception is the SSA Youth Demonstration Project (Fraker & Rangarajan, 2009), a randomized study that is testing the waiver of certain Social Security Administration provisions in combination with employment supports.

The Natural Supports Transition Model. The purpose of the Natural Supports Transition Model is to develop and implement a natural supports approach to achieving competitive employment outcomes for transition-age youth with significant disabilities. Natural supports are defined as human or technical resources that are available or easily offered in a setting to facilitate integration, acceptance, and satisfaction, and to promote the goals and interests of everyone in a given setting. These include supports at various levels, namely organizational, physical, social, training, services, and community (Corbière et al., 2014). The seven-step natural support model consisted of determining individual needs and preferences; brainstorming potential options; assessing job and community supports; identifying individual choices; developing strategies for accessing supports; evaluating support effectiveness; and arranging for ongoing monitoring.

Employer-Based Demand-Side Approaches

For many years, employment training placement programs for individuals with disabilities relied almost exclusively on "supply-side" approaches, which prepare individuals with job skills generally needed for employment. Supply-side approaches do not focus on factors specific to jobs that employers need to fill (Chan et al., 2010). However, in recent years new employer models of disability employment practices have emerged that reflect major efforts by multiple companies to embrace individuals with intellectual disabilities as part of the workforce (Habeck, Kregel, Head, & Yasuda, 2007).

These demand-side (employer initiated and directed) approaches represent a significant departure from conventional supply-side efforts that have failed to solve the intractable problem of lack of employment participation on the part of people with disabilities (Habeck et al., 2010). Many businesses have received national recognition for initiating highly promising new programs that are being promoted and disseminated by major business organizations, such as the Business Leadership Network, as effective ways for companies to incorporate individuals with disabilities into their workforce. While each of the employer-based models is unique, there are common practices that many of the companies use when implementing and replicating their model programs.

The initial success of these new employer-based hiring, advancement, and retention programs has received widespread attention. Many other employers are engaged in efforts to replicate these new program models in their businesses. For example, Walgreens is attempting to expand its practices into other distribution sites around the country and throughout the company's national retail sites.

The existing employer-based approaches can be summarized into six different models. Each of these is summarized below.

Integrated Workforce Models attempt to employ sizable numbers of individuals with disabilities in a single site, provide job training and support through company personnel or collaborative arrangements with local employment service providers, and make extensive use of job redesign, environment modifications, and rehabilitation engineering.

Intensive Internship Models provide persons with disabilities individualized, long-term internships, either paid or unpaid, that allow them to learn job skills in a variety of different settings. Internships may lead to competitive employment in the internship setting or placement into another competitive job.

Internal Disability Resource Center Models establish a regional or site-based program to coordinate functions such as developing collaborative relationships with community service providers, advocate for cultural change within the unit, organize centralized accommodation supports, and other related functions.

Multi-Site Company Wide Supported Employment Models attempt to use a standardized company protocol to place one or more persons with disabilities into multiple company stores or sites through a supported employment approach that relies on either company or external job coaches.

Collaborative Disability Management Models operate comprehensive absence management and return-to-work programs that coordinate services from multiple units in the business to enable the employee and supervisor to be directly involved in all aspects of return to work, including job or work site redesign, accommodation, placement into a new position if necessary, and ongoing support.

Long-Term Employee Development Models attempt to establish a disability-friendly work culture by training all employees in the concepts of diversity acceptance, provide multiple options for individual development and career advancement, and use an embedded retention specialist.

Businesses in each of the models are using one or more of the 31 intervention strategies identified in Table 32.1 (Habeck et al., 2010). Each of these strategies is relevant to the employment and retention of individuals with intellectual disabilities.

Over the past decade, research has consistently found that adolescents and adults with intellectual disabilities participate in the workforce at a very low rate. Siperstein et al. (2013) found that nearly half of these individuals are not currently in the labor force, meaning that they are unemployed and not seeking employment. For the one-third of the population that is employed, 13 % are working in sheltered workshops, leaving only 21 % in competitive integrated employment.

The federal/state Medicaid system continues to emphasize non-vocational day service options that do not lead to competitive employment or increased financial independence. In the Medicaid system, individuals served in non-vocational day programs outnumbered persons in supported employment by a ratio of four to one. The number of individuals with intellectual disabilities served by SVRAs has remained flat over the past decade and only one-third were in competitive employment at the time their cases were closed.

The two main federal programs that fund employment services for individuals with intellectual and developmental disabilities remained too focused on non-vocational service options and closure into noncompetitive employment alternatives. The result is an imbalanced, ineffective vocational training system that is not expanding its capacity, increasing its efficiency, or meeting the needs of individuals with intellectual disabilities. It is clear from the analysis of national data sets that the system has stagnated in spite of recognition of the importance of competitive employment alternatives to non-vocational and sheltered options.

The lack of vocational training service capacity is unfortunate because it is inconsistent with research findings that many individuals with intellectual disabilities express a desire to work and have taken actions toward obtaining employment. Lack of access to vocational training and support services in their local communities is frequently identified as a barrier to employment by individuals seeking competitive jobs. The result is hundreds of thousands of adults with intellectual disabilities needlessly removed from the workforce, living at or near the poverty level, and dependent on federal disability benefits as their sole source of support.

There are a number of vocational training options that have been documented to effectively assist individuals with intellectual disabilities to obtain and maintain employment. Foremost among these options is supported employment, which has an extensive research base that includes multiple random clinical trials, a 30-year history of nationwide success, and recognition by the Institute of Medicine as an evidence-based practice.

Supported employment has been fairly criticized for the low wages and part-time employment status of many participants. However, supported employment outcomes are far superior to those achieved in facility-based employment,

Table 32.1 Employer-based demand-side model intervention strategies

1. Support of corporate leadership
2. Charismatic and iconic leader to drive and support employment of individuals with disabilities
3. Regional staff member dedicated to working with local stores to increase hiring of employees with disabilities and promote use of external job coaches
4. Compelling vision and strategic goals include hiring and retaining employees with disabilities
5. Well-defined opportunities for growth and development (e.g., internal recruitment, tuition reimbursement, career coaching)
6. Inclusion of employees with disabilities viewed as component of overall initiative to be preferred employer in local community
7. Identifying and preventing job-related health risks
8. Promoting healthy lifestyles and disease prevention
9. Vocational rehabilitation-funded external job coaches who provide training and supports to employees
10. Company-funded job coaches who provide training and supports to the employees
11. Employee training and supports provided through a preferred vendor relationship with local community rehabilitation provider
12. Employer-developed standardized supported employment (job coach) protocol for providing training and support in all company sites
13. Extensive orientation program and work ramping provided by company
14. Intensive partnership approach for retaining at-risk employees
15. Long-term supervision provided by company supervisors
16. Embedded retention specialist to provide long-term support
17. Extensive use of job and work site redesign
18. Supervisor receives specialized training in managing and supporting workers with disabilities
19. Supervisor responsible for identifying the need for, designing, and implementing accommodations
20. Placement into paid internship experiences prior to job placement
21. Placement into 9-month unpaid internship experiences prior to job placement
22. Business-wide internship sponsorship program
23. Recruitment through preferred community service provider
24. Recruitment through partnership with public schools
25. Recruitment through partnership with vocational rehabilitation
26. Recruitment through partnership with workforce development board
27. Highly standardized, comprehensive accommodation process, with all roles clarified and key time frames and decision points identified
28. Extensive use of environmental accommodations, job redesign, and rehabilitation engineering
29. Extensive use of job creation and customized employment strategies
30. Supervisor involvement in all phases of the design and implementation of accommodations
31. Centralized accommodation budget

equivalent to other services provided to clients with intellectual disabilities by SVRAs, and successfully for many individuals who have been unable to secure employment through other placement programs.

There are two specific subtypes supported employment service models that are developing a growing research base. The first is customized employment (Griffin et al., 2007), which is very similar to supported employment, but (1) places additional emphasis on an individualized assessment approach that involves family and community members in the assessment process, and (2) uses specialized job development strategies that are applicable to individuals that have been otherwise unable to access the labor market.

The second specialized supported employment model is Project SEARCH that combines supported employment with components of two other models. Project SEARCH is a transition program,

Table 32.2 Employment status of individuals with intellectual disabilities

Employment status	Percentage (%)
Working in competitive employment	21
Working in sheltered employment	13
Not working—seeking employment	21
Not in the labor force (not employed and not looking for work)	45

focusing on adolescents in their last year of school and relying on a series of individual internships (work-based learning) within a host company for an entire year. It is also an employer-based model in which a host company (hospital, bank, office complex, etc.) works with a single supported employment provider agency to establish internships and potential job placements for participants.

The strength of the Project SEARCH model lies in the quality and intensity of its internships, the use of supported employment systematic instruction strategies, and employer support. Participants in Project SEARCH will receive 700 h of training and internship support over the course of a school year, far beyond the depth of experience provided in other internship programs. This level of intensity allows participants to develop the business communication and social skills, workplace safety competence, and specific job skills necessary for long-term employment success. Project SEARCH also incorporates the well-documented supported employment job site training and ongoing support strategies that rely on systematic instruction and applied behavior analysis techniques. Finally, Project SEARCH is designed to assist the business as well as the participants. Host companies benefit from the addition of high-quality employees who have completed that Project SEARCH program and improved morale of the entire workforce, which stems from participation in the program.

Not all individuals with intellectual disabilities require the intense training and long-term support offered by supported employment. Many individuals would benefit from job placement assistance, which includes assessment services to identify their career goals and desires, job placement services that identify an employment opportunity that meets their needs, and short-term assistance in adjusting to the employment situation, much of which can occur before the individual enters the job setting. Sufficient evidence exists to document the effectiveness of this approach with persons with intellectual disabilities, with the Marriott Bridges to Employment program serving as a prime example of a job placement program that demonstrates long-term success.

There are a number of comprehensive transition models that have been proposed for addressing the needs of adolescents with intellectual disabilities. Several of these consist of lists of quality indicators and the identification of promising practices used across multiple states. Some efficacy data exists to show the positive results that can be achieved by these projects, but more rigorous evaluation designs should be used to identify the specific program features that correlate with long-term employment success.

Finally, one of the most promising but least researched service models is employer-driven demand-side approaches. Several models have developed, including employing large numbers of individuals with intellectual disabilities within a large single work site. Other companies have dedicated a single site as a training facility in which individuals learn job skills and receive intensive training and orientation to the workplace and then are permanently placed into another one of the company's facilities. Another model has evolved in which a public–private partnership is developed between a company and an SVRA. The SVRA will ensure a sufficient number of qualified applicants for positions and may provide employment specialists who work in the business. The business then trains the public agency staff on their corporate culture, processes, and protocols, which will greatly enhance an individual's likelihood of long-term employment retention. Conducting research on these types of models is challenging, since much of the data required is sometimes viewed as proprietary by the business. However, the potential of this type of approach is so promising that efforts must be made to compile the information necessary to allow replication or adaptation by other private and public entities.

Conclusion

Many individuals with intellectual and developmental disabilities aspire to work, and most would prefer to engage in competitive employment in integrated settings. This chapter described the numerous work supports and services that are available to qualified individuals with disabilities, and the agencies that provide those services. Although individuals with disabilities face obstacles to employment, those obstacles can generally be mitigated or eliminated through appropriate work supports and services. Among those obstacles are low expectations and misinformation. Service providers should have and convey high vocational expectations, and provide individuals with disabilities accurate work-related information or refer the individual to the correct professional or agency. In sum, individuals with intellectual and developmental disabilities should be encouraged to develop and pursue employment goals and, especially with the appropriate services and supports, can expect to succeed in the workplace.

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Leisure Skills

33

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Introduction

This chapter describes a variety of issues associated with leisure and persons diagnosed with intellectual and developmental disabilities (IDD). Sections cover evidenced based approaches towards assessing and establishing leisure behavior, use of leisure behavior as therapy or in enhancement of other skill domains, and some creative examples of treatment applications associated with both. Additional sections include a review of barriers for leisure engagement for this population, current status of the application of leisure technologies, as well as related mental health and physical health of siblings and caregivers of individuals diagnosed with IDD.

Defining Leisure

Anderson, Lakin, Bruininks, and Hill (1987) defined leisure activities as being "…engaged in culturally normal living experiences, interact[ion] with a variety of persons…[and]…access to community settings for social, leisure and recreational activities [with] friendships and support networks outside of staff and family…" Almost 30 years later, Badia, Orgaz, Verdugo, and Ullan (2013) defined leisure as "…available free choice time and the individually selected activities that characteristically are not related to work or other obligatory forms of activity, which are expected to promote feelings of pleasure, friendship, happiness, spontaneity, fantasy or imagination, fulfillment, creativity, self-expression and self-development." Very simply, the Merriam-Webster dictionary (2015) defines leisure as "…time when you are not working: time when you can do whatever you want to do; enjoyable activities that you do when you are not working." Thus, leisure is understood to be the time in a day where individuals can do enjoyable activities they choose to do and with whomever they choose to do them with.

Typically, leisure activities are identified or defined simply via topographical descriptions or classes of activities (exercise, hobbies such as stamp collection, sports, hiking, bird watching, channel surfing, etc.). While classification and

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description of activities provides needed scope to leisure research, it lacks precision and introduces many related problems. An endless taxonomy of activities may not lead to a useful understanding of motivation or preferences for engagement in certain activities over others. Topographical definitions of leisure fail to capture moment-to-moment shifts in preferences of the individual, account for the influence of environmental variables on behavior, or provide precision across multiple exemplars of leisure. A contextual component such as a functional response of the individual evoked in relation to its environment, if added to the definition of leisure, might offer a more functional and practical approach to understanding leisure behavior.

Descriptions or explanations of leisure activities from a colloquial or topographical approach (i.e., due to strong preferences or positive feelings) are subject to inconsistencies and vary between verbal communities. This approach yields nothing more than a guess and fails to account for important aspects of leisure activities or the means to establish them (i.e., prediction and influence). For example, leisure time for most people may generally consist of activities thought of as positive or the avoidance of negative, effortful, or aversive activities (e.g., manual labor). However, not all leisure activities are void of the latter qualities. Performing chores or manual labor could function as a leisure activity when the majority of a person's time consists of sitting behind a desk. In addition, not all leisure activities are devoid of risk or harm for an individual. Substance use, for example, for some individuals, could be conceptualized as a leisurely activity.

A functional approach can easily account for variation of topographical activities, capture the effects that engagement in the activity has on the individual, and foster an understanding as to how the leisure behavior came about or what variables maintain it. Behavior Analysis offers a number of functional explanations beyond an avoidance of aversive events, positive reinforcement, or history to account for why a particular class of behaviors might be engaged in or chosen over others by accounting for such events as states of relative deprivation, habituation, satiation, and learned motivating operations, verbal community, and relational frame theory. A contextual or functional definition of leisure activities would account for an individual and their environmental relations with respect to leisure activity.

According to Gilbert (2007), leisure is the opportunity and time to complete other things outside of occupations. In other words, engagement or selection of a leisure activity is a result of the relationship between availability and frequency of engagement of activities for the organism. Gilbert (2007) noted that we typically view leisure associated with regard to a time aspect, however, opportunity for engagement is equally important. "Opportunities without time mean nothing" (p. 11). Gilbert went on to note that "time, dead on our hands, affording no opportunities, has even less value."(p. 11–12). This last statement seems to describe the overall state of leisure for many individuals with developmental or intellectual disabilities and also calls into question other needed components for a functional definition of leisure, ability, and competence. If the leisure activity is not within the individual's repertoire or at insufficient strength to be adequately performed, it is unlikely that it will be engaged in or that it will result in naturally reinforcing consequences. Leisure may be defined as an activity engaged in by an individual dependent on strength of repertoire, as well as the time and opportunity to engage in that repertoire, that is functionally related to that individual's environment.

Why Leisure is Important

Leisure activities are very important for individuals with IDD. Such activities help to include individuals into the community, improve overall quality of life, and contribute to learning of adaptive skills and their generalization. In fact, leisure could be considered a major domain of life, similar to work, family, or school (Badia et al., 2012; Cordes & Howard, 2005). Participation in leisure activities enhances physical well-being and can improve self-perception, emotional and social behaviors, happiness, enjoyment, parent relationships, autonomy, language abilities, and psychological well-being (Badia, Longo et al., 2013; Cordes & Howard, 2005; Glausier, Whorton, & Knight, 1995). Leisure activities that are also physical in nature help to improve cardiovascular health, balance, muscle strength, and quality of life (Bartlo & Klein, 2011; Fong, Tsang, & Ng, 2012). Being involved in physical leisure activities can result in greater mobility and lessen chronic conditions (Benz, Halpern, & Close, 1986). This becomes especially important as individuals with IDD age and adaptive skills and behaviors begin to decline (Bigby, 1992). And, given that the life span of individuals with IDD has increased dramatically (Bigby, 1992; Cordes & Howard, 2005), leisure is an area that should be considered in order to ensure quality of life (Bigby, 1992; Cordes & Howard, 2005).

In addition, leisure activities can alleviate behavior problems (e.g., aggression, self-injury, property destruction, stereotypical movements), especially for those who engage in behavior problems when alone or when the environment has few opportunities for engagement (Sigafoos & Kerr, 1994). Providing an increase in leisure activity possibilities has been found to decrease maladaptive behaviors in the presence of those activities (Sigafoos & Kerr, 1994). Consideration of how individuals with IDD might spend their time becomes very important when one considers that some individuals have been reported to spend up to 75 % of their leisure time without an activity or engaging in problem behaviors (Wilson, Reid, & Green, 2006). Finally, leisure activities help to balance the demands of vocational and domestic activities (Aveno, 1987; Glausier et al., 1995).

Notwithstanding the benefits of leisure activities, participation in such activities is also a human right, not a privilege (Glausier et al., 1995). The United Nations Convention on the Rights of the People with Disabilities requires states to "… ensure full participation in the community and their full enjoyment of all human rights and fundamental freedoms on an equal basis…" (cited by Badia, Longo, Orgaz, & Gomez-Vela, 2013).

Unfortunately, Badia et al. (2013) reported individuals with IDD are at high risk for limited participation in leisure activities. Furthermore, research in this area is significantly lacking in comparison to other life domains (Cordes & Howard, 2005). Individuals with IDD tend to participate less than typical peers or they participate in segregated activities, such as daycare settings (Badia et al., 2012; Bigby, 1992). Leisure activities are often chosen by others, do not include preferences of the individuals, and tend to be home-based (Bult, Verschuren, Jongmans, Lindeman, & Ketelaar, 2011; Glausier et al., 1995). Interestingly, even with limited participation, many individuals with IDD are reported to understand the importance of leisure (Cordes & Howard, 2005). In his classic description of "competence" and the world of work and organizations, Gilbert (2007) noted that leisure has taken on disreputable connotations of laziness and frivolity, but added that it is "the most desirable and valuable aim of any attempt to improve human competence" (p. 11) and may well be an important permanent product in the evaluation of a treatment's overall effectiveness. Essentially, the more effectively a task is accomplished or a treatment or training is completed, the more time there is for leisure for all those involved with the task completion, treatment, or training. Leisure may also serve as the most natural outcome of an environmental contingency to maintain treatment results and reinforce improvements in competency. As this chapter will discuss, leisure is essential to quality of life for individuals with IDD, and their loved ones and caregivers. Research into how to promote leisure or make leisure activities more potent with respect to improvements of quality of live may enhance this as well. Simply put, the better that use of leisure time and opportunities available for it, the more we get out of it.

Clinical and Research Knowledge Concerning Leisure and its Related Concepts

The term "leisure" is related to a variety of other issues in the field of IDD. Indeed, an ERIC search specifying "Leisure and Disabilities" yields over 700 articles since 1938. However, adding the term "evidence based" to such a search results in fewer than 50 articles. An analysis of articles published in the late 1980s until 2000 reveals that the vast majority of the published literature was composed of reports from a variety of government and human service organizations and less than a third of the articles were from professional journals. This distribution changes radically after 2000 to include a wide range of philosophical, clinical, and research articles relevant to leisure and intellectual disabilities. We have categorized much of this literature to facilitate an analysis of what is known about leisure today in terms of the epidemiology of leisure activities for those with IDD, related descriptions and survey tool development, standard group comparison research using hypothetical constructs as independent or dependent variables, barriers and single-subject controlled studies on training of leisure skills, barriers to leisure, direct and indirect promotion of leisure activities, and research into different behavioral processes associated with or underlying leisure. By using these general categories we attempt to empirically address the wide variety of activities and phenomena related to leisure and IDD.

Epidemiology of Leisure Behavior and Intellectual Disabilities

It is of relevance to an analysis of leisure that we can empirically evaluate general participation in the community by persons diagnosed with IDD. Verdonschot, de Witte, Reichrath, Buntinx, and Curfs (2009) conducted an extensive and widely content termed literature search (1996–2006) to evaluate to what extent persons diagnosed with IDD participated in their communities. Although space does not permit a detailed account of the paper, its relevant major findings were that there is not much evidence-based research (23 articles from over 2500) on community participation, specifically domestic participation. Persons with IDD participate less than persons without IDD, and mostly participate in domestic (home) passive leisure activities. Another survey study by Leyser and Cole (2004) on leisure preferences and communication about leisure events in elementary students with and without disabilities also indicated that children with disabilities participate less than non-disabled peers in leisure activities. These same basic results have been reported for two group comparison studies of children in Canada; one with students with Autism Spectrum Disorder (ASD) (Solish, Perry, & Minnes, 2010) and one with students with physical disabilities (King, Law, Hurley, Petrenchik, & Schwellnus, 2010).

These general findings are also seen in survey studies evaluating leisure activity participation in boys with Attention Deficit Hyperactivity Disorder (ADHD) (Shimoni, Engel-Yeger, & Tirosh, 2010); Autism Spectrum Disorder (ASD) diagnoses (Orsmond & Kuo, 2011), Cerebral Palsy (Longo, Badia, & Orgaz, 2013), children with IDD and communication problems (Kreiner & Flexer, 2009), and those with profound disabilities (Zijlstra & Vlaskamp, 2005). It seems, therefore, that one evidence-based feature of leisure participation by persons with disabilities is that it is much lower than for normal-peers.

Survey Information on Leisure Activities

Researchers have found that the interests of individuals with IDD tend to be similar to those without disabilities (Glausier et al., 1995). Most survey studies on leisure activities focus on where the activities are occurring and types of activities engaged in. For example, studies have suggested most leisure activities fall into three different categories: social, leisure at home, and physical (Badia, Orgaz et al., 2013). Another way of viewing the same activities includes consideration of activities as leisure activities at home (e.g., cooking, sewing, watching TV), outside of home (e.g., hiking, bowling), or involving physical exercise (e.g., jogging, tennis). These generally constitute structured (e.g., arts and crafts at a day center) or unstructured activities (e.g., shopping, hanging out, talking on the phone) (Botuck & Levy, 1995). Differences in engagement in leisure activities are common across different settings (Anderson et al., 1987).

Tables 1, 2, and 3 include a list of the frequently and infrequently occurring leisure activities for individuals with IDD. The focus of Table 1 includes commonly occurring structured activities (i.e., those that are guided by others) while Table 2 and Table 3 focus upon unstructured activities. In addition to the listed leisure activities, those that individuals tend to prefer to participate in are noted. Interestingly, many of the activities in Table 3 are highly preferred, yet infrequently occurring (Anderson et al., 1987; Badia, Orgaz et al., 2013; Glausier et al., 1995).

Leisure at Home. Individuals with IDD are more likely to engage in social activities and leisure activities at home when compared to engagement in physical activities (Badia et al., 2013). Several survey studies have described a wide variety of activities of persons with IDD and have noted that individuals, over time, are likely to become more socially isolated and to engage in leisure activities primarily in the home setting (Glausier et al., 1995; O'Reilly, Lancioni, & Kierans, 2000). In addition, they are more likely to engage in passive leisure at home activities, although as many as 94 % of individuals also engage in additional types of leisure activities (Anderson et al., 1987; Bigby, 1992). Zijlstra and Vlaskamp (2005) reported on the weekend leisure activities of 160 individuals with profound disabilities in residential facilities in the Netherlands. They found that, on average, during approximately four hours of leisure activities, half of that time was spent watching TV or listening to music.

Social Activities. Badia et al. (2013) found that 64.9 % of those surveyed ($n=237$ individuals) were likely to engage in social activities. In addition, Anderson et al. (1987) found that 62 % of ($N=68$) fostercare residents with IDD had social contact with individuals without disabilities. While these statistics may be encouraging, as many as 69 % of in-state institution residents reported having no friends and anywhere from 22 to 42 % of individuals with IDD reported never receiving visits from family members (Anderson et al., 1987; Badia, Orgaz et al., 2013). Of those who do receive visits, many have less than one visit per year (Botuck & Levy, 1995). In addition, few individuals with IDD have friends of their own age or beyond the school or work setting (Badia, Orgaz, Verdugo, Ullan, & Martinez, 2011). Clearly, this is an area for improvement and suggests a need to help individuals with IDD develop friendships and maintain social supports.

Physical Activities. Badia et al. (2013) found that 27 % of those surveyed were likely to engage in physical activities. Interestingly, however, 64 % of individuals with IDD reported a desire to engage in more physical activities (Badia, Longo et al., 2013; Badia, Orgaz et al., 2013). Unfortunately, adults with IDD have lower rates of physical activity than typically functioning adults (Bartlo & Klein, 2011). The amount of physical activity also varies with the severity of one's disability. Bartlo and Klein (2011) suggested the inclusion of aerobic training, resistance training, and balance training can improve strength, balance, and function. Individuals with IDD reported a preference for physical activities that included horseback riding, petanque, bowling, fishing, soccer, water skiing, swimming, basketball, bicycling, skating, and Ping-Pong (Badia, Orgaz et al., 2013).

Table 1 Frequent structured leisure activities

Activity	Examples	Notes	Authors
Social	Day programs	Often includes training in academic skills, work skills, self-care, arts and crafts and recreational sports	Anderson et al. (1987)
Physical	Exercise classes	Often includes gymnastics, swimming, bowling, basketball, bicycling, jogging, petanque, Ping- Pong, and soccer	Anderson et al. (1987) Badia et al. (2013)

Table 2 Frequent unstructured leisure activities

Activity	Examples	Notes	Authors
Social	Using phone Birthdays Religious Museums Visiting[a] Shopping[a] Restaurants[a]	Finances tend to be a barrier for shopping and restaurants	Anderson et al. (1987) Badia et al. (2013) Glausier et al. (1995)
Home	Television Resting Reading Signing Painting Listening to music[a] Board games[a]	59 % engage in home activities; 92–96 % of individuals listen to music	Anderson et al. (1987) Badia et al. (2013) Glausier et al. (1995)
Physical	Walking[a]	Can significantly improve quality of life; most frequently occurring exercise	Anderson et al. (1987) Bartlo and Klein (2011) Glausier et al. (1995)

[a]Indicates high preference tasks

Table 3 Infrequent unstructured leisure activities

Activity	Examples	Notes	Authors
Social	Boat rides Sporting events Volunteering[a] Camping[a] Going on dates[a] Concerts[a] Picnics[a] Traveling[a] Field trips[a] Taking pictures[a] Dancing[a] Fishing[a]		Anderson et al. (1987) Badia et al. (2013)
Home	Home projects[a] Music instruments[a] Collecting items[a] Gardening[a] Cooking[a] Caring for pets[a] Doing crafts[a] Sewing[a]	Females are more likely than males to do cooking (59 vs. 46 %)	Anderson et al. (1987) Badia et al. (2013)

[a]Indicates high preference tasks

Evidence-Based Treatments

Observations and Comparisons

Unfortunately, there is very little research currently available regarding leisure activities specific to individuals with IDD. Many studies regarding leisure activities focus on survey data regarding the types of leisure activities that are currently available and who is engaging in those activities. Few studies actually evaluate the outcomes of leisure activities. Those that do include interventions are often focused primarily on teaching social skills interventions in the job setting (O'Reilly et al., 2000). In addition, many articles are focused on specific developmental disabilities (e.g., ASDs). The same behavioral principles that apply to individuals with autism, however, may be applicable to other individuals with IDD. Therefore, while this is a chapter on the use of empirically supported treatments for leisure behavior for IDD, demonstrations of effective treatments with other populations may be applicable given the technological and conceptual dimensions of applied behavior analysis (Baer, Wolf, & Risley, 1968).

Prerequisite Skills

Prerequisite Skills and Building Skill Repertoires. It is important to note that prerequisite skills may be needed in order to play some games or to engage in some leisure activities. Much of the literature does not focus on teaching those prerequisite skills (e.g., tying flies to the line for fishing) that may be needed for more complex leisure skills (e.g., catching a fish). For example, using Lego toys only becomes more interesting once one becomes aware of how to construct items with them. Putting the pieces together is a prerequisite skill, which leads to the development of other skills, eventually results in generalization to other Lego kits or sets, and builds a repertoire that allows a child to engage in the leisure activity of playing with Lego sets. A child doesn't learn to build a castle without first learning to put two pieces together. This concept can be applied to many activities (e.g., one doesn't learn how to run a marathon without first learning to walk). It is important to remember that one will not truly engage in 'leisure' as previously defined it if they don't know how to play. Given this, it's important to remember that people have to be taught to engage in all of the activities necessary for any given leisure task.

Choice Making and Preference Assessment. Even something as simple as a preference assessment of one's preferred activities might make a huge difference in leisure activity outcomes. Studies have demonstrated the importance of being able to make a choice, including that individuals will show preferences, participate more, perform better, have fewer problem behaviors, and report less discomfort (Browder, Cooper, & Lehigh, 1997). In addition, it's important to understand that individuals with IDD may have preferences for the types of activities they engage in. For instance, studies have found that females are more likely than males to choose to help with cooking (59 % vs. 46 %) while males are more likely than females to choose to help with taking out the trash (50 % vs. 30 %) or mowing the lawn (7 % vs. 2 %; Anderson et al., 1987). In addition, women are more likely to carry out more leisure activities at home and tend to be more passive while men tend to be more active (Badia et al., 2013; Botuck & Levy, 1995). Badia et al. (2013) reported activities are often chosen by others and do not include the preferences of the individual. The authors found that satisfaction in leisure increases with completion of preferred activities. In addition, whenever conducting choice assessments, individuals with IDD may need to be taught how to appropriately make choices that are relevant to their personal preferences (Browder et al., 1997). And, it is important to remember that choices may vary depending on the person's setting, possible leisure options, skill level, or other environmental variables (Browder et al., 1997; Parsons, Harper, Jensen, & Reid, 1997). Regardless, one of the simplest ways to increase leisure skills in any given setting is to ask the individual, "What do you want to do?" or to have the individual choose amongst options (e.g., "Do you want to read magazines or watch television?") (Wilson et al., 2006). Commonly utilized methods for determining preferences are discussed below.

Interviews. Asking an individual is the simplest way to determine personal preferences (Browder et al., 1997). While this may be effective, some individuals may not have the ability to clearly communicate their preferences (Cobigo, Morin, & Lachapelle, 2007; Ortega, Iwata, Nogales-Gonzalez, & Frades, 2012) and preferences may change over time and across situations (Hanley, Iwata, & Roscoe, 2006). For example, individuals with IDD are more likely to acquiesce with 'Yes' or 'No' options, are likely to choose the last possible answer in an array of choices, and tend to be influenced by social desirability (Cobigo et al., 2007). In addition, using others to fill in the gaps continues to place the individuals with IDD in passive roles regarding their preferences. Furthermore, caregivers may not be aware of actual preferences (Cobigo et al., 2007). Therefore, interviews with staff and family members, while helpful, should not be the only method used to determine an individual's preferences.

Observation of Interaction with Items / Preference Assessments. Typically, in this situation, arrays of items are available and the individual chooses the items of interest. Direct observation of behavior is preferable to interviews (Cobigo et al., 2007). Leisure activities, however, might be difficult to assess if the assessor is unable to display the activity in a manner that the individual understands (Browder et al., 1997; Cobigo et al., 2007). For example, some individuals may not understand that a picture of the beach is meant to suggest that the individual will be going to the beach for the day.

Survey Assessment Tools. Several researchers have also used survey tools to help determine preference for leisure activities. There are several currently available for consideration. Briefly, a few include the Children's Assessment of Participation and Enjoyment (CAPE) (King et al., 2004) and the Leisure Assessment Inventory (LAI; Hawkins, Ardovino, Rogers, Foose, & Olsen, 2002). The CAPE assesses participation in leisure and recreation outside of school for individuals aged 6–21. The assessment includes 55 informal and formal activities across five dimensions—diversity, intensity, with who, where, and enjoyment. The LAI measures leisure behavior in adults and assesses 53 activities, including preference, most preferred, and interest in those activities. This assessment is validated in both English and Spanish (Badia et al., 2012).

Translation of Research to Practice

Leisure Activity Treatments

There are several methods that have been used for teaching individuals with IDD about engagement in leisure skills. This section will briefly cover a few of the most commonly noted methods and considerations when developing leisure-based programs.

Animal Therapy. Farias-Tomaszewski, Jenkins, and Keller (2001) reported on the benefits of horseback riding for individuals with different physical disabilities. It should be noted that there exists a rather large number of reports and articles regarding the use of animals in a variety of settings to promote well being, social interaction, or simply as a preferred pastime. Space does not allow a review of this literature but a cursory overview indicates that there is little evidence-based information on this apparently growing phenomenon.

Using leisure activities to affect other activities. There have been different studies reported in which typical leisure activities have been utilized as therapy or for the promotion of other behaviors or outcomes. Eratay (2013), for example, reported on the effects of leisure activities for the promotion of social interaction skills and reduction of behavior problems in youth diagnosed with IDD. Garcia-Villamisar and Dattilo (2010) reported on the one year effects of a variety of leisure activities on stress levels and quality of life for 37 adults diagnosed with autism spectrum disorder (ASD) as compared to 24 control subjects also diagnosed with ASD.

Activity Schedules. Activity schedules have been implemented effectively across a variety of disabilities for a variety of skills (Cuhadar & Diken, 2011). Cuhadar and Diken (2011) taught leisure skills (i.e., Mr. Potato Head, building blocks with Lego, and Knocking down pins) to children with autism through the use of a photographic activity schedule. Children in this study learned how to engage appropriately in leisure skill activities quickly, even though they were unfamiliar with the activities prior to the study.

Age Appropriate Activities. Calhoun and Calhoun (1993) discussed the principle of normalization, meaning individuals with IDD should '…be influenced to be as much like their non-disabled age peers as possible.' Activities selected for individuals with IDD are often not culturally normative and are often more developmentally based. The authors found that using age-appropriate activities resulted in higher ratings of estimated intelligence and reading level by others. Furthermore, adults with IDD were viewed as more capable of taking on complicated tasks and more competent in their abilities. It is not uncommon to view individuals with IDD as incapable of completing activities, which is why this area may be very important to consider when programming for individuals with IDD (Glausier et al., 1995). Similarly, many researchers have discussed the importance of including programming for individuals with IDD that specifically teach leisure skill activities (Browder et al., 1997; O'Reilly et al., 2000).

Social Skills Problem Solving. O'Reilly et al. (2000) taught adults with moderate intellectual disability how to engage in socially appropriate behavior in a bar setting (e.g., ordering drinks, talking to bar staff, paying for drinks, accepting drinks). Prior to intervention, the individuals attended a bar each week but did not interact with bar staff or order drinks. Intervention began in the client's homes and then was evaluated in the bar setting. The intervention involved teaching generic verbal rules for interacting with others. The rules prompted the individuals to attend to relevant social stimuli, identify appropriate social behaviors, perform those behaviors, and evaluate how they did with the behaviors. This treatment resulted in positive social changes and generalized to other bar settings. The adults involved in this study increased social engagement with the bar staff and other bar patrons. This intervention has also been used successfully in classroom and work settings and is a very simple intervention that can result in significant changes for the individual.

Self-Management. Bambara and Ager (1992) found that self-management of leisure activities may increase self-directions and choice. The authors had individuals with IDD self-schedule what they would do and when they would do those activities. They found increases in choice making and that self-scheduling often cued desired behavior. They used a sequenced picture calendar book to prompt behavior. Training consisted of prompting individuals with IDD involved in the study to look at activity books on a daily basis. They also engaged in a nightly review of activities while staff modeled and provided corrective feedback. This consisted of staff helping individuals with IDD to open books, select activity cards, and place the cards in slots for each day of the week. The authors report this program taught those involved in the study to independently schedule weekly leisure activities. In addition, they reported an increase in self-directed leisure activities, varied task engagement, and that the behavior maintained over time.

Barriers to Leisure

Implementation of leisure activities for individuals with IDD may be difficult for many reasons. Reynolds (2002) surveyed the managers of 34 residential facilities in the UK regarding the extent that residents participated in more complex or "creative" leisure activities such as drama or musical groups. Although managers reported that most residents participated in artistic types of leisure such as painting and pottery, more creative activities were only available in day centers or other specialty locations. The main barriers to such participation were reported to be staffing to accompany an individual, the cost of such activities, and a general lack of support from the community professionals providing the activities. Block, Taliaferro, and Moran (2013) reported on a variety of barriers to participation of youth with disabilities in community physical activities. Essentially the barriers could be placed into two categories: (1) barriers due to the typical conditions of the person with disabilities such as current state of health, lack of knowledge about an organized sport, physical issues such as use of a wheel chair or crutches, and (2) environmental barriers such as lack of community leisure programs and professionals, costs of programs, transportation etc.

An individual's place of residence can significantly affect his ability to engage in leisure activities (Bigby, 1992). For instance, Benz et al. (1986) reported nursing home residents participated in fewer outside day programs than those who resided in other types of residences. Those who did participate in day programs were often male, mobile, and younger. In these settings, staff reported that individuals were too low functioning to participate, although male and females did not vary on disability functioning and older participants actually tended to be less disabled than younger participants. It is possible that mobility (e.g., being in a wheelchair) may have been a barrier to access, due to perception of abilities being affected by caregivers.

Anderson et al. (1987) reported foster care and group homes are more likely to be engaged in leisure activities when compared to private institutions. However, Aveno (1987) reported group home residents tend to spend more time than foster home residents in the community. Specifically, they are more likely to go the grocery store, restaurants, senior citizen centers, or other community resources. Furthermore, Badia et al. (2013) reported that those who use day care or residential settings often have less access to normalized leisure activities than those who live with their families. Even the size of the city where the residence is located is likely to make a difference. Individuals with IDD residing in larger cities tend to engage in more active games and sports or go to the park more frequently than those from urban or rural areas. Urban or rural residents, however, tend to go to the movies more frequently (Aveno, 1987). Therefore, an individual's residence and level of care may significantly affect the amount and quality of leisure activities available just based on possibility of recreational opportunity (Glausier et al., 1995).

Discrimination by others. Some individuals with IDD and their caregivers may actually avoid leisure activities due to negative public responses, which occurs approximately 14–21 % of the time (Anderson et al., 1987; Glausier et al., 1995). Such negative responses might include stares, direct hostility, avoidance of the individual, segregation of services, or inaccessibility to sports complexes or other facilities (Anderson et al., 1987; Badia et al., 2011; Glausier et al., 1995). Glausier et al. (1995) noted that many individuals with IDD are excluded, with seclusion ranging from an occasional incident to total isolation from other individuals. Furthermore, some agencies may create special programs meant to allow individuals with IDD to participate in certain activities at given times. Unfortunately, this may even further segregate individuals, as doing so does not provide opportunity to include oneself within the typical population leisure activities (Corcoran & French, 1977). Thompson and Emira (2011) described the complex barriers for children and youth with ASD in accessing leisure and respite care in the UK as indicated by a survey of parents and providers using telephone calls focus groups and one-on–one interviews. Their findings unfortunately relate to the general fragile state of the inclusion process for those with disabilities. The typical litany of barriers also cause parents to have to choose between unpleasant or otherwise lacking inclusion programs or segregated activities.

Individual Factors. The ability to engage in leisure activities might also be affected by physical health, motor skills, learning ability, school history, finances, gender, and social factors (Anderson et al., 1987; Bigby, 1992; Bult et al., 2011; Dahan-Oliel, Mazer, & Majnemer, 2012).

In fact, Badia et al. (2011) suggested that barriers might be related more to personal factors than to disability factors. For instance, younger individuals with IDD engage in more leisure activities than older individuals with IDD (Badia, Orgaz et al., 2013; Bult et al., 2011). In addition, individuals with IDD who have a partner or friendships are more likely to engage in social activities than those who do not (Badia, Orgaz et al., 2013; Bigby, 1992; Glausier et al., 1995). Interestingly, individuals with IDD who participated in regular school settings also tend to be interested in and participate more in leisure activities than those who attended an unconventional school setting (Badia et al., 2011; Badia, Orgaz et al., 2013; Bult et al., 2011). And, individuals with IDD that also have physical disabilities or health concerns are less likely to participate in leisure activities than other individuals with IDD (Badia et al., 2011; Bult et al., 2011; Cordes & Howard, 2005; Glausier et al., 1995). Specifically, more severe gross motor impairments, fine motor abilities, severe physical disability, number of limbs affected, severe spasticity, and severe spinal cord injury are all related to level of participate in leisure activities (Bult et al., 2011).

Level of income and finances may affect how much one is able to participate in leisure activities. Individuals with IDD from lower socioeconomic backgrounds tend to participate in fewer activities (Badia et al., 2011). In addition, individuals with mild IDD have more options than those with moderate, severe, and profound intellectual or developmental disabilities (Botuck & Levy, 1995; Bult et al., 2011; Corcoran & French, 1977; Cordes & Howard, 2005; Glausier et al., 1995). Bult et al. (2011) reported children with more severe communication difficulties were less like to participate in leisure activities. Finally, females are more likely to participate in leisure activities than males (Bult et al., 2011), although this varies by activity. For example, females are more likely to participate in social activities while males are more likely to participate in physical activities. Given this, even the option of activities available in any given setting may affect one's overall participation.

Discrimination skills. Whereas many environmental variables can be seen to affect engagement in leisure activities, and choice has been associated with the relative amount of engagement and preference for specific activities, the ability to make meaningful choices must be addressed for individuals with very limited operant discrimination skills. Observations and description of basic discrimination abilities were reported by Kerr, Meyerson, and Flora (1977a) who demonstrated an implicit hierarchy of discrimination skills within the visual and auditory senses and for simple versus conditional discriminations in normal children and those diagnosed with IDD. Thirty eight years of research on the now recognized "Assessment of Basic Learning Abilities (ABLA)" has provided several widely replicated aspects of the nature of these skills and observed barriers to functioning in individuals who do not demonstrate these skills (Kerr et al., 1977b; Martin & Yu, 2000; Seniuk, Greenwald, Williams, & Jackson, 2011; Vause, Yu, & Martin, 2007). The test comprises six discrimination levels that research indicates follow in order of difficulty. The discrimination tasks involve (1) a simple operant placement task, (2) a position or other visually based discrimination, (3) a visual discrimination, (4) a quasi-identity visual–visual conditional discrimination, (5) an arbitrary or symbolic visual–visual conditional discrimination, and (6) an auditory–visual conditional discrimination. Widely replicated aspects of the hierarchy are that a person will not pass a level higher than any level on which they fail. Failed levels are extremely hard to teach, if at all. Failure to perform different conditional discriminations has been shown to have strong implications for one's ability to engage in certain activities of daily living, spoken language acquisition, picture communication performance, equivalence formation and relational frame performance (Williams & Jackson, 2009). Performance on the ABLA has also been correlated with several standard tests of adaptive behavior and intelligence (Richards, Williams, & Follette, 2002).

Of particular relevance to the employment of choice or preference for leisure activities are several ABLA demonstrated prerequisite skills that appear to be necessary for an individual to actually make choices (aside from concurrent schedule arrangements where an individual experiences a "forced choice" outcome dependent upon an initial link discrimination (Hanley, Piazza, Fisher, & Maglieri, 2005) and whose subsequent selection indicate preference for the forced choice activity). Note that this procedure (typical of letting someone's behavior show their choice) involves conditional discriminations and a delay.

However, if leisure activities are assessed through typical preference procedures, specific necessary prerequisite skill situations will be discovered. For example, often times leisure activities are "chosen" based on vocal description or labeling presented by a caregiver (e.g., an auditory–auditory or auditory–visual conditional discrimination; or a visual discrimination or "choice" between several possible stimuli in a matching-to-sample paradigm (as in a Picture Exchange Communication System [PECS]; Bondy & Frost, 1996)) using pictures or symbols of objects or activities. The ABLA research has shown that conditional discriminations are not typically observed with individuals who cannot make simple discriminations and that visual discriminations appear easier to learn than auditory discriminations (Clevenger & Graff, 2005; Conyers et al., 2002). This indicates that many individuals may not be "choosing" when they are presented with such tasks, as they are not in fact discriminating any one event from another. Establishing the ability to make such discriminations and to be able to "choose" is an appropriate course of action for such individuals.

Caregiver Factors. In addition, individuals may have the motivation and skill set to engage in leisure activities, but might not be able to do so due to their caregivers. For instance, researchers have reported that as many as 11–28 % of residents actually desired participation in more leisure activities, but lack of transportation and a need for escorts were common barriers (Anderson et al., 1987; Bartlo & Klein, 2011; Corcoran & French, 1977; Cordes & Howard, 2005; Glausier et al., 1995). Individuals with IDD with limited freedom tend to have their activities chosen for them and, therefore, may not be given the opportunities to make choices (Badia et al., 2011; Botuck & Levy, 1995; Glausier et al., 1995). These situations often result in "handicapism" or preventing individuals from making choices (Glausier et al., 1995). Caregivers with limited physical functioning and higher levels of stress are less likely to have their loved ones participate in leisure activities (Bult et al., 2011). In addition, in supported living environments, it is possible that staff may not be trained to promote leisure skills (Cordes & Howard, 2005; Wilson et al., 2006). In addition, staff may not take the time to train individuals with IDD in how to engage in specific leisure activities (Cordes & Howard, 2005). This may result in individuals with IDD spending much of their leisure time engaged in non-functional activity (Cuhadar & Diken, 2011).

Directly related to this issue are other caregiver variables. Gilmore and Chambers (2010) found that support staff and leisure industry staff attitudes markedly affect participation. Singh et al. (2004) demonstrated that when caregivers of very severely disabled individuals are trained in methods of "mindfulness" there is a corresponding increase in "happiness" in those consumers. In a more general finding, as in the treatment of ASD, applied behavior analysis methods in general have been found effective and should therefore be used by caregivers (Hassiotis et al., 2012).

Lack of Planning. Aveno (1987) reported planning for leisure should occur early, given slow learning rates in individuals with IDD. Such planning should include a consideration of age-compatible peer activities for normalization and consideration of future peers to ensure usefulness of the activities. Unfortunately, many programs are focused on other life domains, such as work skills or academic abilities, and leisure skills tend not to be a priority (Cuhadar & Diken, 2011). In addition, being aware of the types of long-term activities and the eventual placement of individuals with IDD may be helpful. For instance, leisure activities such as walking or wheelchair strolling, using a beauty shop, and bowling tend to be highly ranked, regardless of location where an individual may reside. Given this, these types of activities may be good ones to teach younger individuals with IDD who will eventually reside out of the home.

Examination of Relevant Empirical Processes Related to Leisure

There are several literatures that are relevant to leisure, many of which contain a large amount of evidence-based empirical data regarding a variety of individual and group behaviors and variables directly related to leisure behaviors. Social skills training, language and communication training, or basic discrimination abilities are obvious examples. The current space requirements do not allow an attempt at reviewing such sources, but we have provided some exemplars that are specifically relevant to leisure as described in this chapter.

As discussed previously, basic sensory processing abilities and discrimination skills are fundamental to choice behaviors which are in turn essential for determining leisure preferences. Saunders et al. (2005) described a novel method for testing learning and preferences in persons with severe motor constraints. Yu et al. (2002) examined the relative strength of happiness indicators during work and leisure activities with minimal motor movement.

With respect to conducting preference assessments for leisure activities, DeVries et al. (2005) and Lee et al. (2008) demonstrated the relative effectiveness of spoken, tangible, or pictorial representations of leisure activities for persons at differing levels of discrimination abilities and the predictive value of discrimination skills for accurate preference assessments for leisure activities respectively. Researchers have also studied the relative role of motivational operations on preference choices for leisure activities (McAdam et al., 2005; O'Reilly et al., 2008).

Direct Empirical Promotion of Leisure skills

Sheppard and Unsworth (2011) looked at the effectiveness of a short term (8–10 week) educational residential program designed to improve the skills of adolescents with IDD related to self and family care, life management, recreation and leisure, and social vocational skills. The program was conducted in an environment that provided the opportunity for repeated practices of everyday activities to both develop skills and to habituate these skills into regular use. Facilitation of skills development was accomplished through detailed observation and analysis of individual task performance, step-by-step analysis tasks, a system of least intrusive prompts to gradually progress participants to task mastery, a focus on independence, and requirement of maximum task participation. Personal goal setting, encouragement of self-monitoring strategies, and incidental teaching of self-monitoring, self-regulation, and problem solving were also features of the program. Staff received training on implementing the program by participating in lectures and workshops on physical and intellectual considerations for students with IDD, learning ways to promote independence and autonomy, promoting self-determined behaviors, conducting task analyses, observing task performance, identifying and providing appropriate levels of support during task performance, developing and acquiring approaches to facilitation of skill acquisition, and accessing information and support from school staff. A daily routine was established for individuals and individualized instruction based upon baseline performance of task steps was identified in a task analysis. Practice of the steps using a system of least intrusive prompts was provided for a variety of activities of daily living within that routine. Staff members created a task analysis of the activities, which was then reviewed weekly to help monitor performance, independence, and frequency of engagement with tasks. Prompts were faded whenever possible and participants were encouraged to engage in self-management strategies. Participant skills in self and family care, life management and recreation, and leisure were reported to have improved significantly with large effect sizes at the end of the program and at a three month follow up. Authors noted that, in addition to improvements in independence with the skills listed above, self- determination, defined as engagement in choice and decision making skills, problem solving, independence, self-monitoring, and self efficacy, improved as indicated by indirect self-report measures collected from parents, teachers, and participants.

Initial Assessment of Leisure Activity Preferences

Direct observation of adults living in supervised independent living and open-ended interview of staff or family members on their loved ones' preferences may fail to identify a range of potentially reinforcing or preferred leisure activities when few activities (e.g., TV watching) are available to adult patients. Wilson et al. (2006) reported that using a structured interview (e.g., Reinforcer Assessment for Individuals with Severe Disabilities—Fisher, Piazza, Bowman, & Amari, 1996) modified with lists of common leisure activities (Wilcox & Bellamy, 1987) and interviews from adults in the nearby community, support staff, and family members identified a wider range of potentially preferred leisure activities.

Assessment of Preference

Wilson et al. (2006) found increased leisure engagement for participants using a paired-choice presentation of stimuli selected from a list of potentially preferred items and activities described earlier when having staff assess choice of leisure activity.

Prompting Methods

Physical Prompts. Wilson et al. (2006) found that simply offering activity options could occasion engagement in leisure activities. The authors also reported that engagement with leisure activity items improved following a paired choice presentation of leisure items with a brief staff demonstration on how to interact with the leisure item using a least-to-most prompting hierarchy. If the individual selected an item within three seconds of the paired choice presentation, a brief description and demonstration of how to use the item was provided using a least-to-most prompting hierarchy. If the individual did not choose an item within three seconds of the choice presentation, one of the items in the array was arbitrarily removed, while the staff member provided a description and demonstrated how to use the other item, similar to the protocol mentioned above. Many other response-prompting strategies (e.g., video modeling, video prompting, and constant time delay) have been shown to be effective in teaching leisure skills to individuals with IDD such as such as accessing the internet, listening to a Walkman, and playing games such as checkers, UNO, and croquet (Dollar, Fredrick, Alberto, & Luke, 2012).

Other researchers have evaluated the effectiveness of the most-to-least prompting procedure on teaching of advanced movement exploration skills in water to children with autism spectrum disorder (Yanardag, Erkan, Yilmaz, Arıcan, & Duzkantar, 2015) Most-to-least prompting consists of decreasing the intrusiveness of prompts along a hierarchically from more to less intrusive (e.g., physical, model, to verbal prompt). This errorless teaching strategy was used to teach advance movement exploration skills in water, such as blowing bubbles, face submersion, and retrieving an object from the bottom of the pool. The authors found that swimming skills maintained and generalized at follow up sessions.

Video Modeling. Video modeling consists of showing a video with a person performing the task before practice. Video prompting includes showing a video of a person performing a single step of a task before practicing that step. Constant time delay begins with a prompt delivered simultaneously with the instruction. Following this, the prompt is faded along a dimension of time (e.g., 3–5 s) that allows for transfer of stimulus control to the initial instruction. Dollar et al. (2012) demonstrated the use of a simultaneous prompting method and total-task chaining in teaching a set of leisure skills (use of iPod, television, CD and DVD players) to an adult with a severe intellectual disability. In simultaneous prompting, the instruction is immediately followed by a prompt, is never delayed, and is used until mastery of the behavior is demonstrated on probe trials conducted prior to each instructional session.

Staff and Caregiver Training

Increasing leisure activity in supported living situations usually requires specialized training with staff members in order to promote engagement in leisure activities by individuals (Wilson et al., 2006). Behavioral skills training (BST) has been used to successfully train staff and caregivers to implement a variety of behaviorally based interventions (Wilson et al., 2006) and appears to be the primary method of training. BST involves providing a rational for the intervention, written instructions, modeling of the intervention to the trainee, and role-playing with feedback.

Using this method, staff members were successfully trained to implement brief paired-choice preferences assessments (Wilson et al., 2006). For example, the researchers trained staff members to track consumer engagement in leisure activities using a momentary time sampling procedure. Staff were trained to set a kitchen timer for 2 min following a consumer’s initial engagement in a leisure activity, check to see if the consumer was still engaged in the activity when the timer went off, reset the timer if the individual was still engaged, offer a new activity if engagement was not observed, and collect data.

Task Analysis. Helps and Herzberg (2013) used a number of task analyses to teach an individual with multiple disabilities to play games, watch movies, listen to music, and view family photos and videos on an iPad. By the end of the intervention, the individual was independently locating the iPad2, initiating a preferred activity, and switching between her choices of activities.

Activity Schedules. Activity schedules are essentially a task analysis of an activity enhanced with visual cues in the form of photographs, drawings, or written text to prompt an individual's engagement in a activity following a particular organized sequence (Chan, Lambdin, Graham, Fragale, & Davis, 2014). Cuhadar and Diken (2011) noted that there are several studies demonstrating the effectiveness of activity schedules with various populations (e.g., intellectual disabilities, autism) to teach a wide variety of skills (e.g., indoor-life, socio-dramatic play, other play skills, leisure skills). In their study, Cuhadar and Diken (2011) assessed the engagement and fulfillment of leisure activities acquired with instruction and activity schedules on preschool children with autism. Participants were taught specific skills related to engagement in and completion of previously untrained leisure activities (e.g., building lego sets, assembling potato man, bowling). A variety of procedures were used to facilitate the use of the activity schedule and the leisure activities themselves (e.g., prompting methods, error correction, chaining, differential reinforcement for use, accuracy, and compliance). Results indicated that the participants engagement and completion of the initially untrained activities increased from baseline levels, maintained at follow-up, and were observed in the natural environment across different people, places, and time of day. With these results the authors suggested that that the experimental procedures also contributed to improvements in the independent performances of participants. Chan et al. (2014) used a picture-based activity schedule to aid in the training of three adults diagnosed with mild intellectual disability so they could use an iPad to play a videogame.

General Computer and Technology Leisure Skills. Notwithstanding the "double-edged sword" aspects of the current domination of large portions of our time by electronic devices such as computers, mobile phones, tablets, iPod, and so on, the interaction with these devices is definitely considered mainstream leisure. Although there are anecdotal observations regarding media use in persons with IDD, there exists little empirical work. Mazurek, Shattuck, Wagner, and Cooper (2012) described a large scale national study of the prevalence and correlates of screen-based media (e.g., television, computer, and video games) use among youths with ASDs. Approximately 1000 teens diagnosed with ASDs were compared to approximately 900 students diagnosed with intellectual, speech, language, or learning disabilities regarding forms of screen device usage. One major finding was that 65 % of those in the ASD group did not report using social media (e.g., e-mail, chat rooms) even though they demonstrated the highest use of video game playing and television watching.

Not surprisingly, there is a growing literature concerned with teaching that involves electronic devices, including teaching the use of such devices for leisure. Kagohara et al. (2013) have provided a recent review of the current literature involving the use of iPods and iPads to teach a variety of skills such as communication, developing employment skills, leisure skills, and transitioning skills. Three articles described the teaching of leisure skills. Kagohara (2011) taught three students with IDD to use an iPad to access videos. Hammond, Whatley, Aries and Gast (2010) employed video modeling to teach three teen students to watch videos, listen to music, and look at pictures on an iPad. A third study (Kagohara et al., 2011) taught three students how to play music on an iPad. In addition, Jerome, Frantino, and Sturmey (2007) described a backward chaining program and the use of errorless learning to teach internet skills. Yalon-Chamovitz and Weiss (2008) demonstrated effective use of virtual reality as a leisure activity for young adults with intellectual disabilities. Clearly, this interest in media and screen technology is in its infancy and definitely meets any criteria one might imagine for future research on leisure.

Summary

Leisure and the wide variety of behaviors related to leisure are of major relevance to persons diagnosed with IDD. The literature on assessing, describing, and promoting leisure provides some evidence-based assessments of participation and promotion practices from which one can derive suggestions for needed research (e.g., Phillips, Olds, Boshoff, & Lane, 2013).

In terms of the epidemiology of leisure and IDD, the evidence for participation in leisure is clear in regard to several features: (a) persons diagnosed with IDD engage in leisure activities less than persons with other diagnosed disabilities and much less than their normal peers; (b) those persons diagnosed with IDD who do engage in leisure activities mostly engage in such activities that are typically engaged in at home, and that constitute passive consumption, stimulation or manipulation as opposed to organized community activities; (c) physical exercise activities are engaged in by some persons with IDD and are reported to be desirable and with clear health benefits, and (d) there is support for the conclusion that leisure activities that many persons with IDD express that they want to do are not in fact what they are observed to be doing.

Regarding identified barriers to leisure, there appear to be four major categories: (a) individual factors that preclude participation such as functional level or physical limitations, (b) non-inclusionary behaviors and policies of the community, (c) lack of community leisure programs and professional staff that promote participation, and (d) costs and transportation. Specifically regarding the first barrier category in individual factors there is a strong evidence base concerning the need for persons to choose the activities they want to engage in as opposed to those choices being made by others. In addition, there is a strong evidence base regarding discrimination skill level and the ability to make choices that provides clear guidelines for practitioners for assessment and promotion of leisure activities.

Regarding the promotion of leisure skills there is strong evidence for the effectiveness and efficacy of behavior analysis derived direct teaching and training of skills.

The evidence-based aspects of the literature on leisure provide us with some empirical guidance for future research and best practice. For example, there is clear need for creative ways to provide leisure activities in community settings that provide inclusionary management and staff practices. Bartlo and Klein (2011) suggested development of physical activity programs that include participant choice regarding level of participation, allowing for observation, including enough space, and including enough equipment.

Bambara and Ager (1992) suggested research on quantity vs. quality of activities and investigating if more activity may not be as beneficial or preferred as less of a more enjoyable activity. Bartlo and Klein (2011) suggested examining physical activity outcomes for persons with individual and developmental disabilities, including an examination of healthy aging, age associated problems and exercise, program development, and assessment. Badia et al. (2013) suggested comparing interests between those with and without IDD and the effect of participation on quality of life improvements.

Regarding individual variables, continued and more research into the role of conditional discriminations, concept formation, and choice (Williams, In Press) that can translate into service practice are sorely needed as well as much more work on teaching methods for leisure and the continued exploration of motivating operations (O'Reilly et al., 2008).

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Community Living and Participation

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Introduction

Often when professionals and policy makers are talking about services and supports to people with intellectual and developmental disabilities (IDD), community living means that a person lives in the community and not in an institution. This is based on a frame of reference from the mid-1960s, when most people with intellectual disabilities who were not living at home with their families instead lived in large congregate-care living facilities called institutions. Most of these were owned and operated by the state. For the past several decades, advocacy efforts in the USA and many other countries have resulted in a movement of people with IDD from institutions into community settings. Today, most people with IDD live at home with their families and those that live outside of their family home live in community settings.

Today, community living means different things to different people. While most people agree that it does not include institutions, not everyone agrees on what it does mean. In this chapter, community living is defined as a person with IDD living in a community in which a person wants to live and it also means participating in a person's community of choice. Community living means having opportunities to work in the community, to develop skills related to home living, to navigate around in the community, to ensure self-care, safety, and personal health. It also means participating in community activities and things of personal interest, and being able to maintain and expand social networks, friends, family members, and allies. It is not just about being "in" the community, it is about being "of" the community.

Rights and Protections Related to Community Living

People with IDD have rights and protections regarding community living. These are granted in the form of public laws, regulations and policies at international, national and state levels. Advocates have fought hard for these protections and rights. Together, these serve as drivers for the development of effective policy and practice related to life in the community for people with intellectual and developmental disabilities.

One important judicial decision in the USA regarding community living and people with disabilities is the Americans with Disabilities Act and related *Olmstead v. L.C.* (1999) decision. This decision ensures people with disabilities the

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right to freedom from discrimination and unjustified isolation in institutional settings. As a result of the Olmstead decision, there are increased opportunities for people with IDD to transition from nursing homes, institutions and other congregate care facilities to community living. In 2014, the Centers for Medicare and Medicaid Services (CMS) issued a new definition of home and community-based services (HCBS) (Final Regulation CMS-2249-F/CMS-2296-F) which identifies what qualities must be in place for a program to be considered home and community-based. These include (but are not limited to) the following (as identified in the regulation):

1. Be integrated in and provide support for full access to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree as individuals not receiving HCBS.
2. Be selected by the individual from among setting options including non-disability specific settings and an option for a private unit in a residence. The setting options are identified and documented in the person-centered service plan and are based on the individual's needs, preferences, and, for residential settings, resources available for room and board.
3. Ensure an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint.
4. Optimize individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.
5. Facilitate individual choice regarding services and supports, and who provides them.
6. In a provider-owned or controlled residential setting, the following additional conditions must be met:
    (a) The unit or dwelling is a specific physical place that can be owned, rented, or occupied under a legally enforceable agreement by the individual receiving services, and the individual has, at a minimum, the same responsibilities and protections from eviction that tenants have under the landlord/tenant law of the State, county, city, or other designated entity.
    (b) Where landlord tenant laws do not apply, the State must ensure that a lease, residency agreement or other form of written agreement will be in place for each HCBS participant, and that the document provides protections that address eviction processes and appeals comparable to those provided under the jurisdiction's landlord tenant law.
    (c) Each individual has privacy within their sleeping or living unit.
    (d) Ensure individuals have the freedom and support to control their own schedules and activities, and have access to food at any time.
    (e) Ensure individuals are able to have visitors of their choosing at any time.
    (f) Be physically accessible to the individual (Centers for Medicare & Medicaid Services, 2014).

In addition to protections within the USA, Article 19a of the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006) also provides similar protections, such as:

1. An opportunity to choose their place of residence.
2. An opportunity to choose where and with whom they live on an equal basis with others.
3. A right to be free from an obligation to live in a particular living arrangement.

While these policies and regulations are intended to provide rights, opportunities, and choices for people with IDD about community living, not everyone with IDD has the opportunity for community living. This chapter provides an overview of community living for people with IDD including information about where they live, work and participate in their communities of choice.

Home

Where People with Intellectual and Developmental Disabilities Live

Several types of community and residential supports exist which are designed to support people with IDD in developing skills necessary for community living. In the USA, residential and community supports for people with IDD are funded primarily through Medicaid as a long-term service and support. Principal types of residential settings include state-operated institutional facilities, nursing homes, Intermediate Care Facilities For Individuals With Intellectual Disabilities (ICF/IID), and Home and Community Based Services (HCBS), the latter which offer options for both in-home or out-of-home residential options. Residential and community supports differ by state, but similarities exist in both the type of supports provided, as well as outcomes and trends.

Substantial changes in where people with IDD live and receive residential supports are the result of the deinstitutionalization movement, which began in the mid-1960s. The number of people with IDD living in large, state operated institutions designed for people with developmental disabilities which have 16 or more people living in them, and in psychiatric institutions nationwide decreased by 81 % between June 1977 and June 2012, a reduction from 154,638 to 29,221 people. Similarly, there was a 78 % decrease in the number of people with IDD living in large ICF/IIDs, from 207,356 in 1977 to an estimated 45,034 in 2012. However, between 1989 and 2012, there was only a 24 % decrease in the number of people with IDD living in nursing homes, from 37,143 in 1989 to 28,064 in 2012 (Larson et al., 2014; Larson, Ryan, Salmi, Smith, & Wuorio, 2012; Prouty, Smith, & Lakin, 2007). Among states, there is great variability in the utilization of congregate care facilities. While only four states have over 25 per 100,000 of the US population living in state-operated DD institutional settings (i.e., AR, MS, NJ, and NY), when all large facility types are combined (state-operated DD institutional facilities, privately operated DD facilities, psychiatric, and nursing home settings) 16 states have over 25 per 100,000 of the US population living in institutional settings (i.e., AR, CT, IL, IN, IA, LA, MS, MO, NE, NC, ND, OH, OK, SD, UT, and VA.)

Liberalization of funding available under the Medicaid Home and Community Based Services (HCBS) program in the early 1990s was a major force in the rapid shift from institutional to community living. Between 1982 and 2012, the number of HCBS recipients with IDD increased from 1,381 to an estimated 680,610. Likewise, expenditures for HCBS have grown substantially, from $1.14 billion in FY 1992 to $18.37 billion in FY 2006 and $29.5 billion in FY 2012 (average annual HCBS expenditures were $44,160 per person). Considerable growth has also taken place in the use of HCBS to support persons with IDD who live with family members. An estimated 31,200 HCBS recipients lived with family members in 1992, which increased to an estimated 224,264 in 2006. By 2012 an estimated total of 340,702 people with IDD were living in the home of a family member while receiving HCBS supports. Nationally, an estimated 50 % of all support recipients with IDD received that support in the home of a family member. The number of HCBS recipients living in their own home was estimated to be (5,030 in 1992), which increased to 75,234 in 2006, and by 2012 an estimated 93,924 people with IDD lived in their own home (Larson et al., 2012, 2014; Prouty et al., 2007). This is a significant trend toward self-determination and people having choices about where and with whom they live.

The expansion of community supports resulted in significant increases in the selection, number, and flexibility of options available to people across states. While Medicaid is often thought to have an "institutional bias," among the combined estimated total of 781,190 Medicaid ICF/IID and HCBS recipients with IDD, 88.9 % of them were HCBS recipients, demonstrating that the vast majority of Medicaid funded services and supports are provided in the community. Of the estimated 680,610 HCBS recipients, 487,502 are served in their own home, family homes, or host/foster home, with the bulk (296,580) receiving services in family homes as of 2012. National trends are promising for people with IDD, but access to quality community supports still varies greatly among the states. As of June 30, 2012, 13 states have closed all of their large state institutions for people with IDD (i.e., AL, AK, HI, IN, ME, MI, MN, NH, NM, OR, RI, VT, WV, and the District of Columbia) and nationally only 10.6 % of all Medicaid ICF/IID, HCBS, and state funded recipients living in a setting other than family homes lived in a facility with 16 or more people. In comparison, within the same timeframe, of the recipients who lived in a setting other than a family home, seven states (i.e., AR, LA, MS, NJ, OK, UT, and VA) had 20 % or more recipients living in settings with 16 or more people (Larson et al., 2014).

Estimates as of 2012 vary widely in the number of people with IDD waiting for community residential services, from 110,039 to 317,000 (Bragdon, 2014; Larson et al., 2014). Additional challenges discussed in the Arc 2010 FINDS National Survey national survey found that 62 % of family caregivers reported that access to support services was decreasing, 32 % reported that they were on a waiting list for residential, employment and other services, and 9 % reported losing a paid support person due to lack of funds (Anderson, Larson, & Wuorio, 2010).

Self-Direction

As noted previously, services and supports for individuals with IDD have undergone significant changes in the past 50 years. A national growing trend called “self-directed services and supports” has emerged in which individuals with disabilities and their families have the opportunity to exercise greater control and choice in their services and supports.

Self-directed services and supports provide individuals with IDD and their families increased choice and opportunity to live person-centered lives within their own local communities in which their services and support balance what is important to the individual. Self-direction typically means that the person with IDD (or their legal representative) has control over their budget and makes decisions about how to spend the allocated resources on individual services and supports. Other key components include person-centered planning, staff choice, and ongoing quality assurance and accountability measures (Smith, Agosta, Fortune, & O’Keeffe, 2007; Walker, Hewitt, Bogenschutz, & Hall-Lande, 2009; Warfield, Chiri, Leutz, & Timberlake, 2014).

Self-directed supports find its theoretical underpinnings in self-determination. Self-determination refers to the right of people to control their lives as well as the ability to act based on one’s own free will without the control of external influences (Abery & Stancliffe, 2003; Wehmeyer & Bolding, 2001). In other words, individuals with disabilities should not have to relinquish their basic civil rights to obtain the services and supports that they need to live a quality life (Moseley, 2001).

A brief history of self-directed supports reveals a shift in focus from a focus on traditional agency driven and controlled services and supports towards more self-directed models. In the early 1990s, the perspectives of policy makers started to shift as a result of positive research findings around the benefits of self-directed supports when compared to traditional agency managed services (Doty, Kasper, & Litvak, 1996). The results of the research revealed increased positive outcomes from self-directed support options including increased satisfaction with services, improved quality of support, and potential cost savings (Doty et al., 1996). The first implementation of self-directed services and supports can be traced back to a pilot project funded by the Robert Wood Johnson Foundation (RWJ) in New Hampshire in the early 1990s. This pilot project led to later replication projects including the Cash and Counseling Demonstration and Evaluation (CCDE) that provided further evidence of increased quality of care and improved health outcomes under self-directed support models (Kemper, 2007). These projects were designed to promote self-determination in states and they had a significant influence on the development and evolution of this service type (Bradley et al., 2001).

Self-directed support has emerged today as an innovative and effective approach to structuring and delivering Medicaid funded services and supports. States implement self-directed supports in a variety of different ways, allowing for a variety of budget caps and allowable expenditures. In most self-directed support state models, individuals with IDD typically live with their families or in other supported living arrangements (Bogenschutz, Hewitt, Hall-Lande, & LaLiberte, 2010; Hall-Lande, Hewitt, Bogenschutz, & Laliberte, 2011). In most states, the person with a disability or family works with a fiscal intermediary who supports financial payments and can serve as the employer of record, if needed. The individual and their support network will typically develop the individual support plan and individual budget based on the allocated funding. The individual and family typically hire, train and support their own direct support staff, which in many states can include a paid family member or family friend (Hall-Lande et al., 2011).

The number of individuals with disabilities participating in self-directed services and supports within state waiver programs in the USA has grown significantly over the past 20 years (Greene, 2007). Data from the National Resource Center for Participant Directed Services (NRCPDS) Inventory reveals that, as of 2013, all 50 states and the District of Columbia offer at least one self-directed service option, which enables people with disabilities to manage their budgets and exert control of their services. The 2013 national data indicate ongoing moderate growth in self-directed services and supports (National Resource Center for Participant Directed Services [NRCPDS] Inventory, 2014).

Work

Employment can be seen as an essential ingredient to community living. Beyond living in the community, work connects individuals with the economic fabric of their communities and society at large. Many individuals with IDD are not only living in integrated community settings, but also enjoying the many benefits work provides. Increasing opportunities and attention is being paid to the importance of work in community living. As interest in the employment of individuals with IDD increases, so does the notion that full community living incorporates work.

Despite growing interest and attention to the employment of individuals with IDD, they are still sorely unrepresented in employment (AAIDD & The Arc of the United States, 2008; Butterworth et al., 2014; Nord, Luecking, Mank, Kiernan, & Wray, 2013). There are significant gaps in the employment rate for individuals with IDD compared to other groups. Recent data from the 2012 American Community Survey (ACS) highlight that only 23.2 % individuals with cognitive disabilities are employed compared to 33.5 % of others with any disability, and 76.3 % without any disability (Erickson, Lee, & von Schrader, 2014). In addition, individuals with IDD are also living at poverty rates three times that of individuals without disabilities (Erickson et al., 2014).

Employment is one of the primary mechanisms that can provide individuals with IDD an avenue out of poverty. National attention to this issue is widespread and numerous state and federal policies and programs are attempting to address the low employment rate of individuals with IDD (Kiernan, Hoff, Freeze, & Mank, 2011; National Disability Rights Network, 2012; National Governors Association, 2012; United States Senate, 2012, 2013). These include but are not limited to the *Olmstead v. L.C.* (1999), *Lane v. Kitzhaber* (2012), and the Centers for Medicare and Medicaid recent guidance on Home and Community Based waivered services released in 2014.

The types of employment supports and services available to individuals with IDD are varied and often dependent upon an individual's community (Butterworth et al., 2014; Rogan & Rinne, 2011). Historically, most individuals with IDD were served in segregated employment facilities, referred to as sheltered workshops. Sheltered workshops still exist, but there is growing dissatisfaction with these services as they do not support the notion of community living or are not consistently person-centered in their approach

(Butterworth et al., 2014; Migliore, Mank, Grossi, & Rogan, 2007; National Disability Rights Network, 2012). Some employment services also include services such as enclaves, work crews, or supported employment. Services like customized employment and self-employment are also gaining traction and interest as we are redefining what it means to be employed in the community (Niemiec, Lavin, & Owens, 2009; Nord & Hoff, 2013).

While momentum for integrated and community-based work opportunities are growing, policies, reimbursement structures, and practices are struggling to keep up with these changing demands and expectations. Access to employment opportunities for individuals with IDD entails ongoing political, social, and fiscal challenges. Without continued advocacy at the local, state, and federal level, community living that includes employment is obstructed. Recent Department of Justice (DOJ) activity in Oregon and Rhode Island have concluded that the American with Disabilities Act's integration mandate can be extended to employment services (US Department of Justice, 2014; *United States. v. Rhode Island*, 2014). Therefore, the unnecessary segregation of individuals with IDD in sheltered workshops has become a civil rights issue concerning individuals with IDD and their right to be free from a life of imposed segregation. Additional guidance provided by the Centers for Medicaid and Medicare services (CMS) through HCBS is also focused on requiring that services be provided in an integrated community setting (CMS, 2014a). The policy landscape is quickly changing to embrace the principles of community living and full integration.

Current employment services are not fully meeting the needs of individuals with IDD. Recent data on service usage from Vocational Rehabilitation (VR) indicate that only 34.3 % of individuals with IDD served in VR leave with employment (Butterworth et al., 2014). These trends of low employment also extend to state developmental disabilities agencies where many still provide more reimbursement for segregated facility-based services than integrated community-based services. According to the 2012 National Survey of State Intellectual and Developmental Disability Day Services and Employment survey (Butterworth et al., 2014), only 12.6 % of all funding for employment and day services was spent on integrated employment compared to 56.9 % for facility-based non-work and 18.7 % for facility-based work (Butterworth et al., 2014). Over the past decade, there has been an increase in the funding of these segregated settings. In addition, this survey also indicated that almost 80,000 individuals were on waiting lists for day and employment services (Butterworth et al., 2014).

The future of employment for individuals with IDD holds both opportunities and challenges. Opportunities lie in the growing interest, attention, and advocacy focused on increasing the employment of individuals with IDD as well as the focus on including work as an important aspect of community living. Challenges exist in the service dependence and reimbursement rates of segregated facility-based employment and society's low expectations for employment of individuals with IDD. Local communities and states are exploring new ways to address these challenges through policy and funding realignment, increased access to choices for employment services, practical policy solutions, and the development of promising practices and strategies for facilitating employment outcomes for individuals with IDD.

Social and Personal Relationships

Most people with IDD want to be socially included in their communities of choice and to have relationships with people of their choosing that are important to them (Abbot & McConkey, 2006; McConkey, 2006; O'Rourke, Grey, Fuller, & McClean, 2004). This desire encompasses an underlying value that people should be able to participate in their communities as valued, respected, and fully contributing members of society. Social inclusion means comprehensive and equitable access to (a) activities that take place in the community, (b) activities that are valued by others in the community (such as paid work, parenting, and volunteering), and (c) a large and deeply meaningful social network that includes relationships with people with and without disabilities (Bates & Davis, 2004).

Having meaningful relationships is important to most people and leads to satisfaction and overall wellbeing. Thus, it is important to prevent people with IDD from experiencing social isolation. There are varied research findings on the importance of the types of people with whom people with IDD have friendships. The results of some studies show that people with IDD have friendships with people without IDD (Knox & Hickson, 2001) and others show that people with IDD are more likely to have friends who also have IDD (Emerson & McVilly, 2004).

People with disabilities can use the community as a place in which new friendships can be developed. Gaventa (2008) found that people with IDD can form meaningful relationships through active participation in faith-based communities due to strong spiritual beliefs, the perception that a faith community is a place of acceptance and belonging, and the realization that faith communities can be powerful sources of support for their members.

People also evolve friendships through shared experiences, places and activities. Sports fans can meet up at sporting events and root for their team, knitters can show up at the local coffee shop on Thursday nights for knitting circle, people who enjoy helping others can bag food at the local food shelf, or people who like lizards and snakes can belong to the same herpetology club. What is critical is that communities and community members invite people with IDD into these shared events and activities, and that people are supported to belong. Often it is the role of a direct support professional or caregiver to ensure that these connections are made and that people with IDD are afforded equal access and unconditional membership. Regardless of the type of friendship, how it is formed, and where it takes place, meaningful social relationships play important roles in the lives of people with IDD (Knox & Hickson, 2001). An important goal for most people, and where a focus of supports and services should be, is to support individuals in evolving and maintaining relationships that are based on mutual interests and shared experiences of people in the community.

Education and Life Long Learning

Many people make lasting friendships in schools, from grade school, to high school and college. For many people with IDD, once they are done with their formal school program and leave high school, it is difficult for them to maintain these friendships. It is also difficult for them to continue their education in post-secondary programs or through lifelong learning due to few opportunities. There are an increasing number of post-secondary education programs that focus on transitioning young adults with intellectual and developmental disabilities into post-secondary programs. In 2011/12, there were 43 known post-secondary educational programs for students with IDD and over 800 students were enrolled in these programs (Think College, 2014). These programs are sometimes in community and technical colleges and sometimes in 4-year degree programs. Their focus is most often on teaching life skills such as those skills needed for home living and employment. In many settings, individuals with IDD are included in training programs with other students who do not have disabilities and in many the programs are segregated.

People with IDD should have opportunities for lifelong learning in their communities just as other citizens do. Common places where learning can take place are faith communities, community centers, service organizations, and continuing education programs. Often with support from direct support providers, friends, allies and caregivers, people with IDD are connected to and can participate in such programs. In some communities there are segregated programs designed for people with IDD; in all communities there are programs designed for citizens. People with IDD, as well as their communities, can learn and benefit from being included in community programs. When given the opportunity, individuals with IDD can gain skill and experience lifelong learning.

Support Systems for Community Living and Participation

Family as Caregivers

Individuals with IDD most commonly reside with their family members, who act as caregivers (Williamson & Perkins, 2014). Individuals with IDD are most likely to receive care from family over the course of their lifespan (Horst, Werner, & Werner, 2000; Parish, Seltzer, Greenberg, & Floyd, 2004; Singer, Biegel, & Ethridge, 2009). These family caregivers typically provide assistance to their family member on a daily basis with the tasks necessary to maintain independent living. Family caregivers may provide assistance or perform many duties for their family member with IDD, based on the individual's needs and ability to perform an activity. These may include a range of activities and supports, including performing domestic activities, specialized therapies, modifying the home, and completing activities aimed at health and education. As family caregivers are acknowledged to fulfill a vital role in the lives of IDD, there is growing recognition of the importance of supporting these caregiver systems (Singer et al., 2009; Talley & Crews, 2007). Within the context of an aging population, it is clear that supporting the wellbeing of family caregivers is vital to maintaining the support system for IDD (Talley & Crews, 2007). Providing supports to families facilitates their ability to provide effective supports to their family member with a disability.

Impact of Caregiving on Family

Families may experience many stressors as a result of caregiving for a family member with IDD. Families who provide lifelong caregiving to their family member with IDD may be impacted in terms of health outcomes, mental health outcomes, and economic outcomes (Williamson & Perkins, 2014). Parents, siblings, and other family members spend a significant amount of time providing supports to their family member with IDD, equal to that of full-time employment, or more (Anderson, Larson, & Wuorio, 2011; Emerson, 2007). Consequently, the caregiving role may act as a barrier to participation in the paid workforce, especially for mothers (Parish et al., 2004). The emphasis on home and community-based placements results in a greater reliance on family as caregivers (Williamson & Perkins, 2014).

Family caregiving is often taken for granted as a responsibility to be fulfilled as part of familial duty and devotion (Barrett, Hale, & Butler, 2014). Resources are often directed at residential services, leaving families with limited financial supports for their caregiving activities (Parish, Pomeranz-Essley, & Braddock, 2003). Parents and families may provide care well into their old age as individuals with IDD are experiencing longer life spans (Williamson & Perkins, 2014). In addition to a lack of resources (undoubtedly a contributing factor), families in caregiving roles are at risk for high levels of stress and depression (Cummins, 2001). Having unmet support needs and a high level of caregiver stress are associated with families seeking out-of-home placement for their family member with IDD (Williamson & Perkins, 2014).

While the challenges and negative impact on families as a result of caregiving are well understood (e.g., Emerson, 2007; The Arc, 2011), there are also positive family experiences reported as a result of the family member's role as caregiver. The way in which a family frames their experience with caregiving is related to their experience of disability, especially in families who have positive patterns of communication, embrace new experiences and challenges, are adaptable, and have a strong commitment to the family unit (Greef & Nolting, 2013). Family caregivers are often comforted to know their family member is receiving consistent and loving care (Blacher, Baker, & MacLean, 2007; Glidden, Jobe, & Floyd, 2007; Hastings & Taunt, 2002). In addition, many caregivers report finding meaning, personal growth, and an increased sense of purpose through the role (American Psychological Association (APA), 2015).

Paid Support: Direct Support Professionals

While many people with IDD live at home and receive caregiving from their family members, another system of supports exist in the formal (i.e., paid) sector, and often acts as a source of support to the family as well as to the person with IDD. Direct support professionals (DSPs) support people to participate fully in their families, employment settings, social and recreational environments, and other setting in which a person with IDD may need support in accessing and participating in their communities. As such, DSPs provide supports in a wide variety of settings to match the needs of people with IDD. By assisting with personal care, health care, transportation, advocacy, financial management, among other important aspects of living, a DSP plays a vital role in the lives of individuals with IDD, and in the lives of their families (Hewitt & Lakin, 2001). By supporting individuals with IDD in terms of health and safety, as well as personal growth, DSPs are granted an important responsibility (Hewitt & Larson, 2007).

DSPs may be employed by a social service agency or be directly employed by a person with IDD. A DSP may hold a number of different job titles, with one study identifying as many as 155 different job titles assigned to people in direct support roles (Test, Solow, & Flowers, 1999). Examples of job titles for DSPs include home health aide, job coach, and personal assistant.

In their various roles, DSPs provide essential services across the lifespan of a person with IDD. They work with very young children, children, youth, adults and elder adults. While the training of DSPs often focuses on meeting regulatory requirements such as fulfilling a certain number of hours, there is a distinct need for DSPs to be trained in the knowledge, skills, and attitudes necessary to provide high quality supports. A number of efforts have occurred to identify competencies that are required of DSPs. The National Alliance for Direct Support Professionals identified competencies across 15 broad competency areas (with corresponding skill statements) for DSPs. These broad competency areas are: (1) participant empowerment; (2) communication; (3) assessment; (4) community and service networking; (5) facilitation of services (6) community living skills and supports; (7) education, training and self-development; (8) advocacy; (9) vocational, educational and career support; (10) crisis prevention and intervention; (11) organizational (employer) participation; (12) documentation; (13) relationships and friendships; (14) person-centered goals and objectives; (15) supporting health and wellness.

Currently, DSPs are not required to undergo training to meet these competencies, but there is significant growth toward establishing competency-based training in human services and therefore advancing the professional development of the DSP (LaLiberte & Hewitt, 2008). Most recently, the Centers for Medicare and Medicaid Services (CMS) released a set of Core Competencies for direct support workers (CMS, 2014). These identify core competencies across 12 competency areas for direct service workers who support people with IDD or mental health disorders, or people who receive services due to their age.

Like many other professions that interact with people in support or service capacities (such as the American Medical Association and the National Association of Social Workers), DSPs are guided by a code of ethics. For the DSP, this is the National Alliance for Direct Support Professionals (NADSP) Code of Ethics (NADSP, 2015). Acknowledging that DSPs are in positions that may require making decisions involving “practical and ethical reasoning,” this code is meant as a guidebook through the ethical dilemmas they may face in their daily work supporting individuals with IDD (National Alliance for Direct Support Professionals, 2015). The Code of Ethics names several areas and offers detail to guide DSPs in their important work as supports for individuals with IDD. These are: (1) person-centered supports; (2) promoting physical and emotional well-being; (3) integrity and responsibility; (4) confidentiality; (5) justice, fairness, and equity; (6) respect; (7) relationships; (8) self-determination; and, (9) advocacy (NADSP, 2015).

Workforce Trends

While DSPs provide essential supports to people with IDD, they have long been undervalued as a profession (LaLiberte & Hewitt, Fall/Winter 2007/08). DSPs experience a number of challenges that speak to the minimization of the profession and act as barriers to meeting the workforce needs. These include low wages (mean wages have been estimated at $9.49 per hour), a lack of paid health insurance and vacation, and low retirement plan contributions (Larson, Hewitt, & Knoblauch, 2005; PHI, 2013). In addition, the low wages, limited training opportunities (both initially and, importantly, ongoing), and the lack of recognition for the skill required to provide high quality supports, result in high turnover rates, estimated annually at 38 % to over 50 % nationally (ANCOR, 2010; Hewitt et al., 2008; NADSP, 2010).

Turnover, increased demand for services, and demographic changes in the USA results in a high demand for new DSPs. The US Dept. of Labor Statistics estimates a nearly 70 % increase in DSP jobs by 2020 (US Department of Labor, 2015). The expected growth of DSPs (not limited to solely those supporting people with IDD) represents an expected workforce of about five million by the year 2020, making it one of the fastest growing sectors of the American workforce (PHI, 2013). Projections suggest that direct support may be the largest job classification in the USA by the year 2020 (PHI, 2013). While the need is high, it is difficult to recruit, train and keep these workers when their pay is so low and their jobs are so demanding.

Outcomes

In the USA, investments in services and supports for people with IDD are vast. In FY 2011, in the USA, $56.65 billion was spent on services and supports for people with IDD. This included $22.1 billion on Intermediate Care Facilities for people with IDD, $49.2 billion on Home and Community Based Services, $5.6 billion on Medicaid administration, rehabilitation, case management, and personal care, $10.2 billion on federal income maintenance and social service black grants, and $12.84 billion in state and local funds. By any standard, this is a significant investment.

At a national level, little data exist that indicates the outcomes of these investments and the services and supports they fund. One effort to address measuring and monitoring outcomes on a systems level is the National Core Indicators project (NCI). This voluntary program for public developmental disabilities agencies is designed to measure and track state system performance for services and supports to people with IDD. Currently 43 states participate in the NCI. The NCI uses standard measures to assess the outcomes of services provided to individuals and families, allowing for comparisons over time, and across states. The NCI indicators address key areas such as employment, rights, service planning, community inclusion, choice, and health and safety (NCI, 2014).

Outcomes of the residential and employment services used by individuals in states that participated in the NCI program in 2012/2013 are as follows (NCI, 2015):

1. Fifteen percent of people had a paid job in the community.
2. The average hourly wage for community jobs was $7.82.
3. Many respondents reported that they did not have input in major life decisions, such as where and with whom they live and where they go during the day.
4. NCI respondents with IDD also reported that they have relationships and are able to spend time with loved ones.
5. A large majority of respondents reported having friends who were not family or staff (77 %), having a best friend (79 %), being able to see family whenever he/she wants (79 %), being able to see friends whenever he/she wants (79 %), and being able to go on dates without restrictions (or being married) (68 %).
6. While 59 % reported never feeling lonely, 41 % were lonely at least some of the time
7. The majority of respondents reported that they were never scared at home (82 %), in their

neighborhood (85 %), or at work or at their day program (88 %).

8. Ninety-two percent of respondents with IDD reported that if they ever were to feel scared, they have someone to ask for help.

These NCI data provide a glimpse of various outcomes. Many people have good outcomes such as spending time with people they like, having friends, feeling safe and having someone who will help them. In other areas the outcomes were not as good such as people not having jobs or making livable wages and many people feel lonely some or most of the time. However, it is important to keep in mind that the NCI is measuring systems performance and not outcomes at the individual level. Nonetheless, the promise for community living and participation are made to all citizens with IDD and it is important to note that based on NCI data, not all citizens with disabilities have positive outcomes.

Future Implications

Policy Implications

In the USA, an important priority has been to expand community services while decreasing the use of congregate care and institutional services for people with IDD. The federal government has employed a number of strategic programs designed to assist states in community living expansion. For example, the CMS implemented the Money Follows the Person program, which provided financial incentives to states to promote people with IDD moving from institutional services into smaller community settings. The new HCBS regulations refined the definition of community living, requiring additional privacy protections and ensure person centered services. New options provided under the Affordable Care Act to increase self-direction and personal care supports through Medicaid will increase options for community living and participation. Challenges still exist. States vary and some still rely heavily on institutional levels of care to support community living. Efforts to ensure equal access and opportunities for people with IDD to live and participate in their communities irrespective of the state in which they live is critical, as is enforcement of the new HCBS regulations.

There is high demand for real jobs that pay real wages as well as for the opportunity to live in one's own home with supports. Policy makers will need to find effective and less costly residential and employment support models for people with IDD that achieve their desired outcomes. Technology offers some opportunity; the use of home monitoring and sensor technology enables people with IDD to choose a living arrangement that requires fewer staff. It is also important to acknowledge that the majority of HCBS recipients receive residential supports inside of their family's home. In these circumstances, families need training and support to learn how to maximize their family member's independence, growth, choice, self-determination, and ongoing learning to facilitate community participation. Individuals and families that self-direct also need support in how to effectively train and manage paid staff that provide them with support in their home.

In order to meet demand and growth of community living opportunities for people with IDD, it is important that policy makers recognize and plan for the growth needs of the direct support workforce. Creating systems to support people with IDD in the community means that systems have to plan for workforce needs as well. Strategies designed to promote a living wage, health benefits, retirement savings, and other fringe benefits need to be implemented for all DSPs.

Practice Implications

Provider agencies that deliver residential services are facing increased pressure to do more with less money as the federal government and states simultaneously face increased demand for services and budget deficits. Traditional group home models of residential services in which four to six people reside in a home owned or rented by a provider agency are an increasingly undesirable option for funders and people with IDD. Options such as shared living, supported living, and other less costly choices will be needed. People with IDD and their families want more choices and options. They want to choose and control where and with whom they live. It will also be important for service systems to develop models and systems of practice to support families who have their adult children living at home.

Employment providers likely face significant changes in the upcoming decades. People with IDD desire employment in their communities, in settings where they earn real wages. Opportunities for full time meaningful employment will need to be found. Practice changes are needed at the transition level as students move from high school to community living. In addition, within employment organizations changes will need to occur to ensure integrated employment is the first expected outcome of service. Instead of deferring to sheltered workshops following school, funders and providers will need to focus on developing systems to support integrated employment.

Workforce Implications

Competency-based professional development is vital to the workforce in terms of training and ongoing quality, and ethical service provision. Organizations, managers, human resource professionals, trainers, DSPs, people with IDD, families and their allies must work in concert to move towards competency-based professional development. Orientation to the job and minimal annual training based on topics and regulated requirements are not sufficient. DSPs require an individualized and highly complex skill set in order to facilitate opportunities and positive outcomes related to community living. Training should be seen as an investment that can influence staff retention, increase DSP performance, and promote better outcomes for people served.

Finding, keeping and training direct support staff in self-directed supports presents particular challenges because individualized budgets available to people with IDD in self-directed programs are typically not adequate to support robust staff training. Further complicating the issue, many DSPs in self-directed services are relatives or close personal friends of the person with IDD or the family that serves as the employer of record (Bogenschutz et al., 2010; Heller, Arnold, van Heumen, McBride, & Factor, 2012). It may be important to support individuals and families to develop training cooperatives, find opportunities for online training and other methods for connecting DSPs to quality resources.

Conclusion

Community living and participation is an expectation of individuals with IDD, families, policy makers, and practitioners. Promises of community living and participation have been made to people with IDD through many laws, policies, and initiatives in the USA. Opportunities for community living and participation have expanded since the mid-1960s when deinstitutionalization began. The expansion of community living options has led to increased social involvement, better living conditions, more work opportunities, and increased community participation. Yet not all people with IDD have opportunities to be fully included or participate with others in their community. In addition, far too few people with IDD who want to work are actually engaged in paid employment. Ensuring that the services and supports that are available to individuals with IDD fully prepare them to access and participate in their communities is essential.

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Health and Wellness

35

James K. Luiselli

Introduction

Medical and public health officials have long acknowledged that people with intellectual and developmental disabilities (IDD) and related neurodevelopmental disorders experience "poorer health, shorter lifespans, and less access to professional health care" compared to individuals without disabilities (US Public Health Service [USPHS], 2002). Thankfully, this situation is improving due to advances in health care policies, research, and practitioner training, to name a few recent trends (Anderson et al., 2013). Of note, "Increasingly, research and health care are being directed toward preventing conditions that can give rise to disability in the first place and toward increasing access to health and wellness services for individuals already living with a disability" (US Department of Health and Human Services, 2005, p. 7).

Notwithstanding these recent developments, there are several factors that continue to affect poor health and wellness among people with IDD. For example, some medical problems, usually persistent and lifelong, stem from genetic etiology associated with conditions such as Down syndrome, Williams syndrome, and Prader–Willi syndrome (Batshaw, 2002). As well, many people with IDD and their families are often socially isolated, have limited financial resources, and are exposed to environments that deleteriously impact their health (Emerson, 2007; Scheepers, Kerr, & O'Hara, 2005). Third, and perhaps most prevalent, a large number of people with IDD do not have access to health promotion and preventive services, notably routine screening evaluations and information sources about the benefits of proper nutrition, weight management, smoking cessation, and age-relevant immunizations (Krahn, Hammond, & Turner, 2006).

Anderson et al. (2013) delineated additional impediments to desirable health care and promotion in the lives of people with IDD. Many times individuals and families find it difficult locating providers in specialty disciplines such as gynecology, dentistry, and ophthalmology (Ward, Nichols, & Freedman, 2010). Service providers may also be reluctant to see patients because of reduced financial reimbursement from public insurance programs (Birenbaum, 2009). Reichard and Turnbull (2004) noted further that many physicians lack training and the time to care for people with IDD. Similarly, there are frequently communication barriers and quality-of-care deficiencies between medical staff and patients (Ward et al., 2010).

Effective health and prevention efforts for all people demand a three-tier intervention approach. In the case of *tertiary prevention*, the focus is on

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treating individuals who are ill and symptom positive. Whereas this need is both necessary and dictates high-quality services, it is, nonetheless, "after the fact." Hence, *secondary prevention* is aimed at reducing and eliminating risks that jeopardize health status. The third tier, *primary prevention*, emphasizes health promotion that deters the onset of risk factors and afflictions. In the broadest sense, intervention priorities should be "on strategies to reduce or minimize health risk factors, identification of protective factors including methods to improve our understanding of how to support people with IDD in learning the skills needed to live healthy lives, and effective advocacy for their health support needs" (Anderson et al., 2013, p. 392).

This chapter on health and wellness considers the areas of assessment, treatment, and training, primarily from the disciplines of behavioral psychology, applied behavior analysis, and cognitive-behavioral therapy. As it is not possible to comprehensively cover the vast IDD research literature, I selected four health and wellness categories where there are sufficient evidence-based outcomes to warrant conclusions and practice recommendations: obesity-weight regulation, exercise-physical activity, tolerance of medical regimens, and smoking cessation. Within these categories I have included research examples which integrate primary, secondary, and tertiary intervention applications. These categories are discussed further in the concluding section of the chapter that examines research-to-practice translation. Note, too, that I considered research with other neurodevelopmental disorders because the procedures, results, and implications have relevance for people with IDD.

Epidemiology

Obesity is a serious health concern that can lead to heart disease, stroke, diabetes, and hypertension (National Task Force on the Prevention and Treatment of Obesity, 2000). Reported rates of obesity in people with IDD living in the USA range from 21 to 33.6 % (Moran et al., 2005; Stancliffe et al., 2011). In persons with Down syndrome, the prevalence rate among adults is as high as 70.7 % (Rimmer & Wang, 2005). Other industrialized countries report prevalence rates of 19–34.6 % in the UK (Bell & Bhate, 1992), 32 % in Northern Ireland (Marshall, McConkey, & Moore, 2003), and 16.3–26.5 % in Australia (Beange, McElduff, & Baker, 1995). Population-level data reveal that rates of obesity in adults with IDD are similar to or exceed the rates of adults without IDD (Emerson, 2005; Yamaki, 2005).

Closely related to the problem of obesity are findings that people with disabilities, including IDD, are frequently sedentary, do not engage in routine exercise and planned physical activity, and lack physical outlets (Heath & Fentem, 1997; Rimmer, 1999). One survey found that approximately 56 % of "people with disabilities" reported having no leisure-time physical activity (Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004). Tracking a large group of adults (18–64 years old) who had hearing, vision, cognitive, and mobility disabilities, approximately 47.1 % were physically inactive compared to 26.1 % of adults without disabilities (Carroll et al., 2015). These and other data sources underscore that positive health promotion in people with IDD is seriously compromised by not achieving a sufficient level of exercise and cardiovascular exertion (Mann, Zhou, McDermott, & Poston, 2006; Peterson, Janz, & Lowe, 2008; Seekins, Traci, Bainbridge, & Humphries, 2005).

Cigarette smoking is a leading cause of disease and death, including second-hand smoke exposure (Centers for Disease Control and Prevention, 2008). Heart disease, emphysema, stroke, bronchitis, and asthma are just some of the ill effects from chronic smoking (US Department of Health and Human Services, 2010). The Centers for Disease Control *Morbidity and Mortality Report* issued in 2012 estimated that 25.4 % of people "having any disability" smoked cigarettes compared to 17.3 % of people without disabilities. Prevalence data for individuals with IDD vary from 2 to 36 % (Emerson & Turnbull, 2005; Kalyva, 2007; Robertson et al., 2000). It appears that people with IDD smoke cigarettes at levels comparable to the general population and are likely to suffer the same health risks.

Compliance with medical recommendations, also described as adherence, "can mean keeping an appointment, taking a single pill, engaging in preventive care, altering one's lifestyle, and following a complex medical routine such as one required to manage diabetes" (Christophersen & Van Scoyoc, 2013, p. 181). Although problems with adherence are commonly encountered in children and youth without disabilities, there are no prevalence statistics for people who have IDD. Evidence suggests that non-adherence is influenced by illness, individual, family, and health care systems factors, and is strongly linked to treatment failure (Christophersen & Van Scoyoc, 2013).

Of course, obesity, sedentary lifestyle, medical non-adherence, and cigarette smoking are only some of the health and wellness concerns confronting people with IDD. These conditions are similar because they are amenable to behavioral, psychosocial, and environmental interventions, which can be effective as prevention strategies and symptom-focused treatment combined with medical regimens. The epidemiology data represent prevalence markers but if referenced in isolation, do not inform intervention emphasis and decision making. That is, it is critical to isolate the many conditions and influences that set the occasion for and maintain poor health in the IDD population. In illustration, many influences contribute to obesity such as genetics, living in poorly supervised settings, limited access to physical activity options, and nutritionally unsound food choices (Rimmer & Yamaki, 2006). It bears repeating that intervention must be tailored to predisposing and maintaining variables on individuals, the family, and society at large.

Evidence-Base for Treatment

Obesity

Obesity and overweight are determined by a measure of body mass index (BMI) (weight in kilograms divided by height in meters squared: kg/m^2), which in adults represents a range of >30 and >25.0–29.9 respectively. In children, BMI is calculated with growth chart indicators that are age and gender specific. To reiterate, obesity is associated with numerous health problems, including but not limited to "asthma, high blood pressure, high blood cholesterol, diabetes, depression, fatigue, gastrointestinal problems, joint or bone pain, sleep apnea, liver or gall bladder problems, low self-esteem, preoccupation with weight, Blount's disease, early maturation, and pressure ulcers" (Yamaki, Rimmer, Lowry, & Vogel, 2011, p. 282). With regard to being overweight, the most common complications appear to be asthma, high blood pressure, and diabetes (Fleming, 2011). These are sobering lists of symptoms that demand more comprehensive and easily accessed preventive and tertiary care.

Fleming (2011) commented that the existing obesity intervention research in IDD, although promising, has not been sufficiently controlled and experimental. Furthermore, the more extensive research literature within the non-IDD population offers a model, which can be adapted to people with IDD. In particular, Epstein, Paluch, Roemmich, and Beecher (2007) described effective weight loss programs using family-supported behavioral interventions with children and youth. Similarly, Wing, Tate, Gorin, Raynor, and Fava (2006) piloted behavioral self-management strategies with overweight adults. Within the context of a large-scale community program with elementary school children, Economos et al. (2007) decreased BMI *z*-scores through exposure to healthful foods and increased physical activity. These studies point to several methods that, in some instances, have been implemented optimistically with people who have IDD but necessarily have to be evaluated more thoroughly in future research.

Curtin et al. (2013) conducted a family-based weight loss intervention with 21 adolescents and young adults (13–26 years old) who had Down syndrome. One group of participants received nutrition and physical activity education (NAE), while a comparison group had NAE combined with behavioral intervention parent training (NAE+BI). The study comprised 16 sessions during a 6-month period. Adolescents in the NAE+BI group lost more weight than their NAE counterparts, with continued therapeutic gains at 6–12 months follow-up. Further improvement in the NAE+BI group was increased MVPA each day. There was no between-group differences recorded for percentage of body fat.

A less controlled study by Bazzano et al. (2009) reported moderate weight loss, increased physical activity, and improved self-efficacy in a community sample of adults with developmental disabilities. This intervention had multiple components such as health education, peer mentoring, supervision of physical activity, behavior supports, and advocacy.

In addition to borrowing from obesity and weight reduction research with typically developing populations, clinical applications with people who have IDD can be enhanced from findings with other select groups. As one example, Rimmer, Wang, Pellegrini, Lullo, and Gerber (2013) compared weight management interventions with 102 adults (*M*=46.5 years old) who had physical disabilities (e.g., spina bifida, multiple sclerosis, cerebral palsy, stroke, lupus). The study featured a no-intervention control group, a group that received telephone consultation to develop a personalized physical activity program, and a group that received the same physical activity program plus individualized nutrition advisement. The telephone consultation was supported via a web-based remote coaching tool. Other components of the treatment groups were provision of an informational brochure, pedometer, monthly newsletter, and progress monitoring. Compared to the control group, both treatment groups had significantly greater weight loss from baseline to post-treatment phases. Although the treatment effects were admittedly small, this study demonstrated the contribution of a telehealth intervention to tertiary prevention and health care, a rapidly emerging phenomenon within clinical psychology and medicine (Luiselli & Fischer, 2015).

In a controlled single-case study, Singh et al. (2008) evaluated a mindfulness-based wellness program with a 17-year-old boy who had mild IDD, Prader-Willi syndrome, and morbid obesity. At the time of the study he weighed between 250 and 260 lb with a BMI of 57.2. During a 2-month baseline phase, the boy's family maintained their usual meal and diet routines. Next, the boy participated for 12 months in an exercise program that had him walk at a moderate pace for 30 min each morning before breakfast. A subsequent phase, also lasting 12 months, combined exercise with a healthy eating plan comprised of food awareness, food selection autonomy, and mealtime visual cues to aid choice making (Shapiro, 2000). A three-part, mindfulness training was added to the exercise and food awareness program, specifically (a) mindful eating, (b) visualizing and labelling hunger, and (c) mediation practice. Integrated with mindfulness training, the boy and his mother set strategic weight-loss targets, aiming at a maintenance goal of 200 lb. The boy's mean weight was 256.3 lb during baseline, 249.8 lb during the exercise alone phase, and 242.8 lb during the exercise and food awareness phase. Eventually, he achieved the 200 lb weight criterion following 102 weeks of mindfulness training and intervention. Three years later his mean weights were 197.8 lb in the first year, 192.3 lb in the second year, and 190.7 lb in the third year. Though limited to one person, this study illustrates a combined wellness intervention approach to obesity in IDD and notably, a novel application of mindfulness within a family-centered model (Singh et al., 2014b).

Exercise and Physical Activity

The prevalence of sedentary lifestyles of people with IDD and other neurodevelopmental disorders has been attributed to limited access to recreational and fitness facilities, lack of knowledge about physical conditioning, poor information sources, financial constraints, and minimal to no community program resources (De la Vega & Rubio, 2013; Rimmer et al., 2004). By not exercising and being physically active, individuals may develop weight, cardiovascular, and respiratory health problems (De, Small, & Baur, 2008; Rimmer, Braddock, & Fujiura, 1993). Conversely, regular and moderate-to-vigorous physical activity (MVPA) can reduce and prevent health risks (Chanias, Reid, & Hoover, 1998). Exercise also enhances self-concept, intellectual functioning, and mood (Gabler-Halle, Halle, & Chung, 1993). Most parents and care-providers of people who have IDD acknowledge the many positive effects from exercise and physical activity and they support programmatic efforts on many levels (Gibbons & Bushakra, 1989; Glidden, Bamberger, Draheim, & Kersh, 2011; Luiselli, Woods, Keary, & Parenteau, 2013; Weiss, 2008).

Several systematic reviews have identified the types of activities targeted in exercise and physical activity research with people who have IDD and other neurodevelopmental disorders. Lang et al. (2010) reported that among children and youth with autism spectrum disorder (ASD), 61 % of studies included jogging or running, followed by swimming-water aerobics, bike-riding, weight training, and roller skating. In another literature survey of participants with ASD, Sowa and Meulenbroek (2012) found that the proportion of studies concerned jogging (38 %), swimming (31 %), horseback riding (13 %), weight training (6 %), and walking (6 %). A review of research by Lancioni et al. (2009) revealed that 81 % of studies with children who had IDD and motor disabilities incorporated treadmills, with fewer examples of walkers equipped with microswitch technology to produce ambulation-contingent stimulation.

Many of the studies reviewed by Lang et al. (2010) and Sowa and Meulenbroek (2012) relied on established behavioral teaching methods, for example, physical prompting, modeling, verbal instruction, and positive reinforcement. Luyben, Funk, Morgan, Clark, and Delulio (1986) taught three adults (24–52 years old) with IDD to execute a side-of-the-foot soccer pass by combining chaining, gestures, physical prompting, prompt-fading, and visual cueing. Dowrick and Dove (1980) conducted a swimming intervention study with three children (5–10 years old) who had spina bifida by incorporating self-monitoring videotapes and goal-setting. With the objective of teaching a 9-year-old boy with Asperger Disorder to ride his bike as a form of exercise, Cameron, Shapiro, and Ainsleigh (2005) first carried out instruction on a kinetic trainer, established pedaling, braking, and dismounting responses, and then transferred to actual bike riding near the boy's home. Although these studies encompassed a heterogeneous participant population and different types of exercise and physical activity, they depict some of the options available for people who have IDD.

In a more recent example of behavioral methods to increase physical activity, LaLonde, MacNeill, Eversole, Ragotzy, and Poling (2014) intervened with five adults (21–26 years old) who had ASD in an effort to promote walking as daily exercise. The dependent measure in this study was the number of steps the participants took during their typical day at a community program for young adults. Steps were measured with a wireless pedometer that recorded and then transferred data to a laptop computer. In baseline the participants wore the pedometer under natural conditions but were not able to read the data display. During intervention, a researcher interacted with each participant to set a daily step goal and document step frequency on a recording form. Each time the participants matched or exceeded their goals they chose pre-selected tangible "rewards" from a prize box. This combination of automated recording, goal setting, and positive reinforcement increased substantially the number of steps all of the participants took each day. The steps taken each day also consistently matched their self-imposed goals. By conclusion of the study the participants were routinely walking 10,000 or more steps during the school day, without compromising scheduled activities, and with high satisfaction and approval of the exercise-promotion intervention.

Recognizing that walking is a simple, inexpensive, and convenient form of exercise, many people with IDD are not able to ambulate fluently because they have motor, sensory, and orthopedic impairments. Lancioni and colleagues (2010, 2012, 2013) have published extensive research showing that assistive technology devices can be used to facilitate and maintain walking in otherwise inactive children and adults who have IDD and multiple disabilities. To illustrate, Lancioni et al. (2014) designed optic micro-switches on the heels of shoes that when activated through walking, triggered sources of preferred sensory stimulation intended to function as positive reinforcement. One case involved a 23-year-old man with IDD, blindness, and hearing loss. During daily ambulation sessions he had the opportunity to walk a defined travel distance under baseline conditions without micro-switch activation and during intervention in which his steps produced several seconds of preferred vibratory stimulation. The second participant was a 10-year-old girl who also had IDD, vision impairment, and hearing loss. She was involved in a similar baseline-intervention evaluation except her preferred step-contingent stimulation was music and blinking lights. Intervention with both participants increased the percentage of their independent travel and reduced the average time traversing the travel route. Summarizing the results, Lancioni et al. (2014) commented that micro-switch-aided programs represent a vital technology for individuals who have IDD and motor disabilities, enabling them to exercise through planned and spontaneous ambulation.

Sports performance is another venue for supporting health and wellness in the lives of people with IDD (De la Vega & Rubio, 2013; Luiselli, 2014). Cameron and Cappello (1993) developed a training intervention with a 21-year-old man who had IDD in preparation for a Special Olympics track event. The first step of training was having the man jump over four hurdles that were flat on the ground and spaced 12 ft apart. Gradually, each hurdle was raised off of the floor to a terminal height of 12 in. The man also received physical guidance and noncontingent praise throughout the training program. As the result of this training he was able to jump hurdles during practice and competed successfully in Special Olympics 6 months later.

Also focusing on Special Olympics participation, Luiselli et al. (2013) evaluated several procedures to improve 100 m sprint performance of 20- and 21-year-old men who had developmental disabilities. The dependent measure was their time (in seconds) running sprints during practice sessions. Compared to a conventional practice baseline phase, both men averaged lower sprint times while receiving a training intervention comprised of goal setting, performance feedback, positive reinforcement, and video modeling. An additional accomplishment was the men running faster than their baseline average in a Special Olympics sprint competition.

Lotan, Yalon-Chamovitz, and Weiss (2009) designed an innovative physical fitness intervention that involved playing commercially available video games. Thirty adults (average age = 52.3 years) with mild IDD participated in the study and were matched to a comparison group of similar adults. During a 5–6 week program, the adults in the experimental group played video games in two, 30-min sessions each week. As a result of this relatively simple intervention these adults had significant improvements in physical fitness as measured by walk/run and Total Heart Beat Index (THBI) indicators.

Exergaming, another video medium, has not been evaluated with children, youth, and adults who have IDD but represents a potentially effective method for promoting planned physical activity and exercise. With this gaming technology "video games or various auditory or visual stimuli are paired with different types of exercise equipment and activities, and the individual must engage in physical activity to play the game or produce the auditory or visual stimulation" (Fogel, Miltenberger, Graves, & Koehler, 2010, p. 592). Interactive video games themselves have been shown to increase energy expenditure in children compared to sedentary video game interaction (Graves, Stratton, Ridgers, & Cable, 2007; Lanningham-Foster et al., 2006). Also, Fogel et al. (2010) reported that exergaming was associated with more minutes of physical activity and more minutes of opportunity for physical activity than traditional physical education classes. Implementing exergaming with people who have ID may be a practical strategy for motivating exercise, particularly when resources and care-provider support are less than optimal.

One other clinical and research domain that has not been explored among people with IDD is the effects of the physical environment on the types and intensity of exercise and motor activities. Studies by Hustyi, Normand, Larson, and Morely (2012) and Larson, Normand, Morley, and Hustyi (2014) showed that MVPA in typically developing young children was influenced differently by several environmental contexts such as access to an open grassy play area, a play area with outdoor toys, a play area equipped with playground equipment, and a play area containing materials for indoor activities. Making available particular materials and equipment would appear to be low-demand and possibly permanent interventions that schools and community settings can offer to encourage health-beneficial physical activity to a large population of people who have IDD.

Cigarette Smoking

Notwithstanding the pronounced health risks from smoking cigarettes, there is a sparse but emerging treatment literature for people with IDD. Peine, Darvish, Blakelock, Osborne, and Jenson (1998) sought to reduce the number of cigarettes two adults smoked at a developmental disabilities center. Preceding intervention, the adults received positive reinforcement in the form of cigarettes contingent on the absence of challenging behavior. The smoking reduction intervention plan introduced other reinforcers with cigarettes (coffee, soda, candy, magazines) that could be earned by spinning a wheel and accepting the "reward" it landed on. This procedure lowered the probability of receiving cigarettes each day and ultimately reduced smoking by 50 %.

Singh and colleagues have tested mindfulness-based therapeutic and support procedures for people with IDD (Singh et al., 2014b), including smoking cessation programs. Singh et al. (2011) described a 31-year-old man with mild IDD and lengthy history of smoking cigarettes, as many as 30 per day. At the time of the study he lived in a community group home that restricted him to no more than 12 cigarettes daily. In a baseline phase the man self-recorded cigarette smoking frequency before receiving mindfulness training in three phases. First, a mindfulness instructor taught the man to affirm his intention of quitting smoking via verbal reminders such as "I will not smoke anymore." The second phase of mindfulness training concentrated on the man observing his thoughts and endorsing "that he was not his thoughts, and that desires were merely thoughts, so he could observe his 'desire' thoughts and let them go" (Singh et al., 2011, p. 1182). In phase 3, the man learned to use *Mediation on the Soles of the Feet* (*SOF*) (Singh, Wahler, Adkins, & Meyers, 2003) whenever he experienced strong craving to smoke a cigarette. Another element of the program was goal setting by which the man decided to decrease smoking by one cigarette each time he achieved the preceding criterion on 3 consecutive days. Against the baseline number of 12 cigarettes per day, the man stopped smoking after 82 days of intervention and he maintained abstinence 1–4 years later.

Singh et al. (2013) extended their earlier work through mindfulness-based training with three men (23–31 years old) who had mild IDD and smoked cigarettes from 5 to 17 years. They lived together in an apartment and received group-training from a primary therapist. Each man participated in a baseline phase by keeping a daily log of the time and number of cigarettes smoked without intervention. They received the previously described smoking cessation program consisting of mindfulness intention, mindfulness observation of thoughts, and *Mediation on the Soles of the Feet* (*SOF*). Similar to Singh et al. (2011), the therapist met with the men to review their progress and help them decide how to lower cigarette consumption each week according to a decelerating changing criterion sequence. Baseline numbers for the three men of 28.4, 34.8, and 13.8 cigarettes smoked per day decreased gradually to zero cigarettes following 111, 165, and 77 days of intervention respectively. All of the men had not smoked while they continued mindfulness practices for an additional 12 months.

One additional study, by Singh et al. (2014a) was a randomized controlled trial of a mindfulness-based smoking cessation program with 51 people who had mild IDD. There were 25 participants in an experimental group, with an average age of 32.5 years and average smoking history of 15.0 years. The experimental group was exposed to the mindfulness intention, observation of thoughts, and meditation intervention with accompanying goal-setting reductions in the number of cigarettes smoked each week. A control group consisted of 26 participants with an average age of 34.4 years and average smoking history of 17.2 years. Control group participants continued to receive current smoking reduction interventions: motivational therapies (*N*=9), behavior therapies (*N*=7), nicotine replacement therapy (*N*=4), non-nicotine medicines (*N*=4), behavior therapy and nicotine replacement therapy (*N*=1), and behavior therapy and motivational therapy (*N*=1). Results revealed that a significant number of experimental group participants stopped smoking, whether they had completed or dropped out of the study before achieving a termination criterion of not smoking for 4 consecutive weeks or reaching a 40-week cut-off, whichever came first. The same statistically significant results were obtained 1-year later.

Medical Compliance and Adherence

There is strong evidence that behavioral interventions can improve medical compliance and adherence with people who have IDD and other neurodevelopmental disorders. Riviere, Becquet, Peltret, Facon, and Darcheville (2011) introduced compliance training procedures for 6- and 8-year-old boys with autism, targeting medical examination requests to look in their mouths, look in their ears, and cut their toenails. Both medical professionals and the children's parents issued compliance requests in baseline and intervention phases according to a reversal design. Under baseline conditions each child received access to preferred items when they complied within 10 s of a request. Intervention was based on a high-probability (high-*p*)–low-probability (low-*p*) sequence in which each examination request was preceded by three instructions that the children always completed successfully. This method effectively increased compliance without occasioning interfering behavior. Improved compliance also made it possible for the children to tolerate medical and dental examinations without sedating medications.

Cavalari, DuBard, Luiselli, and Birtwell (2013) focused on medical examination compliance with a 16-year-old girl who had autism and IDD. The intervention objective was having the girl tolerate a 12-step physical evaluation that a nurse performed by taking height and weight measures, monitoring blood pressure, examining eyes and ears, and listening to heart and lungs, all of these procedures implemented with respective instruments and devices (e.g., stethoscope, blood pressure cuff). For 2 years preceding the study the girl had resisted physician visits and displayed problem behaviors when parents and staff tried to intervene. In total, there were 74 substeps making up the 12-step examination hierarchy. Before intervention, the girl did not comply with a single step during three formal assessment sessions. Intervention featured graduated exposure to steps in the hierarchy, therapist demonstration of compliant responding, verbal reminders, non-contingent praise, and positive reinforcement. The girl could also terminate an intervention session at any time on request. Following 57 intervention sessions she was able to tolerate the full medical examination without resistance or forced compliance.

To improve compliance with dental procedures, Conyers et al. (2004) evaluated in vivo desensitization and video modeling with six adults (33–54 years old) who had severe-profound IDD. Their compliance with an 18-step "check-up" hierarchy was measured within a multiple baseline design across participants. In vivo desensitization had a dentist and care-provider deliver praise, encouragement, and verbal-physical prompting to the participants throughout the hierarchy. There were pauses between steps to ensure that the participants were "relaxed and calm" before instituting the next step. With video modeling participants watched a 15-min videotape of a well-known care-provider complying appropriately to the dental procedures. Only one of the participants exposed to video modeling achieved acceptable dental compliance whereas all six of them reached near-complete compliance through in vivo desensitization.

Another area of medical compliance and adherence research has been teaching individuals to wear and tolerate devices that have treatment and prosthetic value. Hagopian and Thompson (1999) worked with an 8-year-old boy who had autism, IDD, and cystic fibrosis but did not comply consistently with his prescribed respiratory treatment. The requirement was that the boy hold an aerosol inhaler mask with detachable chamber to his face for approximately 20 s of inhalation. Before intervention, and to overcome aggression and avoidance behaviors, a therapist unsuccessfully attempted to position the mask on the boy's face. The boy received intervention consisting of (a) *shaping* (gradually increasing the duration of time he had to hold the mask to his face), (b) *positive reinforcement* (praise and access to preferred items contingent on compliance), and (c) *stimulus transfer* (releasing a placebo mist and then active medication into the chamber). Intervention produced 100 % compliance with the respiratory treatment regimen and enduring effects 3 months post-discharge.

A study by Richling et al. (2011) applied several procedures to increase compliance with wearing foot orthodics and an in-the-canal hearing aid by an 11-year-old boy who had IDD and a 6-year-old boy who had autism. Neither child wore the devices consistently before intervention. Compliance training combined continuous access to preferred items and music, fixed-time presentation of attention, and replacement of the devices upon removal during 10–30 min sessions. This intervention produced 100 % compliance with both children, which was maintained when only social attention served as reinforcement and when assessed under natural conditions outside of the simulated sessions.

DeLeon et al. (2008) increased compliance with wearing prescription eye-glasses by four individuals with IDD using a multi-procedural treatment package. First, each participant had continuous access to preferred items and social interaction with a therapist during the time they wore their eye-glasses. The therapist physically blocked attempts to remove eye-glasses and also withdrew the preferred items and social attention. The effects of intervention were assessed further by gradually eliminating procedures in a component analysis. The treatment package raised independent wearing of eye-glasses above 90 % for the four participants. Component-wise, it was shown that not all of the procedures were required to maintain compliance overtime.

Finally, several studies have evaluated procedures with children and youth who have IDD and resist needle injections that must be performed for routine health screening (e.g., immunizations), treatment, and blood monitoring to ensure safe and therapeutic dosing of prescribed medications. Effective methods included *stimulus shaping and differential reinforcement* (Shabani & Fisher, 2006), *graduated exposure and distraction* (Grider, Luiselli, & Turcotte-Shamski, 2012; Slifer et al., 2011), and *stimulus fading*, *noncontingent reinforcement*, *and restraint removal* (Hagopian, Crockett, & Keeney, 2001). As applied with adults, Cromartie, Flood, and Luiselli (2014) reported the case of a 21-year-old woman diagnosed with mild IDD and schizoaffective disorder. She refused to comply with scheduled and unscheduled blood draws to properly monitor her serum levels and adjust the dosage of neuroleptic medication. The intervention entailed (a) gradually exposing the woman to task analyzed steps comprising a blood draw during simulated sessions, (b) reinforcing compliance with praise and tokens, and (c) offering a monetary incentive for completing an actual blood draw. Her compliance increased progressively and she was able to have her blood drawn successfully and without resistance 12–24 months following intervention.

Research-to-Practice Translation

In brief summary, the health and wellness research reviewed in this chapter illustrates many person-specific, group, and systems-level clinical applications with children, youth, and adults who have IDD. Other chapters in the book touch on similar topics, for example, feeding, sleep, and safety skills. This broadening focus on health promotion and intervention has several implications for research-to-practice translation, reviewed in this section, and with relevance to the health conditions covered in the chapter.

Interdisciplinary Collaboration and Consultation

The success of behavioral interventions in the area of health and wellness depends on a close alliance between psychologists and multidisciplinary practitioners such as physicians, nurses, therapists, rehabilitation specialists, and the like.

Note, for example, that the process of developing a comprehensive weight reduction program for an adult with IDD would minimally need to integrate the roles of a primary care physician, nutritionist, nurse, and allied professionals. As presented previously, these disciplines would be responsible for constructing a weight reduction program that integrates diet regulation, exercise, routine measurement, social supports, and treatment adherence. More generally, "Current approaches to creating healthier communities for people with IDD require greater involvement on the part of direct care staff and family members to facilitate increased access to 'healthy' lifestyles, including more opportunities for regular physical activity and greater access to nutritious and affordable food choices" (Rimmer & Yamaki, 2006, p. 26).

One approach to foster cooperation and collaboration among multidisciplinary professionals is for psychologists to implement a five-stage behavioral problem solving consultation model (Bergan & Kratochwill, 1990). Stage 1 of this model entails establishing a consultative relationship through rapport building, mutual knowledge sharing, defining expectations, and identifying common objectives. Stage 2 is devoted to problem identification—what are the goals of consultation, how will measurement be performed, from what sources do problems emanate? The next stage is termed problem analysis by which the consultant and consultees carefully assess the variables that influence clinical presentation and the immediate problems. This stage of the problem-solving model relies heavily on assessment data to inform intervention formulation. Stage 4 consists of plan implementation and refinement, as necessary. The final stage, plan evaluation, looks at direct outcome and process measures, social validity, and other determinants of success.

Behavioral problem solving consultation is similar to several models of integrated health care stressing collaboration among medical providers and other professionals (Doherty, McDaniel, & Baird, 1996; Heath, Wise Romero, & Reynolds, 2013). Using integrated teams, patient care is supported on several levels from initial referral through provision of treatment. The role of a behavioral health consultant (BHC) fits well with problem-solving consultation and as an integral member of a primary care team (Guion, Olufs, & Freeman, 2015). A fundamental role of a BHC would be educating physicians about IDD, diagnostic convention, behavioral assessment, contemporary treatment, and many related topics. Such consultation is necessary because most physicians are not trained to care for people who have IDD (Lennox & Diggens, 1999; Phillips, Morrison, & Davi, 2004). Indeed, "Future research is needed to develop best practices and evidence-based approaches to train physicians, nursing, and dental staff to effectively provide care to people with IDD in a person-centered manner" (Anderson et al., 2013, p. 393).

Intervention Integrity

The potential effectiveness of any behavioral intervention is largely dependent on procedural fidelity. That is, prescribed procedures must be applied as formulated, written, and trained in order to properly judge whether they actually contribute to treatment success or failure. In many cases seemingly poor results may stem from inaccurate implementation and not the procedures themselves.

Intervention integrity assessment measures the procedural fidelity of practitioners through direct observation and accompanying performance documentation. Recall the study by LaLonde et al. (2014) in which young adults with autism increased the number of steps they walked daily through goal-setting, pedometer read-outs, and positive reinforcement. The researchers were present every day to monitor intervention integrity and recorded whether the participants wore their pedometers correctly, completed data sheets, indicated performance goals, and selected reinforcers. Likewise, Singh et al. (2014a) had a second person independently listen to selected audiotapes of mindfulness training sessions. This type of intervention integrity assessment was designed to verify the procedural fidelity of the primary instructor.

Another facet of intervention integrity assessment is providing feedback to practitioners after observing them implementing procedures (DiGennaro Reed & Codding, 2011). Feedback usually consists of praise, approval, and similar positive consequences when procedures are applied correctly. Correction occurs if procedures are misapplied. Research suggests that feedback is most effective when it happens immediately following observation, is behaviorally specific, and focuses on skill development (Luiselli, 2015). Of course, the ultimate goal of intervention integrity assessment is making sure that practitioners consistently apply and maintain the procedures that have been selected for service recipients. Therefore, such assessment should take place on a regular schedule within normal service delivery settings and activities.

Outside of a research program where intervention integrity assessment is conducted as standard protocol, different options and adaptations must be considered in purely clinical settings. For example, in a school or residential facility, existing care-providers could be trained to perform intervention integrity assessment. Consultants to such settings can also complete assessments during scheduled visits (Minor, DuBard, & Luiselli, 2014). Within home-based services parents can assess their intervention integrity through periodic observations of one another during health and wellness routines. It is also possible to conduct intervention integrity assessment through self-monitoring, as described by Fischer, Luiselli, and Brent (2015) in a clinic and home intervention with an adolescent who had chronic food selectivity and associated health problems. Both the clinician and parent were responsible for self-recording completion of specific intervention procedures during clinic and home meals. Their self-recorded data served as a simple proxy measure of procedural fidelity. Because practitioners may favor certain methods to improve intervention integrity (Strohmeier, Mule, & Luiselli, 2014), it is wise to assess those preferences before intervening.

Social Validity

Social validity refers to satisfaction with and acceptance of intervention procedures and outcomes by service recipients and practitioners (Kazdin, 1977; Wolf, 1978). Positive social validity is desirable because it indicates that the people who receive and implement procedures approve of their treatment and the results. Positively endorsed procedures and outcomes also have salutary effects on intervention compliance, adherence, and motivation. Notably, a person is likely to comply with treatment demands when the procedures are not judged as being harsh, time-consuming, or difficult. At the same time, it can be expected that practitioners will implement affirmatively perceived procedures with greater integrity and precision. Therefore when social validity is poor, the professionals responsible for intervention must revise procedures with the objective of improving satisfaction and acceptability.

The process of social validity assessment asks service recipients and practitioners about how they perceived treatment, through either verbal report or more definitely, by completing a written survey or questionnaire. Informants endorse various statements, usually according to a Likert-type scale, and their ratings are quantified to produce statement-specific and overall average ratings. Again, the information gathered from assessment is used to revise procedures that have poor acceptance and satisfaction.

Referencing the study by LaLonde et al. (2014) again, the researchers assessed social validity in two ways. First, the four participants were queried about whether they liked wearing a pedometer each day and would they want to wear a pedometer and set physical activity goals in the future? All of the participants responded "yes" to both questions. The second part of social validity assessment asked the primary instructor three questions from the *Modified Treatment Acceptability Rating Form Revised* (TARF-F) (Reimers, Wacker, Coopers, & Raad, 1992): (a) how acceptable was the treatment, (b) how willing were you to carry out the treatment, and (c) how effective was the treatment. The instructor responded with high social validity to all three questions.

Maintenance

Many of the studies reviewed in this chapter reported maintenance of treatment effects, some as long as 4 years post-intervention (Singh et al., 2013, 2014b). Maintenance concerns the persistence of therapeutic change after treatment has been eliminated, altered, or substituted in some way. Apropos to health and wellness, it is many times the case that an effective treatment regimen is not removed or discontinued but instead, implemented at reduced strength and intensity. Attenuating treatment demands, in fact, is one method to enhance long-term maintenance (Luiselli, 1998). However, practitioners are still burdened with the task of designing effective maintenance-facilitating strategies since many factors can impede desired results.

Naturally, a person's desire to maintain treatment, or the motivation of those providing care, will be dependent on the success of intervention, whatever the therapeutic intent and level of intensity. Even small revisions to intervention plans can lessen treatment burden and affect maintenance positively. Whenever possible, teaching people self-management skills can be a fortuitous maintenance-enhancing strategy. Because people with IDD are commonly followed by multiple health providers, coordinated communication among professionals is essential so that intervention is continuous and does not deviate from prescribed procedures. This caveat is synonymous with the objectives of treatment integrity, outlined earlier.

Advances in telehealth technology and treatment (Luiselli & Fischer, 2015) gives health and wellness professionals other options for promoting maintenance. An illustrative example is the weight reduction program reported by Rimmer et al. (2013) that featured a telephone-based and web-assisted remote coaching system. Such treatment was implemented more efficiently with the clinical population, and sustained over time, when contrasted to traditional in-person health visits and intervention. Immediate contact with practitioners, rapid access to information, automated data recording, real-time video monitoring, and multi-platform flexibility are some of the advantages of telehealth modalities for fostering intervention compliance and maintenance.

Summary

This chapter on health and wellness of people with ID reviewed epidemiological statistics, factors contributing to several health conditions, promising behavioral interventions, and issues of research-to-practice translation. There has been meaningful progress developing integrated medical-behavioral approaches to prevention and treatment, leading to more effective care, systems of service delivery, and clinical-research inquiry. Building multidisciplinary collaboration remains a priority, as does dissemination of evidence-based practices at the primary level of care. Health and wellness initiatives in IDD should strive to monitor and improve intervention integrity, assess social validity, perform multi-measure outcome and process evaluation, promote enduring treatment effects, and continue to have a community and family focus.

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Safety Skills

36

Jina Jang, Anurati Mehta, and Dennis R. Dixon

Introduction

Safety skills are those many things that a person learns as they develop, which helps them to successfully navigate their environment in order to avoid situations or elements that can lead to harm. In the typically developing population, these skills are developed with age and the cognitive ability of an individual plays an instrumental role in the successful implementation of these skills. In persons with intellectual and developmental disabilities (IDD), there is often a mismatch between cognitive or behavioral abilities and the environment, which may result in the person with IDD being placed in an unsafe situation. Due to cognitive impairments, the individual may be unaware of danger or lack the ability to correctly implement safety skills (Gaebler-Spira & Thornton, 2002). Given that these skills follow a typical developmental course, children with IDD are at particular risk for not developing these skills appropriately. Children with IDD may have impaired skills such as the ability to learn and obey safety rules, to estimate their own physical strength, to understand the risks of a given situation, and to understand the cause of an injury after its occurrence (Schwebel & Gaines, 2007). The risk of injury for individuals with IDD is further exacerbated due to the presence of related physical disabilities (e.g., poor gross motor skills, visual impairment) or comorbid psychopathology (Sherrard, Tonge, & Ozanne-Smith, 2002). As a result, these individuals are either not aware of the harm that can be caused to them if they are exposed to dangerous situations or they lack the skill to carry out an escape plan (e.g., how to find the exit in case of a fire). All of these factors put individuals with IDD at an increased risk for injury or victimization.

Typical day-to-day environments, such as home, school, or public places, present with a number of hazardous situations. Harm may come to persons with IDD if they do not possess the skills to identify and appropriately handle these situations. For instance, in the home environment, individuals are exposed to elements like cleaning products, sharp household items (e.g., knives, forks, scissors), and broken glass (Winterling, Gast, Wolery, & Farmer, 1992). Obviously, if these elements are not handled appropriately, then serious injury may occur.

Harm may not only come from passive sources such as cleaning products or kitchen knives, but also active sources such as caretakers, peers, and community members (Lennox & Eastgate, 2004). Predators may target individuals who show signs of an inability to recognize unsafe situations, verbally protest, or escape from such situations.

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As such, it is also very important to teach individuals with IDD how to identify and protect themselves from physical and sexual abuse. Further, if a crime occurs, such individuals are less likely to know that it is important to report the incident. Individuals with IDD may not comprehend that they have a right not to suffer this abuse. Enabling people with IDD to become aware that abuse is illegal is an important first step in countering abuse (Reiter, Bryen, & Shachar, 2007).

Researchers have identified that there are a number of factors that play a part in increasing the vulnerability of individuals with IDD. In general, researchers report that these individuals are at a higher risk due to poor communication skills, physical disability, gullibility, and the tendency to acquiesce with requests from others (Greenspan, Loughlin, & Black, 2001; Howlin & Jones, 1996; Sullivan, Brookhouser, Scanlan, Knutson, & Schulte, 1991; Zhu, Xia, Xiang, Yu, & Du, 2012). Further, research by Howlin and Jones (1996) and Sullivan, Brookhouser, Scanlan, Knutson, and Schulte (1991) indicated that due to limited communication skills, children with disabilities might lack the ability to disclose abuse. As a result, they may be seen as easy targets. Such abuse could manifest as physical or sexual and may involve their peers or caregivers (Lennox & Eastgate, 2004).

Gullibility and acquiescence are of particular note for persons with IDD. Individuals with IDD often have an unquestioning belief and tend to put their trust in others (Kempton & Gochros, 1986). Additionally, individuals with IDD often have a learning history of being reinforced for compliance with requests. A prevalence study done in the UK noted that in 84 % of the instances the perpetrator of sexual abuse faced little to no resistance (McCarthy & Thompson, 1997). However, training compliance is also essential for many important daily activities such as taking medications, eating, and dressing, to name only a few examples. The key element then is in teaching the individual to identify inappropriate requests and to create transparent and accountable systems of care for those persons who are unable to acquire the discrimination skills.

Sociocultural factors also play a part in the abuse of individuals with IDD. The attitudes of peers may increase the risk of bullying, ridicule, or acts of violence (Hodges & Perry, 1996). In social settings, an individual with IDD may not comprehend or develop awareness of cues that alerts them that a situation is unsafe.

Given the increased risk for persons with IDD, teaching safety skills is of the utmost importance. However, in spite of the potential for serious injury or victimization, the training of appropriate safety skills may be neglected in the education of persons with IDD (Petersilia, 2000). In this chapter, we look at safety skills across seven broad categories: fire safety, first aid, accident prevention, fall-related prevention, pedestrian, self-protective, and emergency telephone skills.

Epidemiology

The prevalence of injury in children and adolescents with IDD is 1.5–2 times higher than typically developing children (Slayter et al., 2006). The most common unintentional injuries in this population are burns, poisoning, foreign body injuries, fractures, dislocations, and internal injuries (Rowe, Maughan, & Goodman, 2004). According to the US Department of Homeland Security (2011), every year an estimated 85 deaths and 250 injuries occur due to residential building fires involving individuals with IDD. In 40 % of the cases, the fire was intentional and an IDD was the human factor contributing to ignition.

Adults with IDD have a higher rate of injuries and falls as compared to the general population (Finlayson, Morrison, Jackson, Mantry, & Cooper, 2010). The authors reported that over a 12-month period, incidence of at least one injury was 20.5 % in which falling was listed as the cause of the injury in 12.1 % of the reported injuries. In a population-based comparative study specifically designed to investigate public health implications of injury in young people with IDD, Sherrard et al. (2002) found that this group had mortality rates from injuries that were eight times higher than the general population. In their study, falls were the most frequent cause of injury (60.2 %) followed by burns (7.3 %).

In regard to victimization, Wilson and Brewer (1992) found that adults with IDD are twice as likely to experience crimes against the person (physical assault, sexual assault, robbery, and personal theft) and 1.5 times more likely to experience property crimes such as breaking-and-entering and household property theft. Concerning sexual abuse, Sobsey and Mansell (1994) reported that 15,000–19,000 people with developmental disabilities are raped in the USA. Further, women with IDD are assaulted, abused, and raped at a rate two times greater than women without disabilities (Sobsey & Mansell, 1994). Unfortunately, it is not uncommon for individuals with IDD to also be physically, sexually, psychologically, and financially abused by family members, neighbors, and peers (Sobsey & Varnhagen, 1988; Williams, 1995).

Evidence-Base for Treatments: Review of Research

Fire Safety Skills

The alarming number of fire-related injuries and deaths among individuals with IDD brought a good deal of attention during the late 1970s and 1980s to the development of programs to teach fire-related safety skills (US Department of Commerce, 1978). Although fire emergencies occur less frequently than other accidents, due to their devastating effects, it is important to teach individuals with IDD skills to prevent and safely react to fires (Mechling, 2008). Many studies and reviews on fire safety skills have been conducted (Bannerman, Sheldon, & Sherman, 1991; Cohen, 1984; Haney & Jones, 1982; Jones & Thornton, 1987; Katz & Singh, 1986; Knudson et al., 2009; Luiselli, 1984; Matson, 1980b; Mechling, 2008; Rae & Roll, 1985; Rowe & Kedesdy, 1988). As such, research on the area of fire safety skills with individuals with IDD is well established and demonstrates that individuals with IDD are able to learn fire safety skills through behavioral training.

One of the earliest studies to teach fire safety skills to person with IDD was conducted by Matson (1980b). In his study, he developed task-analysis steps for escaping fire and used classroom training to teach five adults with moderate IDD to safely escape from a fire (Matson, 1980b). The task analysis steps included: (1) crawl out of bed keeping the face down and go to all fours; (2) crawl to the nearest door with little smoke; (3) open the door while staying bent down and go outside as fast as you can without running; and (4) stay outside and wait for directions from authorized persons. The participants were first taught to verbally describe the steps to escape a fire using verbal instructions and social reinforcement. Then the instructor modeled step-by-step target behaviors using the cardboard model of the living area and figures. With verbal and physical prompts, the participants imitated and rehearsed the step-by-step behaviors. Matson (1980b) found the participants were able to verbally report how to respond to a fire emergency and maintained the knowledge 7 months after the training. Results of the study revealed that the participants with moderate IDD who lived in an institution for a long period of time were able to verbally describe how to escape a fire.

Although Matson (1980b) demonstrated that the participants could successfully gain appropriate knowledge of fire escape skills, the question remained whether individuals with IDD could perform these skills in real-life situations. To address this question, Haney and Jones (1982) taught four children with moderate and severe IDD to exit from their living environment in fire-emergency situations. The participants were 12–16 years of age and resided on the second floor of a group home. Each training session lasted approximately 20 min and consisted of verbal instructions, modeling, behavioral rehearsal, corrective feedback, and social reinforcement. Role-playing was used to help generalize these skills, and simulated environments using props such as a tape recording of the house's fire alarm, a heated pad, a cool pad, a blow dryer, and pictures of smoke/fire were used. The multifaceted behavioral training was effective in teaching children with moderate to severe IDD to safely exit simulated fire emergencies from their home; across their participants, 60–100 % successful performance was achieved in 10–30 training sessions. Furthermore, the participants demonstrated maintenance of the learned skills at 6 months follow-up.

Further research has expanded on these results, showing that similar behavioral techniques including verbal instruction, reinforcement, prompting, and feedback are effective techniques for teaching adults with IDD to perform fire safety skills. For example, Luiselli (1984) taught fire safety skills to a 43-year-old man with severe IDD who resided at a residential facility. After 3 months of unsuccessful attempts to teach him the skill, he was referred for behavioral training which consisted of instruction, prompting, feedback, and reinforcement. More specifically, during the initial 2-h session, the participant was taught to go outside upon hearing the fire alarm and successful performance was reinforced. The participant was further trained over 13 consecutive days, practicing one fire drill each day. When the participant successfully evacuated the residence and met at a predetermined location within 2.5 min of an alarm ringing, he was rewarded. When he did not meet the 2.5 min criteria, he did not get the reinforcer and was told why he did not receive it. After failing to exit on the first 2 days, the participant successfully performed fire safety skills on 11 consecutive days, averaging 54 s to exit. The participant learned to independently evacuate the facility after 2 weeks of behavioral training. The participant also demonstrated 100 % successful performance during seven post training drills all within 2 months of the training. At the 1-year follow-up, the participant successfully evacuated the building within 2 min upon hearing the alarm.

Similarly, Cohen (1984) taught fire safety skills to a 30-year-old male with profound IDD and blindness who resided at a group home. The participant learned to independently evacuate the bedroom using instruction, forward training, reinforcement, and verbal prompting. The forward chaining procedure was used to teach safety skills, which were divided into ten steps. The mastery criterion for each step consisted of five successive independent correct responses. Upon demonstration of the correct response, the participant was given social praise and edible reinforce. A verbal prompt was provided if the participant did not respond independently. It took a total training time of 2.5 h to teach the participant to independently exit the building; the average exit time was 28.5 s which met the 2.5-min requirement set by the state. Furthermore, the skills were generalized across different locations and were maintained at a 1-year follow-up. The rapidity of training was attributed to the simple procedure.

Rae and Roll (1985) implemented an intensive fire safety training program for ten individuals with profound IDD, ages 22–42 years, who resided on the tenth floor of their group residence. The training program consisted of daily fire drills for 1 year. Following the verbal cue, the fire alarm rang to signal the drill. When the participants did not respond within 30 s, verbal and gestural prompts were provided. If the participants did not respond within 60 s, then physical prompts were used. All participants received social praise upon completion of the drill within the time limit. After 1 year of daily practice. The mean evacuation time for all participants decreased from 87 s to a mean of 24 s. Also, the amount of physical prompts given significantly decreased from 57 to 7 %. Noticeable progress was observed after 6 months of daily fire drill training.

Following these studies, Katz and Singh (1986) extended upon previous research on fire safety skills and taught more comprehensive fire safety skills such as exiting a burning building, reporting fire, and extinguishing fires by using the stop, drop, and roll procedure to adults with mild to moderate IDD. Five females and four males, ages 30–50 years old, who resided in a group home participated in the current study. The exiting training was conducted in the participants' bedroom and other safety skills such as reporting and extinguishing fires were taught in various locations to ensure generalization. Props such as pictures of smoke and flames and a hair dryer were used to simulate more realistic environment. Training procedures consisted of verbal instructions, modeling, rehearsal, feedback, and reinforcement. All participants acquired knowledge of more comprehensive fire safety skills, and these skills were maintained over 6–18 weeks follow-up.

Consistent with previous research, Jones and Thornton (1987) also successfully taught fire evacuation skills to four adults with IDD, ages 30–55 years. In addition to teaching fire safety skills, the authors aimed to enhance the maintenance. An average of eight daily sessions was conducted lasting approximately 15 min. Training consisted of instructions, modeling, behavioral rehearsal, feedback, and reinforcement. The participants were trained in their own apartments using simulated fire cues and in vivo situations. All participants successfully learned to evacuate during fire emergencies. In order to promote maintenance, a maintenance program was followed over a 30-day period. The maintenance program consisted of presentation of mastered situations, self-evaluation, and booster sessions and showed that the acquired skills can be maintained over a 6–8-months period. Rowe and Kedesdy (1988) used a time-limited fire evacuation program to teach 37 institutionalized adults with mild to profound IDD. The participants were taught to independently evacuate their two-story cottages within 2.5 min of a fire alarm ringing. Backward chaining, delayed least-to-most prompting procedures, reinforcers, and social praises were used to teach target skills. Following 3 weeks of training, a large percentage of participants passed training drills. Participants continued to improve and their evacuation skills maintained at 3- and 6-month follow-ups.

The majority of studies within this domain have included participants who were verbal. Bannerman et al. (1991) extended upon the research by demonstrating that these techniques could also be used for nonverbal adults with severe and profound IDD. The participants included three adults, ages 25–40 years. The participants were taught to evacuate their group home residence within 2 min of surprise fire drills. Modeling, rehearsal, prompting, and reinforcement were used. All participants successfully learned to exist independently and demonstrated maintenance for 3–16 months. In addition, all participants demonstrated generalization of target skills across locations and people.

Many studies have successfully taught fire safety skills to individuals with IDD, but are limited by the contrived nature of the teaching environment. In order to ensure better generalization, it is necessary to set-up a seemingly real fire emergency and train individuals without their knowing that they are being assessed. Towards this end, Knudson et al. (2009) conducted a study to evaluate training procedures for teaching individuals with severe and profound IDD in the most naturalistic way possible. Seven participants with severe and profound IDD were taught to exit their residence upon hearing a fire alarm when they were not aware of the assessment. The participants were taught to immediately engage in exit behaviors until they were safely out of the building upon hearing a smoke detector. A multiple baseline across-subjects design was used to evaluate the effectiveness of behavioral skills training and in situ training. The first trial consisted of the experimenter modeling the correct behaviors. Each subsequent trial involved the experimenter using the least intrusive prompt necessary to get the participant to exit the building. The results of this study showed that one of the seven participants learned to exit the group home quickly without prompts and four participants required less intrusive prompting to exist the building.

In summary, previous researchers have successfully taught fire safety skills to individuals with varying degrees of IDD and ages; the participants in these fire safety studies ranged from children to older adults, and their level of IDD also varied from mild to profound. Earlier studies increased the participants' knowledge by teaching them to verbally describe what to do in a fire emergency. Although knowledge is an important part of safety training, researchers pointed out that knowledge alone does not necessarily generalize into actual skills. Thus, many researchers have focused on teaching the individuals to perform fire safety skills and have reported promising results. Based on these studies, it is clear that when teaching individuals with IDD fire safety skills, behavioral techniques including verbal instruction, prompting, reinforcement, rehearsal, and feedback should be used. The fire safety skills research is limited by several factors. Because it is difficult to simulate a real fire in training, creating a more naturalized environment still is a limitation. Each study varied in training time, from several weeks to 1 year. More research is needed to determine which factors increase or decrease the training time. Moreover, only a few studies had long-term follow-up data. Taking the participants' low intellectual functioning into consideration, future studies should conduct long-term follow-up assessments to determine longevity of the treatment effects.

First Aid Skills

Knowing what to do in emergency situations can prevent more serious injuries, harm, and even death. Injury rates for individuals with IDD are higher than those without disabilities due to their cognitive and behavioral deficits (Matson, 1980b). As such, an additional focus on safety skills training should be on teaching individuals with IDD to perform basic first aid.

In the same study that used classroom training to teach five adults with moderate IDD to escape a home fire, Matson (1980b) also taught the same participants how to care for of a minor cut and to properly respond to a person having a seizure. Task analysis steps for taking care of a cut included letting the cut bleed to wash out the dirt, washing the cut, putting on a bandage, and informing staff members if the cut does not get healed. Task analysis steps for taking care of a person having convulsions included catching the person if possible, lowering the person to the ground, turning the person's head to the side, and not putting objects in the person's mouth. The participants were taught to describe the steps and to demonstrate the behaviors by role-playing. After the classroom training only, the participants were able to describe the steps of target behaviors; however, this knowledge did not lead to correctly performing the skill. Upon receiving both role-playing and classroom training together, the participants successfully performed the first-aid skills.

Spooner, Stem, and Test (1989) replicated Matson's study (1980b) and taught three adolescents with moderate IDD, ages, 16–17, to demonstrate first-aid skills for minor injuries and choking. The trainer led short group discussion on different types of wounds (e.g., scrapes, punctures, bites, burns), bandages (e.g., types, sizes), signs of choking, and foods that make can make people choke. Following the discussion, the trainer conducted individual training sessions using modeling, rehearsal, prompting, and reinforcement. The total training time ranged from 90 to 165 min. All target first-aid skills were acquired and maintained at 12-weeks follow-up.

These methods were later extended to teaching first aid skills to children with IDD by Marchand-Martella and Martella (1990). In their study, four children, ages 7–11, living in a behavioral residential treatment facility, were taught to perform first-aid skills. Of those four children, one child was diagnosed with IDD. The study used a first-aid training program called *Mouse Calls*. The program consisted of puppets, a first-aid kit, and an activity book which included task analysis steps for treating minor wounds that bleed, scrapes that stop bleeding, and minor burns from heat. First, the trainer read task analysis steps, which were described in a story format with illustrations. Then the participants performed first-aid skills using the puppets and the first-aid kit. Ketchup and/or a red mark were used to represent injuries (i.e., blood, burn) on the puppets. The participants were provided with reinforcement and corrective feedback. The participants reached the mastery criteria when they performed all steps at 100 % across four consecutive sessions. The participants acquired, generalized, and maintained the skills up to 66 weeks. This study added to existing research by successfully teaching children to demonstrate basic first-aid skills.

Marchand-Martella, Martella, Christensen, Agran, and Young (1992) also conducted a study that used peer-administered behavioral training to teach first-aid skills to children with moderate IDD. Four children, ages 7–11 years, with moderate IDD were taught to treat simulated abrasions, burns, and cuts by two peers with mild IDD. After target skills were modeled and verbally instructed, the participants practiced the skills on simulated injuries on their own and others' bodies. Feedback and social praise were provided during the training. Overall, the participants learned to apply first aid skills, and the skills were generalized across sites and injury locations.

To evaluate the impact of a time-delay procedure on teaching first-aid skills, Gast and Winterling (1992) evaluated students with moderate IDD. The participants, ages 17–21, were taught to properly respond to a minor cut, a burn, and an insect bite. A first-aid kit containing tape, gauze pads, antiseptic, cleaning towels, tissues, cloth, plastic bag, lotion, and cotton swabs was provided; ice cubes that were used on the insect bite were located in the classroom freezer. Injuries (e.g., cuts, burns, insect bites) were simulated using costume make-up. The task analyses for first aid skills were developed and validated with the American Red Cross guidelines and professional registered nurses. Each first-aid skill was taught using a backward chain with instruction and a 5-s constant time delay procedure. A multiple probe design across participants and behaviors was used to evaluate the treatment package. Following training, all students were able to apply first-aid skills.

Most recently, Ozkan (2013) expanded upon previous research by comparing peer and self-video modeling in teaching three children with IDD, ages 9–14. Two videos were recorded for each child. In the peer-model video, the participants watched their peer apply first-aid skills, and in the self-video model, the participants watched the pre-recorded video of their performing first aid for bleeding and burns on other children. The first aid for the bleeding was 3 min, and the burns video lasted 8 min. Make-up and paint were used to illustrate simple bleeding and burns. The results of the study showed that both peer and self-modeling were effective and efficient in the acquisition and maintenance phase for teaching first aid skills to children with IDD. Of particular note, the participants who played the role of sufferers acquired both sets of first aid skills by only observing their peers.

The available studies demonstrated that behavioral techniques such as modeling, rehearsal, prompting, and reinforcement were effective in teaching first-aid skills to individuals with IDD to treat minor injuries (e.g., abrasions, burns, cuts, inset bites). In general, verbal instructions alone were not effective in generalizing the skills; role-playing and practicing the skills were especially important for the participants to acquire the first-aid skills. Studies varied in the degree to which maintenance data were collected. This is an important component of training any skill. Spooner et al. (1989) provided an example of how individuals with average cognitive functioning were encouraged to have yearly refresher courses in CPR training. Therefore, periodic check-ups and booster sessions were highly recommended in training individuals with IDD as well. In terms of role-playing and other attempts to improve generalization to real-life situations, most studies reported participants were trained to treat minor injuries on themselves or on a puppet.

Accident Prevention Skills

As noted above, persons with IDD have a much higher prevalence of injuries due to accidents. While first-aid skills are useful when an injury has occurred, the prevention of the injury altogether is obviously preferred. Previous studies on accident prevention focused on teaching simple precautionary tasks such as locking up poisons and sharp objects and proper disposal of broken materials. The available studies examining accident prevention skills used various measures such as written checklists of task analysis and instructional manuals. A few studies used reactive, behavioral intervention to teach home accident prevention skills.

O'Reilly, Green, and Braunling-McMorrow (1990) used written checklists and task analyses to teach home accident prevention skills to four adults with brain injuries, ages 18–37 years. Potential home hazards were identified and task analyses for each dangerous situation were developed. The specific task analysis described hazardous situations for different locations (e.g., kitchen, living room, bedroom, bathroom) and steps to prevent the potential accident. One of the hazardous situations in the kitchen was identified as paper napkins placed on stovetop. Behavioral steps for this particular situation were to remove the paper from stovetop and to place it in trash. The participants were instructed to read the written checklists, follow instructions, and check off each step. Feedback, praises, and prompts were used. The participants were able to appropriately remediate potential hazards using the checklist, and the acquired skills were maintained over a 1-month period.

Many studies used the delay procedure and multiple exemplars during instruction. For example, four adolescents with moderate IDD were taught to read key words from product warning labels using flash cards using a progressive time delay procedure (Collins & Stinson, 1994). Target words (e.g., caution, contamination, irritant, swallowed, vomiting), and their definitions and the contextual examples were written on white index cards. The teacher presented the flash card with the target word, and praise was given on a continuous reinforcement schedule for correctly identifying target words. Praise was eventually faded to a variable ratio schedule. In order to facilitate observational learning, training was conducted in dyads. The progressive time delay procedure was effective in teaching the students with IDD to read warning labels; however, generalization across products and settings was poor. More instructions may be needed to facilitate generalization so that students understand the meaning of the labels and have a truly functional skill. Based on previous studies, Collins, Belva, and Griffen (1996) further taught four children with moderate IDD to perform a safe, age-appropriate response to warning labels. The participants were presented with multiple exemplars of products with warning labels and were taught to demonstrate safe responses to potentially dangerous products using a constant time delay procedure. Praise was given on a continuous reinforcement schedule for correctly identifying and responding to target word and was eventually faded into a variable ratio schedule. The students were guided to demonstrate a safe motor response to a dangerous product on their daily, generalization, and maintenance sessions. The participants were taught to appropriately demonstrate both verbal and motor responses to potentially dangerous products using the constant time delay procedure and multiple exemplars. This procedure was also effective in generalizing responses to novel settings and materials.

Winterling et al. (1992) also conducted a study that taught three students with moderate IDD (17–21 years) to appropriately respond to potentially harmful situations. Specific skills taught included removing and discarding broken plates and glasses safely from a sink, countertop, and floor. The study used a multicomponent treatment package, which consisted of an orientation lecture, simulation, multiple exemplar training, and the time delay procedure to teach the target skills. A multiple probe design across participants and tasks was applied to evaluate the training. All participants learned the target skills; however, their levels of maintenance yielded mixed reports. Overall, the results showed that the treatment package was effective in teaching appropriate and safe responses to potentially dangerous situations.

When parents with IDD are not taught adequate parenting skills, their lack of knowledge and skills may result in unintentional child maltreatment (Feldman, Case, Towns, & Betel, 1985; Keltner, 1994). Because being able to recognize home hazards may prevent accidents, Tymchuck, Hamada, Anderson, and Andron (1990) taught four mothers with IDD to understand home hazards and to implement safety precautions. The mothers were trained as a group in a community facility and individually in their own home. Two assessment instruments, the Home Safety Observation Inventory (HSOI) and the Safety Precautions Inventory (SPI) were developed. These instruments included 14 categories: fire, electrical, suffocation by ingested objects, suffocation by mechanical objects, fire arms, solid/liquids, heavy objects, sharp objects, clutter, inedible, dangerous toys, cooking, general safety, and other. During weekly training, the mother and the trainer discussed accidents from each criteria in detail and how they could have been prevented. They developed a plan for each danger by identifying the best ways to remove the identified danger. At the end of the training, the authors found that two mothers with mild IDD could be trained to identify home dangers and to implement precautions and concluded that future research is needed to identify the mothers who need additional support given the variability in their results.

Given that some individuals with IDD could learn parenting skills to provide safe environment for their children, Feldman and Case (1999) further wanted to develop the self-instructional material for those who do not have resources to receive intensive behavioral interventions. The authors taught safe parenting skills to ten parents with mild IDD using self-instructional audiovisual manuals. The manual consists of illustrated picture books depicting 25 child care skills from birth to about 2 years of age and the checklist covering topics such as newborn care, feeding and nutrition, health and safety, and positive parent-child interactions. Each picture also has a brief text describing a task analysis of a specific skill. In addition, the participants listened to audio recordings of the manual; the instructor on the audiotape directed the listener to look at the picture and read the text. Prompting, discussion, demonstration, feedback, and reinforcement were also implemented when necessary. The results of the study showed that audiovisual self-learning was an effective and efficient method to improve safe child care skills in parents with mild IDD.

More recently, Llewellyn, McConnell, Honey, Mayes, and Russo (2003) evaluated a home-based intervention to teach child health and home domestic safety skills to parents with IDD. The authors used instructional lessons to teach child health and domestic safety skills to 45 parents with IDD. Home Learning Program (HLP), which was designed to help parents learn the skills to safely manage home dangers and accidents, was delivered by a trained educator during weekly visits to the participant's homes. The HLP consisted of ten sessions, each lasting about 1 h. During each session, the educator went over the illustrated booklet, covering lessons such as identifying and properly responding when a child is injured and preventing potential home hazards. All participants received the HLP but depending on which group they were placed in, it determined when they received the HLP and what other conditions that would participate in. The findings showed that parents' ability to recognize home dangers significantly improved and the gains were maintained at 3 months post-intervention. Also, the participants' knowledge of health and symptoms of illness and life-threatening emergencies managing skills increased.

Overall, existing research on accident prevention demonstrated that skills to identify potential dangers and safely respond to hazardous situations could successfully be taught in individuals with IDD. The studies focused on teaching accident prevention skills (e.g., reading warning labels, identifying dangerous situations, performing safe responses) using written checklists, instructional manual, and behavioral techniques. The results of the reviewed studies showed clear evidence that simply teaching to identify what is dangerous was effective in increasing the participants' safety knowledge, which could potentially save lives by preventing serious accidents. Most of the studies taught skills that were relevant in the home environment; future studies should target generalizing these skills to other environments such as workplace, school, and community settings.

Fall-Related Prevention Skills

Individuals with IDD are at an increased risk for physical injury caused by falling (Hale, Bray, & Littmann, 2007; Tannenbaum, Lipworth, & Baker, 1989). Falling may result in serious consequences, as it may cause individuals to be institutionalized and decrease physical activity (Bruckner & Herge, 2003). In addition, falling may result in higher health care costs, increased fear of falls, and decreased quality of life (Bruckner & Herge, 2003). While research in fall prevention in the older adult population has been widely examined, there is a general lack of studies investigating fall prevention in the IDD population. Currently, there are a few epidemiological studies investigating fall incidence and risk factors in individuals with

IDD; however, studies teaching skills to prevent potential falls are limited.

In the review by Willgoss, Yohannes, and Mitchell (2010), the authors examined risk factors and preventatives strategies in the IDD population. Seven studies met the inclusion criteria using search terms: "intellectual disability," "falls," "injury," "fractures," "risk factors," and "prevention." Four studies were epidemiological; from these studies, the authors concluded that up to 57 % of individuals with IDD have previously experienced a fall, which caused approximately 50–62 % of recorded injuries. Risk factors for falls included older age, decreased mobility, other comorbid conditions and challenging problems. However, no intervention studies teaching preventative skills were identified in this review. The authors suggested that a multidisciplinary approach, addressing environmental hazards, and exercise interventions are needed, and more research is warranted to develop effective strategies for fall prevention.

Carmeli, Merrick, and Berner (2004) conducted an exercise intervention that examined the balance capability in 27 adults with mild IDD, age 55–77 years, living in a foster home. The participants were divided into two groups. One group received balance exercise training, and the other received muscle strength training. The balance training program included warming-up movements, large body movements in sitting and standing positions (i.e., toe-to-heel walk on straight and rounded lines, side walking), dancing, rolling a ball, pushing, pulling, lifting, catching, and throwing. Balls, balloons, bands, sticks, and scarves were used in the program. The muscle strength program consisted of warming-up movements, weight lifting, and repetitive exercises that focused on extension and flexion movements of different body parts. Both programs lasted for 6 months. The results showed that the participants who underwent the balance exercise program had significantly more improvement in balance, social function, and quality of life. Therefore, the authors concluded that balancing, which is a key aspect of gait, may help to reduce falls in people with IDD.

Despite the fact that there is a high incidence of falling accidents in individuals with IDD, no research was conducted in teaching fall-prevention strategies in the IDD population. One study (i.e., Carmeli et al., 2004) focused on improving balance in individuals with IDD to reduce injuries by strengthening their physical health. In addition to exercise interventions, studies teaching skills to identify and address environmental hazards that may cause falls should be conducted. Given that other behavioral strategies were effective in teaching other safety skills in this population, future studies should incorporate such strategies in teaching fall-prevention skills.

Pedestrian Skills

Previous literature for teaching pedestrian skills to individuals with IDD is well established. Pedestrian skills include identifying traffic signals and signs, using sidewalks, and safely responding to traffic-related signs. The following studies used task analysis, most-to-least prompting, and progressive time delay procedures in simulated and in vivo settings. Some studies used simulated instruction to teach pedestrian skills.

One of the earliest study teaching pedestrian skills to individuals with IDD was conducted by Page, Iwata, and Neef (1976). They taught pedestrian skills to five individuals with IDD, ages 16–25 years, using the classroom model. The authors reported that the classroom intervention provided fewer environmental problems than training at community streets. The environmental factors included inclement weather conditions, additional time and staff, inherent dangers of the community streets. A simulated model using the poster board was constructed, and street, houses, cars, trees, and people were drawn or glued to the board. Target skills included recognizing intersection and pedestrian lights and properly crossing the street with pedestrian signals, tricolored traffic signals, stop signs, and no signals. One-on-one training was conducted in a classroom. First, the trainer gave instructions and the participants performed the target skills using a model city and a figure. The participants explained their behaviors as they performed them. Praise, feedback, modeling were provided as necessary. The training was evaluated using a multiple baseline design across participants and behaviors. All participants learned the pedestrian skills, and the skills generalized to the actual street. The acquired skills were maintained at 2–6 week follow-up.

Matson (1980a) also taught pedestrian skills to 30 adults with moderate to severe IDD, ages 21–55 years, using the classroom training. He compared the effectiveness of classroom training versus independence training. Target behaviors included proper sidewalk behavior, recognition of an intersection, and crossing the street. Task analyses steps for each target were developed. The participants were divided into three groups: classroom training, independence training, and control group. The classroom training used a model intersection and figurine. Shaping, social reinforcement, instructions, and various prompts were used in the training. The independence training included an additional training component that emphasized self-evaluation of performance, provided more information, and encouraged more involvement. In addition to using the model intersection and figurine that were used in the classroom training, cardboard traffic signs, feedback and evaluations were provided at the end of each training session for the independence training. While both classroom and independence training were effective in teaching pedestrian skills, the independence training was significantly more effective than the classroom training.

Following the early studies, Horner, Jones, and Williams (1985) taught pedestrian skills to three individuals with moderate to severe IDD, ages 12–53 years, using community streets. One-to-one training was conducted using multiple community cross streets including one-way, two-way streets with traffic signals, stop signs, and no traffic signals. The trainer instructed the participants to cross the street and stood behind the participant and provided verbal and physical prompts when necessary. Social praises were given upon correct crosses. The trainer slowly faded prompting, reinforcement, and feedback. The training was evaluated using a multiple baseline design across participants. Two participants showed significant improvement in their street crossing skills and generalized their skills to novel streets.

Some studies used both classroom simulation and community-based interventions to teach pedestrian skills. For example, Marchetti, McCartney, Drain, Hooper, and Dix (1983) taught pedestrian skills to 18 adults with IDD, ages 19–59 years. The authors compared the training administered in classroom or community. Target skills included crossing at an intersection with no signs or traffic lights, crossing with a stop sign with cars moving in the same direction as the pedestrian, crossing with a stop sign with cars crossing the path of the pedestrian, crossing with a pedestrian lights, and crossing with a single and multiple traffic lights. The participants were placed in either the classroom group or the community group. The classroom training used a model city and doll, and the participants rehearsed the target skills. The participants in the community training performed the skills in natural settings. Both training techniques were conducted in groups. Prompting and social reinforcement were implemented and were gradually faded. The results of the study favored the community training, demonstrating that participants in the community training showed significant improvement in pedestrian skills while no significant changes were noted in the participants who received the classroom training.

In a further evaluation of the effectiveness of in vivo instruction, Collins, Stinson, and Land (1993) compared teaching with and without a preliminary simulation component in teaching eight students with moderate IDD, ages 15–19 years, to cross streets. The in vivo training was conducted in natural settings. The task analyses for street crossing were developed, and the participants practiced the target skills with a delayed prompting procedure. The simulation training session was conducted in the participants' classroom; the teacher simulated a street using two parallel strips. A multiple probe design across participants was used to evaluate the training methods. The results showed that both training procedures were found to be effective in teaching street crossing skills, and the authors also found that teaching first in simulation did not have an effect on instructions within the community.

Branham, Collins, Schuster, and Kleinert (1999) taught three secondary students with moderate IDD, ages 14–20 years, community skills including safe street skills. The classroom simulation was conducted using a masking tape to simulate the edge of the streets, and peers served as approaching cars. Videotaping modeling instruction consisted of a videotape of a peer crossing a street. A constant time-delay procedure was used with three instructional formats: videotape modeling plus community-based intervention, classroom simulation plus community-based intervention, and videotape modeling plus classroom simulation plus community-based intervention. The results showed that all instructional formats were effective in teaching target skills and demonstrated generalization to novel settings. Efficiency data showed that classroom simulation plus community-based instruction was the most efficient format.

In a recent study, Kelley, Test, and Cooke (2013) extended upon previous studies by teaching the participants to navigate back to starting locations with a focus on independent travel. The authors investigated the effects of using picture prompts displayed through a video iPod on pedestrian navigation with four young adults with IDD, ages 19–26 years. Correct and independent travel of a route to and from specified locations and the percentage of correct pictured landmarks reached for each route were measured. A multiple probe design across participants and behaviors was used to evaluate the treatment. The participants were given a video iPod with pictured landmarks and were instructed to use the pictures to guide them to get to a location and back to the starting place. Prompts were provided upon requests or if they navigated off the route for more than 30 s. Results of the study indicated a functional relation between the picture prompts displayed on the video iPod and pedestrian navigation skills for all four participants. All four participants became confident and did not rely on the video iPod much, by the second or third walk with each route. The iPod then started to serve as a backup if they forgot a turn or one of the featured landmarks. This indicated the iPod was used as a prompting device.

In summary, early pedestrian studies used classroom training with simulated environment (Matson, 1980a; Page et al., 1976). More studies in the 1980s and 1990s incorporated more naturalized settings to teach safe, street crossing skills to individuals with IDD (Branham et al., 1999; Collins et al., 1993; Horner et al., 1985; Marchetti et al., 1983). Some studies showed mixed results in comparing the classroom and community training (Branham et al., 1999; Marchetti et al., 1983). Overall, existing research demonstrated that individuals with IDD effectively learned basic pedestrian skills using behavior techniques including reinforcement, modeling, prompting, and feedback.

Self-Protective Skills

Sexual Abuse Prevention

Individuals with IDD are more vulnerable to exploitation due to their disabilities, lack of social skills, and poor judgment skills (Chamberlain, Rauh, Passer, McGrath, & Burket, 1984; McCabe, Cummins, & Reid; 1994; Sobsey, 1994). Chamberlain et al. (1984) revealed that among 87 female patients with IDD who attended an adolescent health clinic, 25 % had a known history of sexual assault. Hard (1986) also found that among their 95 adult participants with IDD, 83 % of women and 32 % of men reported being victims of sexual abuse. The incidence of sexual exploitation among individuals with IDD is higher than those without disabilities (Horner-Johnson & Drum, 2006; McCabe & Cummins, 1996; Sobsey & Mansell, 1994). According to one study, women with IDD have twice the risk of sexual abuse than women without disabilities (Sobsey & Mansell, 1994). Children with disabilities are 3.4 times more likely to experience maltreatment (including sexual abuse) than those without disabilities (Sullivan & Knutson, 2000). Therefore, it is crucial to teach those with intellectual disabilities skills to help protect themselves from these predators.

Over the past 30 years, only a few researchers have evaluated methods to teach self-protective skills to individuals with IDD. In 1984, Foxx and his colleagues used a training program to teach social/sexual behaviors to six female residents with mild and moderate IDD (Foxx, McMorrow, Storey, & Rogers, 1984). The target behaviors involved verbal action or reaction to sexually related situations, and the participants were taught using a card game called '*Sorry*.' The program trained the participants to differentiate between public and private sexual behavior and to safely and appropriately respond to boyfriends, acquaintances, or strangers. Positive and negative feedback, self-monitoring, reinforcements, and individualized performance criterion levels were used. The results showed that the participants' appropriate social responses to the social/sexual skills program improved and generalized to untrained situations.

Later, Haseltine and Miltenberger (1990) taught self-protection skills to eight adults with mild IDD. The training curriculum covered topics such as the concepts of private body parts, good and bad touch, and safety skills (i.e., say no, get away, and tell). Instructions, modeling, rehearsal, feedback, and praise were used to teach skills to safely respond to potential abduction and sexual abuse situations across nine 25–30 min sessions. Most participants successfully learned self-protection skills and maintained them at a 6-month follow-up.

Most recently, Egemo-Helm et al. (2007) evaluated the effectiveness of a combined program to teach sexual abuse prevention skills to women with IDD. The researchers combined behavior skills training (BST) and in situ training to improve upon generalization to real-life situations. The participants in the study were seven women with mild to moderate IDD, ages 26–47 years. The training and assessment sessions were conducted in either the group home or the apartment where each women lived, respectively. The target behavior was the reaction exhibited by the participant when a research confederate posing as a staff member initiated a lure for sexual abuse. A scoring system was put in place and one point was given for each of the following reactions: (a) did not comply/engage in the behavior requested; (b) verbally refused; (c) left the situation or asked the staff member to leave; and (d) reported the incident to a safe staff member. The participants received a maximum score of 4 points if they exhibited all the behaviors listed above, and they received a score of 0 if they complied with the request of the staff member. The participants were taught sexual abuse prevention skills using self-report (i.e., participants were asked how they would respond to a particular scenario) and role-play (i.e., where the trainer acted as the abuser and the participant asked to react). The other strategy used was in situ training using a research assistant unknown to the participant. In this scenario, the participant was not told in advance that they were being assessed. A mastery criterion for the in situ training was a score of 4 for three consecutive in situ assessments. Two of the seven participants terminated their participation during baseline and early training. For the remaining five participants, three required between 1 and 2 in situ training sessions; one of them required 12 in situ training sessions and an additional three booster sessions; one of them quit the study after 2 in situ sessions. The results indicated that the safety skills were generalized to the natural environment. At the 1-month follow-up, three of the four participants performed at criterion and at 3 months, two of the participants performed at criterion. While these results are promising, the number of early withdrawals from the study is concerning and may indicate that the training method is not appropriate for all individuals with IDD.

Lures of Strangers

In addition to sexual exploitation, abduction is another problem that may result in serious consequences. Early research demonstrated that typically developing children were able to learn skills to avoid abduction (Miltenberger & Thiesse-Duffy, 1988; Poche, Yoder, & Miltenberger, 1988). Given that individuals with IDD are at higher risk of being victims of such abuse, it is imperative to teach similar skills to children with IDD. Watson, Bain, and Houghton (1992) taught self-protective skills to seven children with moderate and severe IDD, ages 6–8. Three target behaviors included to firmly say/sign/gesture 'no' toward the stranger who made an inappropriate request, to 'go' by leaving the stranger and the scene within 15 s of the interaction, and to 'tell' by reporting the interaction to a known, safe adult. The participants were taught across 15 sessions to describe and identify a stranger using questions, guided discussion, pictures of known/unknown people, and role-playing. Six participants showed improvement in self-protective skills against the strangers, and a 14-day follow-up showed maintenance of the taught skills.

Peer Pressure

Collins, Hall, Rankin, and Branson (1999) described a program, called "Just say 'no' and walk away," that taught students with IDD to resist peer pressure (i.e., behaviors or persons that are harmful to one's health and achievement). The instructor defined inappropriate behaviors and discussed consequences of these behaviors. Then the correct responses to these inappropriate behaviors were modeled and role-playing was implemented to practice the correct responses. Daily probe sessions using a confederate were conducted, and instructional sessions were provided following incorrect responses. The results showed that teaching peer pressure resistance to individuals with IDD was effective.

As previously discussed, individuals with IDD are more prone to be victims of abuse; therefore, it is critical to teach self-protective skills to prevent sexual abuse and resist lures of strangers and peer pressure to individuals with IDD. Available research showed that such protective skills can be taught to individuals with IDD using feedback, self-monitoring, reinforcements, and role-play. In situ training and assessment should be used while evaluating the self-protective skills to promote generalization; however, in situ assessments should be used with caution because it may cause distress and/or trauma for the participants.

Emergency Telephone Skills

Making emergency telephone calls is an important safety skill to obtain assistance in case of an emergency. The following studies taught children, adolescents, and adults with ID of varying levels to make emergency telephone calls in various scenarios. Smith and Meyers (1979) taught 60 adults with moderate to profound IDD telephone skills. The participants were placed in one of six experimental groups: (1) individual modeling and verbal instruction; (2) group modeling and verbal instruction; (3) individual modeling only; (4) group modeling only; (5) Individual control group and (6) group control groups. All participants improved on the telephone skills; they learned to pick up the telephone, dial, accurately report the fire and relevant information, and correctly request to see the doctor.

Extending from previous research that taught skills such as dialing the correct number and making emergency calls, Risley and Cuvo (1980) focused on more advanced telephone skills such as deciding whom to call (i.e., fire, police, doctor). The authors trained three adults, ages 26–52 years, with IDD to make emergency phone calls. The participants were taught to decide whom to call, locate the telephone number in the directory, dial the number, and answer questions by the operator. Successive levels of prompting (e.g., verbal, modeling, physical) were implemented during the training. Praise was provided after a correct response with and without prompts, and the feedback was given after each training trial. All three participants acquired the skills, and the target skills were generalized across different people and settings and maintained at 1 and 2 weeks follow-up.

Spooner et al. (1989) taught three adolescents with IDD, ages 16–17 years, to use home telephones to call 911 and explain different types of emergency situations (e.g., fire, poison, falls, shock). The training procedure included modeling, rehearsal, prompting, and reinforcement. All participants learned to communicate an emergency rapidly, and the skills were maintained at 6 and 12 weeks follow-up.

Collins et al. (1993) compared the effectiveness of in vivo instruction with and without a preliminary simulation component in teaching eight students with moderate IDD, ages 15–19 years, to operate a payphone. The in vivo training was conducted in natural settings (e.g., entry street to the high school, public pay telephones). The task analyses for telephone use were developed, and the participants practiced the target skills with a delayed prompting procedure. The simulation training session was conducted in the participants' classroom; the teacher simulated a street using two parallel strips and placed a disconnected telephone and an empty cardboard box. A multiple probe design across participants was used to evaluate the training methods. The results showed that both training procedures were found to be effective in teaching telephone skills.

Taras, Matson, and Felps (1993) taught three children with visual impairments (two of whom had borderline to mild IDD) to make an emergency telephone call. Group training was conducted; remaining participants listened while the selected participant performed the task. Verbal instructions and physical prompting were used using the least to most intrusive prompting. Once the participants completed the steps, they were asked to self-evaluate their performance and provide explanation. Then, feedback and positive reinforcement were provided by the trainer, and their peers who listened to their peer perform the task. Furthermore, all participants received edibles for attending the session regardless of their performance in order to maintain motivation. Different emergency situations, reporting addresses, and types of telephone were incorporated to increase generalization. All children successfully completed the task analysis of calling 911, and their skills were maintained at 10-months post-treatment.

Recently, Ozkan, Oncul, and Kaya (2013) conducted a study to evaluate the effectiveness of computer-based instruction (CBI) to teach emergency telephone skills to students with IDD. This study focused on teaching children which emergency service to call in a specific situation. Five students, ages 8–13 years, were taught to identify the correct emergency service to call in a specific situation and the number to call. The CBI consisted of audiovisual presentation of animated scenarios along with verbal instructions on a computer screen. Each scenario was linked to a different service and the corresponding number to call for that specific service. Clapping animation and verbal praise were provided at the end of the program. The results of the study proved CBIs to be an effective technique. However, different numbers of sessions were needed by different participants in order to reach criteria. The number of sessions required in order for the participants to know which emergency service to call after seeing a scenario, ranged from 14 sessions to 29 sessions. The number of sessions required for associating the correct number with the right service ranged from 21 to 46. The target skills were maintained at 4, 8 and 12 weeks after training and were generalized to different responses.

Existing research indicates individuals with IDD were able to learn to dial emergency telephone numbers, give relevant information, and identify which emergency services to call (Collins et al., 1993; Ozkan et al., 2013; Risley & Cuvo, 1980; Smith & Meyers, 1979; Spooner et al., 1989; Taras et al., 1993). Most commonly used behavior techniques include instruction, reinforcement, modeling, and prompting. While the skills were maintained after the training, it is not yet known if the skills would be generalized in real emergency situations. Future studies need to incorporate in situ training without informing the participants that they are being assessed. Moreover, most telephone skills research was conducted several decades ago. Since then, telephone has evolved immensely; pay phones are difficult to find and traditional landline telephone usage has decreased as the use of cell phone is continuously increasing. This change may affect the older population who may not be familiarized with newer cellphones (i.e., different designs, smaller sizes, touch screen). More studies are warranted to accommodate to this change.

Translation of Research to Practice

Teaching safety skills to individuals with IDD has been extensively investigated over the last 30 years; previous studies examined a variety of methods to teach safety skills to individuals with IDD of different age groups and different levels of functioning. Results of the reviewed studies in the current chapter showed that individuals with IDD were successful at identifying harmful situations and implementing safety skills to prevent potential emergencies.

Research showed that education-based training is effective for teaching the individual to verbalize the skills; individuals with or without IDD were successful at exhibiting knowledge of safety skills after receiving education-based training (Feldman & Case, 1999; Gatheridge et al., 2004; Llewellyn et al., 2003; Matson, 1980b). However, this does not necessarily mean that they can successfully execute the skills in actual dangerous situations. In fact, many studies showed that those who received instructional procedures only were not able to demonstrate the safety skills very well (Gatheridge et al., 2004; Himle & Miltenberger, 2004). Researchers found behavioral skills trainings that incorporated behavioral approaches such as modeling, prompting, role-playing, and feedback to be more effective for teaching the desired safety skills. Typically developing children successfully demonstrated safety skills upon completion of behavioral skills trainings (Bevill & Gast, 1998; Gatheridge et al., 2004; Himle & Miltenberger, 2004). Furthermore, individuals with IDD who received behavioral skills training were also able to perform safety skills including teaching fire safety skills (e.g., Bannerman et al., 1991; Cohen, 1984; Haney & Jones, 1982; Jones & Thornton, 1987; Katz & Singh, 1986; Luiselli, 1984; Rowe & Kedesdy, 1988), first aid skills (e.g., Gast & Winterling, 1992; Marchand-Martella et al., 1992; Marchand-Martella & Martella, 1990; Spooner et al., 1989), accident prevention skills (e.g., Collins et al., 1996; O'Reilly et al., 1990; Tymchuck et al., 1990; Winterling et al., 1992), pedestrian skills (e.g., Branham et al., 1999; Collins et al., 1993; Horner et al., 1985; Kelley et al., 2013; Marchetti et al., 1983; Page et al., 1976), self-protective skills against crime (e.g., Collins et al., 1999; Egemo-Helm et al., 2007; Foxx et al., 1984; Haseltine & Miltenberger, 1990) and emergency telephone skills (e.g., Risley & Cuvo, 1980; Taras et al., 1993).

One common limitation of many of these studies is a lack of generalization; skills that were taught through behavioral training may not always generalize to the natural environments. It is important to incorporate stimuli that are common in the natural environments. More specifically, in response to fire safety skills, future studies should consider using more generalized stimuli such as real, contained fires, smoke, and heat to better simulate a real fire emergency situation. Additionally, training during nighttime (Knudson et al., 2009) and learning to use a fire extinguisher (Mechling, 2008) should also be considered. Prevention skills such as abduction prevention skills, pedestrian skills, and fall prevention skills should be conducted in the generalized setting (e.g., school, outside, road, playground).

During in situ training, a simulated safety threat is presented in natural environments without informing the individual to determine if the individual will perform the safety skills without being prompted or cued. Previous studies showed that although behavioral skills training was effective in acquiring the skills, the behavioral training itself was not sufficient to produce consistent safety responses as children often failed to demonstrate safety skills during an in situ assessment. The use of in situ training significantly enhanced generalization of safety skills (Gatheridge et al., 2004; Himle & Miltenberger, 2004). Therefore, in situ assessments should be conducted following behavioral training to ensure that the skills can be generalized to more naturalistic conditions (Miltenberger, 2008).

Moreover, maintaining safety skills over an extended period of time is as important as acquiring the skills. Unfortunately, results of the reviewed studies yielded mixed reports of maintenance of the skills. Therefore, conducting in situ assessments at periodic intervals is recommended (Miltenberger, 2008). If the individual fails to demonstrate safety skills at periodic intervals, follow-up training is warranted.

The current chapter's literature review shows that research on teaching skills to individuals with IDD is well established; however, it is interesting to note that most research in this area was conducted in the 1980s and 1990s. Only a few studies have been conducted in the early 2000s (Carmeli et al., 2004; Egemo-Helm et al., 2007; Llewellyn et al., 2003). Over the last 30 years, technology has been rapidly changing and advancing. With this advancement, the use of assistive technology devices has increased as well. Mechling (2008) suggests that with such advancements, safety skills research should be revisited as it closely relates to innovative technologies. Interestingly, the most recent studies on safety skills have all used devices such as speech-generating device, an IPod, videos, and a computer to teach safety skills (Davis et al., 2013; Kelley et al., 2013; Ozkan, 2013; Ozkan et al., 2013), and results of these studies that incorporated technology into their training are promising. Technological innovations may expand training opportunities, especially in dangerous and unethical situations that are difficult to present the actual safety threat (Dixon, Bergstrom, Smith, & Tarbox, 2010). For example, being able to track and locate persons and their locations using wireless communication and alert devices (Mechling, 2008) may expand procedural options. Virtual environments that closely mimic the natural environment may also tremendously help to expand generalization of safety skills.

In summary, existing research in safety skills showed promising results in teaching appropriate safety skills to individuals with IDD. Future researchers should focus on generalizing and maintaining safety skills, as they remain main issues in teaching safety skills in individuals with IDD. Combination of behavioral techniques and technology may provide more realistic and creative training in teaching safety skills. Therefore, future researchers are recommended to use behavioral techniques that are already proven to be effective and incorporate new technology and innovations.

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Toilet Training

37

James S. Smith and Brandy Chaneb

Introduction

Learning to achieve bladder and bowel continence is a practice, which traverses time and culture. Civilizations around the world, prior to development of the scientific method, have employed a variety of strategies aimed at teaching appropriate time and place for elimination. These strategies have been passed down, each generation adding to the next, as caregivers grapple with this difficult task. Indeed, toilet training is a significant developmental milestone as it provides an individual with more independence and social inclusion. For individuals with intellectual and developmental disabilities (IDD), the prospect of toileting training may be especially challenging (Fleisher, 2004).

It has long been recognized that toileting difficulties may result in numerous issues, including urinary tract infections, constipation, hygiene problems, decreased independence, and social stigma (Burgio & Burgio, 1989). Although there is a paucity of published literature related to prevalence rates, some studies have suggested rates of incontinence among children with intellectual and developmental disabilities to range between 23 and 86 % (Van Laecke, Raes, Vande Walle, & Hoebeke, 2009). While not exclusive to this population, toilet training may often be complicated by differences in learning and co-occurring physical conditions (Lancioni, 1980).

Despite recognition of challenges associated with toilet training, published scientific literature did not begin to emerge until the early twentieth century. The earliest studies, mainly in Europe, focused primarily on the treatment of enuresis utilizing conditioned-response techniques (Genouville, 1908; Pfaundler, 1904). A variety of mechanical devices that would alert the person with an alarm in response to wetness were used for this purpose. They theorized that if a stimulus occurred close enough to the time of bladder tension, an individual would subsequently learn to recognize bladder tension and eliminate in a toilet (Mowrer & Mowrer, 1938; Morgan & Witmer, 1939).

Mowrer and Mowrer (1938) published one of the earliest systematic studies employing the conditioned-response technique. They posited that bladder distention could become a conditioned stimulus resulting in waking before it became an unconditioned stimulus resulting in urination at an inappropriate place or time. By using a pad and bell device, elimination of enuresis was reported in all cases within 2 months. Subsequent conditioned response studies reported significant immediate outcomes (Baller & Schalock, 1956). Although good outcomes were reported, use of these devices diminished

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over the following decade due to cumbersome designs, cleaning and powering requirements, as well as fear of electrical shock (Mowrer, 1980).

It was not until the early 1960s that empirical studies examining toilet training in people with intellectual and developmental disabilities began to emerge. These studies utilized the operant designs (Ellis, 1963). These techniques aimed to shape toileting behavior through the application or removal of reinforcement (Baumeister & Klosowski, 1965; Dayan, 1964; Ellis, 1963; Giles & Wolf, 1966; Hundziak, Maurer, & Watson, 1965; Pumroy & Pumroy, 1965). In the most widely cited toilet training model of this era, Ellis (1963) introduced a stimulus-response (S-R) paradigm. Ellis (1963) theorized that providing reinforcement, positive or negative, at various points along the S-R chain would shape and solidify the desired behavior (e.g., appropriate toileting). Subsequent studies employing methods outlined by Ellis (1963) reported significant improvement in bowel and bladder control of subjects; however, long-term gains could not be demonstrated (Rentfrow & Rentfrow, 1969). In addition, aversive conditions used in some studies of this time, including tethering ropes, restraint jackets, blindfolds, tying individuals to a toilet or leaving individuals in soiled clothing for prolonged periods of time created significant ethical concerns regarding their continued use.

Empirical studies utilizing more efficiently designed mechanical devices (e.g., bed and pants alarms) coupled with behavior modification techniques began to be published in the late 1960s and early 1970s. In the early 1970s, Azrin and Foxx (1971) and Foxx and Azrin (1973b) presented their rapid toileting training program. From 1971 to present, most of the published literature on toilet training in individuals with intellectual and developmental disabilities has involved the Azrin and Foxx technique or variants thereof.

The aim of this chapter is to provide clinicians with an overview of empirically validated toilet training methods and examine the relative effectiveness of these methods. In general, we reviewed studies if they were completed within the last 20 years. We included studies older than 20 years if they were repeatedly cited in studies within the last 20 years—suggesting relevance to current practice—but we did not review any studies that were published before Azrin and Foxx (1971). Our primary focus is on bladder elimination as opposed to bowel elimination due to the relatively small number of studies focusing on bowel elimination ($N = 11$). Those that did focus on bowel elimination, in part or in whole, utilized similar methodology to those focusing on bladder elimination (Boles, Roberts, & Vernberg, 2008; Cox, Morris, Borowitz, & Sutphen, 2002; Dalrymple & Angrist, 1988; Joinson et al., 2007; Ozturk et al., 2006; Richmond, 1983; Smith, 1994, 1996; Smith, Smith, Lee, & Kwok, 2000; Taubman, 1999; Wendt, Similia, Niskanen, & Jarvelin, 1990).

We reviewed the studies using the What Works Clearinghouse (WWC) standards (What Works Clearinghouse (Institute of Education Sciences), Institute of Education Sciences (US), & National Center for Education Evaluation and Regional Assistance (US), 2014) using the protocols for either single-subject or multiple-subject design, as appropriate. The WWC protocols require exacting standards for ratings for “Moderate” or “Strong” evidence. The process involves an initial screening for eligibility. Studies eligible for review with a WWC protocol include those that are primary studies of a particular intervention (i.e., literature reviews and meta-analyses are ineligible), have an eligible design with random assignment and a control group, use a study group appropriate to the protocol studied, report an outcome domain relevant to the protocol, and published within the previous 20 years (WWC et al., 2014; see our exception above).

Once a study was determined to be eligible for review, the study was analyzed for design integrity. This involved reviewing such factors as interrater agreement, attrition, controlling for error, determining if the statistics used were appropriate to the study design, and evaluating if there were sufficient subjects and data points in a study to generate the power needed. If a study was determined to have few, if any, design concerns, the outcome data were reviewed for strength of evidence. We decided that interrater agreement studies on less than 20 % of intervals would not be a disqualifying factor for two of the reasons stated by Cicero and Pfadt (2002, p. 326): (a) the target response is operationally defined and readily observable, and (b) multiple previous studies of toileting show very high inter-rater agreement (e.g., Averink, Melein, & Duker, 2005; Azrin & Foxx, 1971; Didden, Sikkema, Bosman, Duker, & Curfs, 2001); however, poor interrater agreement within a study was a disqualifying factor.

It is important to note that we made no attempt in this review to scrutinize the definition of toilet-trained in any of the studies. If a study reported that a trainee had achieved continence according to the definition used in that particular study, that definition was accepted in our analysis of median times to train. It should be noted that most, if not all, of the studies included in this chapter utilized similar definitions of toilet-trained.

We reviewed a total of 30 studies which indicated at least moderate evidence of a positive outcome after toilet training (Table 37.1). These studies were published between 1971 and 2014, with 23 of the 30 studies being published between 1994 and 2014. The seven studies between 1973 and 1993, which we included in our review, received extensive citation in the current literature and still provide the basis for current interventions (Azrin et al., 1973, 1974, 1979; Azrin & Foxx, 1971; Azrin & Thienes, 1978; Barman et al., 1981; Foxx & Azrin, 1973a). Subjects included in the reviewed studies included 191 males, 77 females, and 6 for whom sex was not reported in the study. Subjects ranged from 1.5 to 62 years of age.

Characteristics of Empirically Validated Toileting Techniques

Scheduled Toileting

With the exception of five studies (Barman et al., 1981; Friman & Vollmer, 1995; Lancioni et al., 2002; Lancioni & Marcus, 1999; Tarbox et al., 2004), regular toileting schedules were utilized. Toileting intervals were most commonly scheduled for 30 min (Azrin & Foxx, 1971; Cicero & Pfadt, 2002; Didden et al., 2001; Kroeger & Sorenson, 2010; Luiselli, 1994; Post & Kirkpatrick, 2004; Rinald & Mirenda, 2012; Sells-Love et al., 2002; Taylor et al., 1994; Wilder et al., 1997) or 1 h (Azrin et al., 1973, 1974, 1979; Azrin & Thienes, 1978; Cocchiola et al., 2012; Ricciardi & Luiselli, 2003; Saloviita, 2000, 2002). Some used intervals longer than 1 h (Averink et al., 2005; Duker et al., 2001; Lee et al., 2014; Luiselli, 1997, 2007); however, a few were shorter than 30 min (Foxx & Azrin, 1973a, 1973b; LeBlanc et al., 2005).

When the median number of training days required was examined, protocols that used an interval shorter than 30 min required a median of 9.1 training days. The median number of training days required for 30-min, 60-min, and >60-min toileting intervals were 13.5, 14.0, and 21.0 days, respectively. Studies focusing on bed-wetting (Azrin et al., 1973, 1979; Azrin & Thienes, 1978; Saloviita, 2002) utilized 1 h intervals, all with strong supporting evidence, requiring a median 14 days of training. This would indicate that using a shorter interval is beneficial in shortening the training period; however, this requires allocation of dedicated resources. If resources are not available to implement toileting intervals of shorter than 30 min, the data would suggest that one could extend the toileting interval to upwards of 1 h with little impact on the total duration of training.

LeBlanc et al. (2005) provide a thorough description of a toileting schedule that was able to be implemented on an outpatient basis. In their study, the trainee started at stage 1 (defined as 10 min on the toilet and 5 min off) and progressed through stage 12 (5 min on the toilet and 4 h off). See Table 1 in their study for a detailed description of the 12 stages (p. 100). The trainee was determined to be trained once he or she was able to successfully demonstrate continence in stage 12. While the trainee was sitting on the toilet, he or she was presented with varying, individually determined preferred stimuli in order to make toileting more reinforcing. Given the large proportion of time on the toilet as opposed to off, at least in the early stages, LeBlanc et al. (2005) demonstrated the importance of providing a set, predictable toileting routine as well as maximizing the

Table 37.1 Characteristics of studies included in analysis of methods

Study	Sample size	Study sample	Age range (years)	Methods	Setting	Time of day	Study design	Average duration of training (days)	Evidence
Averink et al. (2005)	40	27 M/13 F	4–44	H, PP, R+, RR, Sc, U	Mixed (institution/home)	Day	ABCA	4	Strong
Azrin and Foxx (1971)	9	9 M/0 F	20–62	A, H, P+, R+, Rn, RR, Sc, U	Institution	Day	ABA	4	Strong
Azrin, Hontos, and Besalel-Azrin (1979)	44	29 M/15 F	3–15	H, R+, Rn, Sc, U	Institution	Night	ABA	21	Strong
Azrin, Sneed, and Foxx (1973)	12	7 M/5 F	$M = 37$	A, H, R+, Rn, Sc, U	Home	Night	ABA	14	Strong
Azrin, Sneed, and Foxx (1974)	26	19 M/7 F	$M = 8$	A, H, R+, Rn, Sc, U	Home	Night	ABA	14	Strong
Azrin and Thienes (1978)	55	41 M/14 F	3–14	H, R+, Rn, Sc, U	Home	Night	ABA	14	Strong
Barman, Katz, O'Brien, and Beauchamp (1981))	3	3 M/0 F	4–8	PP, R+, Rn	Institution	Day	ABA (concurrent multiple baseline)	24	Strong
Cicero and Pfadt (2002)	3	2 M/1 F	4–6	H, R+, Sc, U	School	Day	ABA	11	Strong
Cocchiola, Martino, Dwyer, and Demezzo (2012)	5	5 M/0 F	3–5	H, R+, Sc, U	School	Day	ABA	96	Strong
Didden et al. (2001)	6	unstated	6–19	H, PP, R+, RR, Sc	Institution	Day	ABA (non-concurrent time series)	17	Strong
Duker, Averink, and Melein (2001)	8	6 M/2 F	4–14	PP, R+, RR, Sc, U	Mixed (institution/home)	Day	ABA (non-concurrent multiple baseline)	4	Strong
Foxx and Azrin (1973a)	34	22 M/12 F	1.5–3	A, H, PP, R+, U	Home	Day	ABA	0.17	Moderate
Friman and Vollmer (1995)	1	0 M/1 F	15	A	Institution	Day	ABAB	35	Moderate
Kroeger and Sorenson (2010)	2	2 M/0 F	4–6	H, R+, Sc	Home	Day	ABA	5	Moderate
Lancioni and Marcus (1999)	1	1 M/0 F	9	A, U	School	Day	ABAB	27	Moderate
Lancioni, Van Bergen, and Furniss (2002)	1	1 M/0 F	14	A, U	School	Day	ABAB	13	Moderate

LeBlanc, Carr, Crossett, Bennett, and Detweiler (2005)	3	2 M/1 F	4	A, C, H, PP, R+, Sc	School	Day	ABA (non-concurrent multiple baseline)	18	Moderate
Lee, Anderson, and Moore (2014)	1	1 M/0 F	4	R+, RR, Sc	Home	Day	ABA (changing criterion design)	25	Moderate
Luiselli (1994)	2	2 M/0 F	2	R+, Sc	Institution	Day	ABA	56	Moderate
Luiselli (1997)	1	1 M/0 F	8	RR, R+, Sc	School	Day	ABA	63	Moderate
Luiselli (2007)	1	1 M/0 F	6	R+, R-, Sc,	Institution	Day	ABCDC	21	Strong
Post and Kirkpatrick (2004)	1	1 M/0 F	3	R+, Sc	Home	Day	ABA	29	Strong
Ricciardi and Luiselli (2003)	1	1 M/0 F	11	R+, Sc, U	School	Day	ABA (withdrawal design)	62	Strong
Rinald and Mirenda (2012)	6	4 M/2 F	3–5	H, PP, R+, Sc	Home	Day	ABA (non-concurrent multiple baseline)	6	Strong
Saloviita (2000)	1	0 M/1 F	28	A, H, R+, Rn, Sc, U	Institution	Day	ABA	14	Moderate
Saloviita (2002)	2	0 M/2 F	17–20	A, H, R+, Rn, Sc, U	Institution	Night	ABA	3	Strong
Sells-Love, Rinaldi, and McLaughlin (2002)	1	0 M/1 F	19	H, R+, Rn, Sc	School	Day	ABAB	16	Strong
Tarbox, Williams, and Friman (2004)	1	1 M/0 F	29	U	Home	Day	ABABA	5	Strong
Taylor, Cipani, and Clardy (1994)	1	1 M/0 F	10	A, H, PP, R+, Rn, Sc, U	Home	Day	ABAB	4	Strong
Wilder, Higbee, Williams, and Nachtwey (1997)	1	1 M/0 F	21	A, H, R+, Sc	Institution	Day	ABAB	59	Moderate

A alarm, *H*=overhydration, *PP*=positive practice, *R*+=positive reinforcement of successful toileting, *R*−=negative reinforcement of successful toileting, *Rn*=restitution, *RR*=response restriction, *Sc*=scheduled toileting, *U*=removal of absorbent underpants probability of success and reinforcement in the early stages of toileting.

Overhydration

A common feature of empirically valid toilet-training is an overhydration protocol. At its most basic, an overhydration protocol involves encouraging an individual to drink more liquid than they would otherwise normally drink for the purpose of increasing the frequency of urination (Thompson & Hanson, 1983). This provides more frequent opportunities for training to occur, and protocols that utilized overhydration (Averink et al., 2005, Azrin et al., 1973, 1979; Azrin & Foxx, 1971; Azrin & Thienes, 1978; Cocchiola et al., 2012; Didden et al., 2001; Foxx & Azrin, 1973a; Kroeger & Sorenson, 2010; LeBlanc et al., 2005; Rinald & Mirenda, 2012; Saloviita, 2000, 2002; Sells-Love et al., 2002; Taylor et al., 1994; Wilder et al., 1997) as opposed to those that did not were able to perform training in significantly less time (median of 14 days vs. 26 days, respectively), although the interval of encouraging fluid intake varied among studies. Studies that focused on bedwetting offered fluids less frequently than those that focused on daytime wetting.

A major consideration when using overhydration is the individual's risk for electrolyte imbalance. Thompson and Hanson (1983) provided guidelines for determining the maximum amount of fluid that should be used in an overhydration protocol with the recommendation that the individual obtain medical clearance prior to the initiation of the protocol (see also Brazelton et al., 1999 for a discussion of medical issues that can affect toilet-training). Based on available research, the amount of training time needed can be significantly shortened by using an overhydration protocol, and best practice would support using the shortest duration protocol that is clinically effective. However, given the strength of research on both sides, toilet training is still a realistic goal if overhydration is medically contraindicated.

Averink et al. (2005), while exploring the effectiveness of response restriction, utilized a clearly defined overhydration protocol, following the limits defined by Thompson and Hanson (1983). In their study, Averink et al. (2005) provided fluids at the beginning of the training day, following each appropriate elimination, following each incontinent episode, and every 30 min period without fluid intake. This procedure was followed for the entire training day (in this study, 6 h). As noted by Azrin and Foxx (1971), urination, especially in adults, may occur only a few times per day; however, for rapid and effective learning to occur, multiple frequent training trials are needed. Increasing fluid intake to stimulate an urge to urinate is a relatively innocuous method (when accepted guidelines regarding fluid intake are followed) to accomplish increased training frequency.

Wetness Alarm

The use of a wetness alarm has been consistent in the literature on enuresis since the early days of empirical study (Mowrer, 1938; Mowrer & Mowrer, 1938). Mowrer and Mowrer (1938) used a 14-day training protocol in which they reported significant success, but intermittent relapse after discontinuation of the wetness alarm. The outcomes noted by Mowrer and Mowrer (1938) are consistent with results of studies performed over six decades later (Friman & Vollmer, 1995; Lancioni et al., 2002; Lancioni & Marcus, 1999). Consistent use of a wetness alarm as a component of toilet training began with Azrin and Foxx (1971) and Azrin, Bugle, and O'Brien (1971)).

In the studies we reviewed, there was a difference in median training time required between studies that utilized an alarm versus those that did not use an alarm (14 days vs. 21 days, respectively). A possible confound was noted in that some studies utilized a clear operant paradigm in combination with use of the wetness alarm, whereas others did not have clear reinforcement noted. When controlling for three different combinations (those using both the alarm and reinforcement, those with only the alarm, and those with only reinforcement), a much different picture emerges. In studies that utilized both an alarm and reinforcement for appropriate urinations (Azrin et al., 1973, 1974; Azrin & Foxx, 1971; Foxx & Azrin, 1973a; LeBlanc et al., 2005; Saloviita, 2000, 2002; Taylor et al., 1994; Wilder et al., 1997), the median time to train was 14 days. For the studies that utilized only the alarm (Friman & Vollmer, 1995; Lancioni et al., 2002; Lancioni & Marcus, 1999) or only reinforcement (Averink et al., 2005; Azrin et al., 1979; Azrin & Thienes, 1978; Barman et al., 1981; Cicero & Pfadt, 2002; Cocchiola et al., 2012; Didden et al., 2001; Kroeger & Sorenson, 2010; Lee et al., 2014; Luiselli, 1994, 1997; Post & Kirkpatrick, 2004; Ricciardi & Luiselli, 2003; Rinald & Mirenda, 2012; Sells-Love et al., 2002), the median times to train were 27 and 19.5 days, respectively.

Consideration should be given to the invasive nature of using an alarm for toilet training. A major concern is that an alarm can be uncomfortable and lead to significant noncompliance (Boelens, van den Broek, & Beishuizen, 2003). In addition, by their nature, alarms are audible to others in the vicinity unless accommodation is made for the use of a silent alarm. Although there is a social approval component to continence (Azrin & Foxx, 1971), the goal of toilet training should not be to shame the individual being trained. If achieving continence is not time critical (i.e., incontinence is not likely to give rise to medical complications within 3–4 weeks), then it may be preferable to pursue toilet training without a wetness alarm.

Despite concerns over the invasive nature of urine alarms, Lancioni et al. (2002) demonstrated that sustained improvement can be achieved with use of an alarm and reinforcement. In this study, a 14 year old male with multiple physical and developmental disabilities was placed in a brief with small alarm while at his educational day program. He was prompted to urinate in the toilet at fixed times during the day and was also taken to the toilet upon request without the alarm (A). During treatment, the urine alarm was introduced and the individual was taken to the toilet each time it was requested or if the alarm signaled (B). Reinforcement was provided both during urination in the toilet and immediately after. Utilizing an ABAB design, the individual demonstrated a reduction in significant toileting accidents to nearly zero. Self-initiated toileting was sustained over a 3 month follow up period. In addition, only small accidents (lightly wetting a disposable tissue in the brief) were noted. The researchers suggest that small accidents with completion of urination in the toilet may indicate acquired control of urine flow.

Use of Briefs

Using regular briefs has been a staple of toilet training since the early days of the empirical study of toilet training (Mowrer & Mowrer, 1938). The advantage of using a regular brief is increasing the ease of the trainee feeling accidents (Azrin & Foxx, 1971; Tarbox et al., 2004) and increasing the ease of detection by the alarm apparatus (Azrin & Foxx, 1971, Azrin et al., 1971; Mowrer, 1938; Mowrer & Mowrer, 1938; Tarbox et al., 2004). In addition, use of regular briefs allows escape from the sensation of wetness to be used as a negative reinforcer for appropriate toileting (Tarbox et al., 2004).

A review of the studies supports the use of regular briefs over a diaper. Study protocols which utilized regular briefs (Averink et al., 2005; Azrin et al., 1973, 1974, 1979; Azrin & Foxx, 1971; Azrin & Thienes, 1978; Cicero & Pfadt, 2002; Cocchiola et al., 2012; Duker et al., 2001; Foxx & Azrin, 1973a; Lancioni et al., 2002; Lancioni & Marcus, 1999; Ricciardi & Luiselli, 2003; Saloviita, 2000, 2002; Tarbox et al., 2004; Taylor et al., 1994) as opposed to using a diaper (Barman et al., 1981; Didden et al., 2001; Friman & Vollmer, 1995; Kroeger & Sorenson, 2010; LeBlanc et al., 2005; Lee et al., 2014; Luiselli, 1994, 1997, 2007; Post & Kirkpatrick, 2004; Rinald & Mirenda, 2012; Wilder et al., 1997) showed significantly shorter training periods (median of 13 days vs. 24 days, respectively). Given these results, the evidence is overwhelmingly in favor of using regular briefs as opposed to diapers (Tarbox et al., 2004).

Tarbox et al. (2004) utilized a brief to demonstrate that use of a brief in and of itself, in the absence of other specific training, can lead to a significantly fewer episodes of urinary incontinence during the day. In this study, the trainee, a 29-year-old male, was placed into a brief upon arriving at a vocational workshop (A). For the next 6 h, the individual was prompted to use the toilet every 30 min throughout the day. Once verbally prompted to the bathroom, the individual independently pulled his pants and brief down and used the restroom. During control trials (B), the individual followed the same procedure with the exception of wearing a diaper rather than a brief. This study followed and ABABAB withdrawal design. This study is of particular note because of its clear manipulation of only one aspect of the training protocol (brief vs. diaper) rather than addition and withdrawal of an entire protocol. In the brief condition vs. diaper condition, the individual exhibited significantly more episodes of urinary incontinence per day when wearing a diaper vs. a brief ($M = 1.5$ vs. $M = 0.1$) and significantly fewer successful voids in the toilet ($M = 0.5$ vs. $M = 1.8$). The researchers suggest that the diaper exerted some type of stimulus control over voiding in the toilet. Additionally, the researchers suggest that successful voiding is likely maintained through negative reinforcement in the form of avoidance of the sensation of wetness. On the whole, this study clearly demonstrates that use of a brief should be an essential component of any toileting program.

Overcorrection

Overcorrection is a behavioral consequence that is often viewed as a variation on punishment (MacKenzie-Keating & McDonald, 1990, Miltenberger & Fuqua, 1981; Murphy, 1978). Two types of overcorrection have been reported in the literature, restitution and positive practice. Restitution is the act of reversing the negative effects of a particular behavior on the environment, whereas positive practice is the exaggerated repetition of the desired behavior (Azrin & Foxx, 1971; Miltenberger & Fuqua, 1981). In this review, 13 studies utilized either restitution (Didden et al., 2001), positive practice (Averink et al., 2005; Duker et al., 2001; Foxx & Azrin, 1973a; LeBlanc et al., 2005), or both (Azrin et al., 1973, 1979; Azrin & Foxx, 1971; Azrin & Thienes, 1978; Barman et al., 1981; Saloviita, 2000, 2002; Taylor et al., 1994). When studies that used overcorrection were compared to those that did not, there was a significant decrease in the number of training days required when using an overcorrective procedure (median of 14 days vs. 28 days, respectively), lending at least pragmatic support to the use of overcorrection. The median time to train varied among the studies that utilized restitution only, positive practice only, or both, with the median training times being 14, 4, and 14 days, respectively.

Restitution is often seen as a form of positive punishment (MacKenzie-Keating & McDonald, 1990, Miltenberger & Fuqua, 1981; Murphy, 1978), which may have a deleterious effect on the performance of a desired behavior (Thompson, Iwata, Conners, & Roscoe, 1999). In addition, Thompson et al. (1999) noted that punishment is a poor teaching methodology when used in isolation, and it generally produces a stronger behavior suppression effect when paired with reinforcement for some desired behavior (such as positive practice). Given the effect noted by Thompson et al. (1999) and the median times required for training, it may be better to forego using restitution and use positive practice alone to develop the desired skill of toilet sitting. Although the use of punishment is not inherently misguided (Axelrod, 1990; Foxx, 2005; Reed & Lovett, 2008), the use of an aversive consequence should be guided by ethics, taking into consideration the laws and regulations on using punishment in a particular environment, the severity of the behavior being targeted for decrease, the availability and feasibility of less restrictive alternatives, and organismic factors (LaVigna & Donnellan, 1986).

Averink et al. (2005) described a positive practice methodology in their study of response restriction. In their training paradigm, when an incontinent episode occurred, the individual was progressively prompted (least-to-most intrusive) to go to an area within a defined radius from the toilet. At that point, the individual was instructed to engage in positive practice (i.e., walk to toilet bowl, lower pants, sit on toilet bowl for 3 s, raise pants, walk to a defined area of the bathroom, repeat four times). During positive practice, tangible reinforcement was withheld and only verbal approval was provided for appropriate urinations. The goal of positive practice is to develop familiarity with toileting through a classical conditioning paradigm where each step serves as a prompt for the next. While positive practice may be perceived as inconvenient, or even aversive, at first, the individual is acquiring a necessary skill to complete the desired task which will become reinforcing upon acquisition. That serves as the major difference, and advantage, of positive practice over restitution. With restitution, the consequence is not necessary to the acquisition of the target behavior. In fact, upon skill acquisition, restitution will be utilized only minimally, if at all, as an aversive consequence to be avoided rather than a skill set integral to the target behavior that will be reinforced (as in positive practice). Even in severe cases of incontinence requiring rapid training, it is difficult to endorse a program that utilizes restitution when available studies suggest that positive practice can be at least as effective as, if not more so than, restitution or a combination of the two procedures.

Response Restriction

Response restriction is a training methodology in which the trainer prevents the trainee from engaging in any behavior (usually escape behavior) except the target behavior (Duker et al., 2001). Response restriction has been a component of a number of studies over the previous 40 years (Duker et al., 2001; Lee et al., 2014; Luiselli, 1997). In the studies that utilized response restriction as a component of training (Averink et al., 2005; Azrin & Foxx, 1971; Didden et al., 2001; Duker et al., 2001; Lee et al., 2014; Luiselli, 1997), a shorter time to train was realized than in those studies that did not utilize response restriction (median of 10.5 days vs. 16 days, respectively). Response restriction works by preventing behaviors that are not related to the target behavior. Duker et al. (2001) noted that, in their procedure, restitution was omitted (being a punishment procedure) and replaced with response restriction with similar results, suggesting that response restriction may be a viable alternative to restitution.

Duker et al. (2001) utilized a fairly salient response restriction paradigm that involved physically preventing the individual from engaging in any other behavior except the target behavior. In this study, the trainee was positioned next to the toilet while the trainer physically prevented the trainee from sitting, falling, escaping, or otherwise engaging in any other behavior except the target behavior. The trainee received no form or reinforcement (social or otherwise) during the training procedure except following an appropriate urination.

While the response restriction paradigm utilized by Duker et al. (2001) might be more intrusive than verbal redirection and the like, the study demonstrates the importance of limiting extraneous stimuli in the training area. Not all trainees will require as extreme a response restriction paradigm. The restrictiveness of the paradigm is largely individual to the needs of the trainee (see Didden et al., 2001, for an example of a moderately less restrictive form of response restriction.

Reinforcement

Ellis (1963) and Giles and Wolf (1966) utilized operant techniques for toilet training. The results of those studies were sufficiently convincing that Azrin and Foxx (1971) specifically cited their work in developing their Rapid Toilet Training protocol. From then on, the overwhelming majority of research on toilet training (26 out of 30 studies in this review) have utilized reinforcement of appropriate toileting as a feature in subsequent studies (Azrin & Foxx, 1971; Azrin et al., 1973, 1974; Foxx & Azrin, 1973a; see also Averink et al., 2005; Azrin et al., 1979; Azrin & Thienes, 1978; Barman et al., 1981; Cicero & Pfadt, 2002; Cocchiola et al., 2012; Didden et al., 2001; Duker et al., 2001; Kroeger & Sorenson, 2010; LeBlanc et al., 2005; Lee et al., 2014; Luiselli, 1994, 1997, 2007; Post & Kirkpatrick, 2004; Ricciardi & Luiselli, 2003; Rinald & Mirenda, 2012; Saloviita, 2000, 2002; Sells-Love et al., 2002; Taylor et al., 1994; Wilder et al., 1997). Suffice it to say, it has become standard practice in toileting training to utilize reinforcement of appropriate urination. If fact, reinforcement of a desired behavior is critical if one is using a restitution component (Axelrod, 1990; Foxx, 2005).

Rinald and Mirenda (2012) demonstrated the importance of not just providing positive reinforcement for engaging in the target behavior (appropriate urination) but also of providing reinforcement for engaging in the necessary steps to complete the target behavior. In their training protocol, the trainee is provided access to a preferred activity for sitting on the toilet (regardless of urination or not), thus utilizing positive reinforcement to elicit the target behavior of sitting on the toilet. Once the trainee appropriately urinates in the toilet, the trainee is allowed off the toilet (negative reinforcement via escape), given lavish verbal praise (positive reinforcement via social interaction), and provided access to a preferred food item (positive reinforcement via access to a tangible reinforcer). Rinald and Mirenda (2012) is notable in that it the researchers avoided using aversive techniques such as restitution and positive practice to accomplish toilet training. Using only a positive reinforcement paradigm, significant strides toward urinary continence were achieved in a median of 6 days across subjects.

Conclusions

Toilet-training is one of the more essential skills to master for a person with intellectual and developmental disabilities in order to develop functional independence at home and in the community (Kroeger & Sorenson, 2010; LeBlanc et al., 2005). Some of the ways that caregivers attempt to address incontinence, such as the use of diapers, have been shown to increase incontinence (Tarbox et al., 2004). Multiple studies have demonstrated that toilet training may typically be accomplished in relatively short periods of time when following a structured protocol (Azrin & Foxx, 1971, Didden et al., 2001; Duker et al., 2001; Lancioni & Marcus, 1999). Given the benefit to ones' quality of life and independence, as well as the relatively short time commitment involved, toilet-training is a worthwhile endeavor in increasing the independence and dignity of the individual.

The most effective toilet-training programs utilized a number of similar procedures, including reinforcement, overhydration (subject to appropriate precautions), use of briefs, and schedules. A significant minority of studies also utilized an overcorrective procedure, either restitution or positive practice, or both. Given the ethical concerns regarding the use of overcorrection (MacKenzie-Keating & McDonald, 1990, Miltenberger & Fuqua, 1981; Murphy, 1978), its use should be minimal and limited to positive practice.

While this chapter reviews current and empirically validated methodologies for the toilet-training of individuals with developmental disabilities, the major changes that have occurred over the previous 40 years have been in the areas decreasing the aversive consequences associated with toileting accidents and lessening training intensity, few studies were able to be identified that utilize the vast array of technology currently available. Chang, Lee, Chou, Chen, and Chen (2011) utilized a mobile phone based wireless device as a wetness alarm to assist with toileting. Although some of the methodology of the study was not as robust as would be needed for a large-scale review, their use of technology can serve as an example of what is possible with present technology. In their study, they utilized a silent wetness alarm that was devoid of the wires present in apparatus based on Azrin et al. (1971) in such a way that many of the ethical and comfort concerns raised by Boelens et al. (2003) are addressed. The silent alarm served as a prompt only to the teacher to prompt the child to use the toilet with no loud noise alerting others to a toileting accident. Future studies should explore the possibility of using current technology to perform toileting training in more naturalistic settings.

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Substance Use Disorders

38

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Introduction

There is a growing body of research on substance use and substance use disorders among individuals with intellectual and developmental disabilities (IDD). They have been identified as a group at risk for negative consequences of substance use and abuse (McGillicuddy, 2006; Slayter, 2010a, 2010b). The abuse of substances may have a range of somatic, psychological and social adverse consequences for individuals with IDD, such as mental health problems (e.g., McCusker, Clare, Cullen, & Reep, 1993), problems related to health (e.g., Gale, Naqvi, & Russ, 2009), daily activities and relationships (e.g., To, Neirynck, Vanderplasschen, Vanheule, & Vandevelde, 2014), and offending (e.g., Lindsay et al., 2013; McGillivray & Moore, 2001).

According to the American Psychiatric Association (2013), substance use disorders (SUD) encompass a wide range of disorders from a mild to severe state of chronicity, relapsing and compulsive substance use. In SUD, substances are used in larger amounts or over a longer period of time than was intended (DSM-5, criteria 1–4), despite social impairment due to substance use (DSM-5, criteria 5–7), risks associated with substance use (DSM-5, criteria 8 and 9) or the development of tolerance and withdrawal (DSM-5, criteria 10 and 11) (APA, 2013). It should be noted that not all substance use leads to these adverse consequences. Substance use, especially the use of alcohol and tobacco, is widespread in society, and is related to social conventions both for individuals with IDD and those without IDD (Simpson, 2012; Van Duijvenbode et al., 2015). In this chapter, however, we focus on problematic substance use or substance use disorders. We use the terms "substance use disorder" and "substance abuse" interchangeably.

Aim of the present chapter is to provide a concise and selective review of studies on prevalence and risk factors, and treatment for substance (ab)use in individuals with IDD. Conclusions are drawn about the current evidence-base and suggestions are provided for improving policy and practice (i.e., case identification, cross-system collaboration) as well for future research.

Prevalence and Associated Factors

Even though individuals with IDD, and especially those with mild to borderline IDD (IQ range 50–85), are increasingly recognized as a group at risk for substance use disorders, little is known about its prevalence and associated (risk)

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factors. In this section, studies are summarized on the prevalence and associated (risk) factors of (ab)use of tobacco, alcohol and/or illicit drugs in individuals with IDD. Also, methodological shortcomings of studies on establishing prevalence rates are discussed.

Tobacco

The prevalence of tobacco use in individuals with IDD varies between 7 and 36 % across studies (see Singh et al., 2011), depending on the sample size, living arrangements, age, gender, level of ID, and comorbid psychiatric disorder. In their review of tobacco use in individuals with IDD, Steinberg, Heimlich, and Williams (2009) concluded that prevalence rates of smoking are based on small-scale surveys including heterogeneous samples of individuals with differing patterns of tobacco use. Smoking rates are reported to be higher in individuals with mild IDD than in individuals from the general population; higher in males with IDD than in females; and higher in individuals living independently or in a group home than in those living in a family or residential facility. The highest percentages of smoking (up to 83 %, Westermeyer, Kemp, & Nugent, 1996), however, were found among those who also used other substances such as alcohol and illicit drugs.

Alcohol and/or Illicit Drugs

Chapman and Wu (2012) conducted a review on 37 studies across different disciplines and concluded that while the overall prevalence of alcohol and illicit drug use in IDD is low, the risk of having substance-related problems among IDD substance users is comparatively high. A small number of studies on the prevalence and patterns of substance (ab)use show that alcohol is the most commonly used and abused substance in individuals with IDD. For example, based on 67 cases of substance use in individuals with IDD identified by community IDD teams and addiction teams in Northern Ireland, Taggart, McLaughlin, Quinn, and Milligan (2006) found that alcohol was the main substance to be abused, with one-fifth of the substance users also using a combination of illicit drugs and/or prescribed medication. Nearly three-quarters of the sample were found to be hazardously using alcohol for more than 5 years. Being male and young, having a mild to borderline IDD, living independently and having a mental health problem appeared to be risk factors for substance abuse. VanDerNagel, Kiewik, Buitelaar, and De Jong (2011) asked staff members of 39 IDD service providers to comment on lifetime, current, and problematic substance use among their clients. Alcohol was used most often, but at lower rates than reported in the general population. Cannabis and other drugs, on the other hand, were used relatively often when compared with rates in the general population. However, reported rates of substance use diverged to such an extent that establishing reliable prevalence rates from these data was not possible.

The prevalence of substance abuse may be especially high in specialist (forensic) services. For example, Didden, Embregts, Van der Toorn, and Laarhoven (2009) investigated substance abuse in 30 clients with mild to borderline IDD admitted to a treatment facility in the Netherlands between 1995 and 2005. Upon admission, 18 clients (46 %) showed substance abuse of whom four clients abused alcohol, seven showed abuse of illicit drugs (e.g., cannabis) and seven clients abused alcohol and drugs. Comparative analyses showed that clients with substance abuse had a more palliative coping style, and had more emotional and behavioral problems (e.g., anxiety/depression, aggressive/rule breaking and antisocial behaviors) than those without substance abuse. Recently, McGillivray, Gaskin, Newton, and Richardson (In press) compared prisoners with and without IDD on their substance use prior to imprisonment. Results showed that substance (ab)use may be as common in prisoners with IDD as in those without IDD.

Chaplin, Gilvarry, and Tsakanikos (2011) collected data on substance use for consecutive new referrals ($N = 115$) to mental health services for adults with IDD in South-East London (UK).

In this sample, there were 25 individuals with SUD (21 %), including 15 with single SUD, and 10 with poly SUD. Alcohol was the most frequently abused substance (20 cases, 17.4 %) followed by cannabis (7 cases, 6.1 %) and cocaine (3 cases, 2.6 %). Results also revealed that SUD was about five times higher in individuals with a forensic history, and illicit drug use was about three times more likely among individuals with schizophrenia spectrum disorders.

Studies Based on Meta-Data

A relatively new approach for assessing population estimates of SUD in individuals with IDD is the use of meta-data, that is the extraction of this type of comorbidity from case registers. Slayter (2010a), for instance, found in 2.6 % of the Medicaid files of 9,484 patients with IDD a diagnostic code for SUD treatment. VanDerNagel et al. (2014) compared case registers of 88 individuals with SUD in an IDD service (4 % of this sample) with those of 114 clients with mild to borderline IDD in an addiction center (5.2 % of this sample) in the same semi-rural area in the Netherlands, and found limited overlap. They found that only 12 individuals were in both samples. Using capture–recapture calculations, it was calculated that the "hidden population" for the largest strata (males over 30 years old, $N=97$) was 215 (95 % CI 143–481), thus indicating that the original data represented less than a third of the total population of individuals with mild to borderline IDD and SUD within this stratum. This illustrates that data from single sources (i.e., IDD service and addiction center) underestimate prevalence rates and consequently underestimate treatment and service needs.

Shortcomings of Epidemiological Studies

Reliable data on the prevalence of substance (ab)use in individuals with IDD are lacking (Carroll Chapman & Wu, 2012; Van Duijvenbode et al., 2015). This is not surprising given the challenges associated with assessing such rates, including: (1) definition of IDD group (including or excluding those with borderline IDD) or subgroups (such as those with co-occurring psychiatric disorder), (2) definitions and scope (including or excluding use of tobacco and/or prescribed drugs) of substance (ab)use, (3) measurement issues (e.g., lack of valid instruments), and (4) problems associated with stigma and denial of substance related problems (by both users and their caregivers). Also, (5) prevalence rates may have increased in recent years possibly due to increased integration in the community, or alternatively due to increased awareness and attention by caregivers to such problems. Finally, it is likely that (6) differences between countries in socioeconomic factors, IDD care and addiction treatment facilities and alcohol and drugs related policies and legislation account for differences in prevalence rates among those with IDD.

Interventions

In this section, we summarize studies on treatment programs addressing the (ab)use of tobacco and/or alcohol in individuals with IDD. As far as we know, no studies have been conducted on the effectiveness of an intervention for illicit drugs in this target group.

Tobacco-Related Interventions

Several studies have been conducted aimed at reducing tobacco smoking. In three studies, the intervention consisted of a program in which participants were educated about smoking. Kelman, Lindsay, McPherson, and Mathewson (1997) investigated the effectiveness of a smoking cessation program for individuals with IDD. They implemented a health education program with five adults (range: 26–40 years) of whom two were smokers. The training package consisted of role-play, video, and quizzes, and was implemented in seven weekly group sessions that focused on adverse financial, physical and social consequences of smoking and benefits of being a nonsmoker. Results showed that knowledge levels increased in all five participants following intervention, an effect that was largely maintained at a 3-months follow-up.

Tracy and Hosken (1997) also evaluated a smoking educational course in a sample of 11 individuals (<25 years) with IDD who were all smokers. The course was an adaptation of an established generic smoking cessation program and consisted of seven weekly group sessions with discussions, videos, role-play, and board games. Overall, the knowledge scores improved and three participants stopped smoking after the intervention while another three participants reduced their smoking. Chester, Green, and Alexander (2011) reported nicotine replacement therapy, combined with health education, to be effective in cutting down smoking rates and tobacco consumption in 79 individuals with IDD residing in a forensic inpatient unit. There were seven weekly group sessions consisting of discussions, quizzes, and videos. In addition, nurses provided one-on-one health information that supported clients in the cessation of smoking. There were 48 smokers on admission and 15 were successful in their attempt to stop smoking.

In addition to programs aiming to increase tobacco-related knowledge, there are a small number of studies on intervention programs aiming primarily to cut down or stop smoking. For example, Peine, Darvish, Blakelock, Osborne, and Jenson (1998) implemented an intervention in which they used a spinning wheel (similar to the Wheel of Fortune television program) to reduce smoking by two adults with IDD who, up until the intervention, had received cigarettes for not engaging in challenging behavior (e.g., aggressive behaviors) for an hour. During intervention, absence of challenging behaviors for an hour led to the opportunity to spin the wheel that offered various choices including among others, cigarettes, coffee, diet candy, and magazines, thus replacing the “reward” of a cigarette with other options. Eventually, this led to a 50 % reduction in smoking by the end of the 3-year study.

Singh and colleagues conducted three studies in which they used mindfulness as an intervention for smoking. In their first study (Singh et al., 2011), they used this procedure with a 31-year-old man with mild IDD who had been a smoker for 17 years, smoking 12 cigarettes per day. During intervention, he was instructed to keep a daily log of his smoking, taught to verbally self-affirm his intention to quit, handle his thoughts about smoking, and to move the focus of his attention from the craving to a neutral point on his body. He was scheduled to decrease smoking by one cigarette every time he was able to maintain three consecutive days on his previous number of cigarettes. In 90 days, he stopped smoking and maintained this result at 1-year and 3-year follow-up. Singh et al. (2013) reported similar results of this mindfulness-based program in three adults with mild IDD who lived together in an apartment. Recently, Singh et al. (2014) used a mindfulness-based cessation program versus treatment as usual in a randomized controlled group design study with 51 individuals with mild IDD, smoking between 80 and 85 cigarettes per week. Results showed that the mindful-based program was more effective than treatment as usual in reducing the number of cigarettes smoked per individual. Also, individuals who received the mindful-based intervention were more successful at abstaining from smoking cigarettes at a 1-year follow-up.

Alcohol-Related Interventions

Education programs have also been used in treatment programs for alcohol (ab)use. McCusker et al. (1993) evaluated the effectiveness of an alcohol education intervention for five individuals with mild IDD (IQ 60–69) during six 1–2 h sessions one/twice a week over a period of 4 weeks. Group sessions involved the use of video clips from television programs about alcohol, role-plays (e.g., refusing drinks), discussions and trips to a public bar where basic pub skills (e.g., drinking slowly) were practiced. Results showed that the intervention resulted in increased knowledge about alcohol and a change in attitude towards alcohol (e.g., positive attributions decreased). Mendel and Hipkins (2002) used motivational interviewing techniques with seven males (18–54 years old) with a learning disability who had a history of alcohol abuse from a medium secure forensic unit. Group intervention consisted of three 1-h sessions over a 2-week period and was delivered by four therapists. Data were collected in a pre–post test design (no controls). Findings indicated that there had been a cognitive shift in that six individuals recognized more negative than positive consequences of their behavior than prior to their participation in the group. Also, four participants reported increased confidence in their ability to change their level of alcohol consumption once discharged back to the community. Finally, Steel and Ritchie (2004) used an educational approach to increase knowledge and motivation to change the harmful drinking behavior of a 23-year-old male with mild IDD. The intervention consisted of 12 weekly 40-min sessions that resulted in an increase in the participant's alcohol-related knowledge.

Tobacco and Alcohol-Related Interventions

Lindsay, McPherson, Kelman, and Mathewson (1998) evaluated an education program for smoking cigarettes and drinking alcohol in a large sample of individuals with IDD. Both alcohol (2×23 participants) and smoking (3×16 participants) groups were compared to age and gender-matched control groups, and data on knowledge about smoking and drinking were collected in a randomized controlled group design. The training consisted of eight sessions given by one trainer to groups containing five to six participants and included group discussions, role-play, quizzes, fact sheets and team games. The intervention resulted in a significant increase in knowledge regarding smoking and alcohol drinking.

Demers, French, and Moore (2000) evaluated a program to address alcohol and tobacco use and prevention needs of 138 students with special needs that were between 14 and 17 years of age. The intervention consisted of five lessons delivered during class time and in which the dangers of alcohol and tobacco, resisting peer pressure, avoiding risky situations and dealing with stress were taught. Information was gathered on, for example, use of alcohol and tobacco during the last 30 days, intent to use alcohol and tobacco, and perception of harm of alcohol and tobacco. Although the scores on each of the above items for the students in the experimental groups at the end of the year were higher than those of the control groups, the differences were not statistically significant.

Evidence-Based Practice

Although several educational and intervention programs to educate clients about the adverse effects of tobacco and alcohol use, and to reduce the actual use of these substances have been evaluated in the past years, the evidence on the feasibility, appropriateness, meaningfulness and effectiveness of these interventions remains small (Kerr, Lawrence, Darbyshire, Middelton, & Fitzsimmons, 2013). In a systematic review of the effectiveness of substance use-related interventions for individuals with IDD, Kerr et al. identified only nine articles published between 1996 and 2011, most were of poor to moderate methodological quality in terms of design, reliability and description of procedures, and had been conducted with a small number of participants.

Also, only a small range of different intervention approaches (i.e., education, motivational interviewing, cognitive behavioral techniques) have been used in the treatment of substance (ab) use in individuals with IDD. In all cases, interventions were adapted (e.g., simplified language, use of pictorial stimuli) to the needs of individuals who functioned in the mild to borderline range of IDD. Most often, treatment packages were implemented for reducing substance (ab) use in participants and no conclusions can be drawn on which elements contributed to the effectiveness of an intervention. Furthermore, educating participants about the (adverse) consequences of substance (ab)use did not lead to a decrease in actual substance use. As far as we know, interventions targeting illicit drugs or prescribed medications in individuals with IDD have not been reported in the literature.

In sum, despite the favorable outcomes of some of the studies we described in this chapter, little can be deduced regarding the evidence-base for tobacco and/or alcohol-related interventions for individuals with IDD (also see Van Duijvenbode et al., 2015). The study by Singh et al. (2014), published after Kerr et al.'s (2013) review, should be mentioned as it is of high quality because of an internally valid design (in which a mindfulness-based approach was compared to treatment as usual), reliability measures on dependent variables, and clear description of the procedure.

Policies and Practices

Several articles have been published that report challenges in providing SUD services for individuals with IDD and provide suggestions how to circumvent these.

Case Identification

To be able to provide adequate care and treatment, recognition of comorbid SUD and IDD needs to be improved. This includes both identifying individuals with (mild to borderline) IDD in addiction care as well as recognizing substance use disorders in those with IDD. The first is not routinely done yet, even though there are some promising results using instruments for screening for cognitive impairment in addiction medicine (e.g., To, Vanheule, Vanderplasschen, Audenaert, & Vandevelde, 2015). Assessing substance use and substance use patterns on an individual basis (i.e., interviewing individual clients) is probably the most straightforward way to improve early detection and intervention in individuals with IDD. Unfortunately, widely used substance use screening instruments may be unreliable in this population (VanDerNagel, Kemna, & Didden, 2013), and there still is a lack of (validated) questionnaires on substance use, tailored to the needs of those with IDD.

A new instrument in this area is the *Substance Use and Misuse in Intellectual Disability—Questionnaire* (SumID-Q), a Dutch instrument developed to assess substance use, its risk factors and consequences among individuals with mild to borderline IDD (VanDerNagel, Kiewik, Van Dijk, De Jong, & Didden, 2011). An important principle incorporated in the structure and methodology of this questionnaire is to discuss substance use and abuse in an empathetic, open and non-confrontational manner (see also VanDerNagel et al., 2013). In those individuals with substance use, further assessment is necessary to reveal whether DSM-5 criteria for SUD are met, and how substance use is related to biological, social and psychological risk factors, and adverse consequences. Generally, this procedure entails a clinical interview, retrieval of information from significant others (family or professional care givers), and a comprehensive health check. Special attention should be given to the possibility of polysubstance use, and co-occurring symptoms of a psychiatric disorder. The latter can be both result of SUD and a risk factor for SUD, and generally warrants a comprehensive multicomponent treatment approach.

Cross-System Collaboration

In addition to case identification, access to substance abuse treatment also needs to be improved for individuals with IDD. Individuals with IDD experience barriers to accessing substance abuse treatment, for example in addiction services. A small number of studies have explored factors that limit accessibility to addiction services for individuals with IDD. In an early study, Lottman (1993) found that most services had little experience in the treatment of individuals with IDD. Lack of expertise of staff was the strongest barrier to treatment access. This outcome was corroborated by those from a survey by VanDerNagel, Kiewik, Buitelaar and De Jong (2011) among 39 IDD services in the Netherlands. Most services reported to have inadequate expertise with substance use of clients with IDD. Respondents also noted that substance users face a number of psychosocial problems that the service providers were poorly equipped to address.

Slayter (2010a, 2010b) conducted two studies on access to treatment in a large sample of individuals who were Medicaid beneficiaries. She compared individuals ($N = 5099$; between 12 and 99 years of age) with IDD and comorbid mental health problems and substance abuse to a sample of individuals ($N = 221{,}875$) without IDD. Results indicated that individuals with IDD were less likely to access treatment than individuals without IDD. In a second study among youth ($N = 1669$; 12–21 years), she found that youth with IDD were less likely to initiate, engage and remain in substance abuse treatment than their non-IDD peers. McGillivray et al. (in press) found that the completion rate of alcohol and/or drugs programs in prison was much lower in prisoners with IDD when compared to prisoners without IDD.

A cause for clients' drop out may be that therapists in addiction services have little or no expertise in working with individuals with IDD. Existing integrated treatment models are insufficiently adapted for use in these individuals. Slayter (2010a, 2010b), Van Duijvenbode et al. (2015) and other researchers have identified a need for more cross-system collaboration and the use of integrated treatment approaches for the benefit of individuals with IDD and comorbid substance abuse and mental health problems. Cross-system collaboration also implies involvement of IDD services in prevention, care and treatment for those with comorbid SUD and IDD. This includes establishing policies regarding the prevention of substance use by clients, and staff members to protect other clients and staff members from the harmful effects and undesirable role models of clients' (and staff's) substance use, while avoiding repressive policies that may discourage clients to seek help. Furthermore, staff members in IDD services can play a crucial role in screening and assessment of substance use to enhance case identification, adequate referral to addiction services as well as supporting clients during the process of substance use treatment. To be able to do so, staff members in IDD care need to be educated on substance use, signs and symptoms of use as well as SUD treatment options (McLaughlin, Taggart, Quinn, & Milligan, 2007). More so, IDD services need to acknowledge SUD as a complex and potentially serious health problem that warrants clinical attention, intensified staff support, and possibly referral to an addiction center, rather than seeing SUD as a behavioral problem that can be remediated by relatively simple measures (Van Duijvenbode et al., 2015). Also, staff members in IDD services should be aware that their support, role behavior, and continuous support are crucial to prevent and remedy substance use related problems. Addiction centers on the other hand, not only need to adapt their treatment protocols and patient communication to the need of those with IDD, but also need to learn how to work together with and learn from staff in IDD services to provide optimal care for this patient group.

Future Research

Although the topic of SUD in individuals with IDD has enjoyed increased attention during the past decade, there are still many gaps in the literature on prevalence and risk factors and there is a lack of valid tools and effective treatment interventions. Van Duijvenbode et al. (2015) have proposed several lines of research that will be briefly summarized here.

First, research in larger samples of individuals with IDD is called for in order to plan treatment capacity and develop strategies for prevention and early detection of substance abuse. It should include a variety of research methods, such as biomedical markers of substance use and abuse (to validate measurement instruments), administrative data, and multicenter studies addressing the methodological shortcomings in extant studies (also see VanDerNagel et al., 2014). In epidemiological studies, risk factors may be explored such as motives for substance use, client characteristics (e.g., personality traits) and social factors (e.g., living arrangements). Furthermore, the prevalence of so called "triple diagnosis" (IDD, substance use disorder, and mental health problem) may be of interest as there is a relatively large number of individuals with mild to borderline IDD with substance abuse who have comorbid mental health problems (see also Didden et al., 2009). Such risk factors may then be targeted for primary or secondary prevention strategies.

Second, instruments should be developed and/or validated for the screening and assessment of substance abuse in individuals with IDD. These instruments may then be incorporated in the routine diagnostic process. Examples of instruments that are now being validated are the *SumID-Q* (VanDerNagel et al., 2011) and implicit measures of cognitive biases and executive functioning (see Van Duijvenbode, Didden, Bloemsaat, & Engels, 2012; Van Duijvenbode, Didden, Korzilius, Trentelman, & Engels, 2013; Van Duijvenbode, Didden, Voogd, Korzilius, & Engels, 2012).

Finally, although an increasing number of studies have shown that interventions for substance (ab)use in individuals with mild IDD may be feasible and even effective in reducing substance (ab) use, the evidence base is still rather small. Future studies on the effectiveness of interventions should therefore use stronger methodological designs whereby comorbidity with somatic, mental health, and other psychosocial problems is taken into account. The development of "dual diagnosis" (IDD plus SUD) and "triple diagnosis" treatment interventions is especially warranted given the high rate of comorbidity of such factors in many individuals with IDD. As substance abuse is often a chronic condition, future research should be directed at psychotherapeutic and pharmacological relapse prevention strategies, long-term care and harm reduction strategies.

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