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Implementing Evidence-Based Practices Wisely

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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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