Fred R. Volkmar
Brian Reichow
James C. McPartland
Editors

Adolescents and Adults with Autism Spectrum Disorders

Foreword by
Sir Michael Rutter

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Editors
Fred R. Volkmar
Child Study Center, Yale University
New Haven, CT, USA

James C. McPartland
Child Study Center, Yale University
New Haven, CT, USA

Brian Reichow
AJ Pappanikou Center for Excellence
in Developmental Disabilities
University of Connecticut Health Center
Farmington, CT, USA

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Dedicated to the memory
of Eric Schopler, Ph.D.
And in honor of Gary Mesibov, Ph.D.,
pioneers in the field.

Foreword

As the introduction to this new volume well brings out, despite the enormous increase in research into autism spectrum disorders (ASD) there has been a paucity of good systematic studies into ASD in adolescents and adults. Nevertheless, this book does a good job in bringing together what has been found out since the first volume some three decades ago. It is now evident that ASD is diagnosed much more often than used to be the case, although uncertainty remains on whether the rise in diagnosis involves a true rise in incidence rather than just better ascertainment and a broadening of the diagnostic concept. Several studies have shown an increased mortality compared with the general population but whether this is a function of autism as such or rather associated intellectual disability and/or epilepsy is unclear. Follow-up studies have shown a remarkable heterogeneity in outcome, although possibly the outcome may be somewhat better than it used to be. In many regions of the world, the transition from childhood to adulthood has been accompanied by an increased difficulty in obtaining the care needed. There is knowledge on what is required but different services all too often argue over whose budget is used to provide the resources. If he were alive today, Eric Schopler would be gratified by what has been achieved (well summarized in this volume), but with an awareness of the remaining gaps, he would be fighting for more to be done.

London, UK — Sir Michael Rutter

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About the Editors

James C. McPartland, Ph.D. is an Assistant Professor of Child Psychiatry and Psychology at the Yale Child Study Center. He graduated magna cum laude in Psychology from Harvard University and received a doctoral degree in Child Clinical Psychology from the University of Washington. He completed pre- and postdoctoral clinical fellowships focusing on autism and related disorders at Yale and is a licensed child psychologist and Director of the Yale Developmental Disabilities Clinic. He is Director of Undergraduate Studies at the Child Study Center and offers an undergraduate seminar focused on autism spectrum disorders. Dr. McPartland's program of research investigates the brain bases of neurodevelopmental disabilities to develop biologically based tools for detection and treatment. His research is supported by NIMH, NARSAD, the Autism Science Foundation, the Waterloo Foundation, Autism Speaks, the Patterson Trust, and the Simons Foundation, and his contributions to the field have been recognized by the University of Washington's Bolles and Gatzert Child Welfare Fellowships, a Clinical and Translational Sciences Scholar Award from the Yale Center for Clinical Investigation, a Behavioral Science Track Award for Rapid Transition and a Patient-Oriented Research Career Development Award from the National Institutes of Mental Health, the NARSAD Atherton Young Investigator Award, the International Society for Autism Research Young Investigator Award, the Patterson Trust Clinical Research Award, and the Brain & Behavior Research Foundation Klerman Prize. Dr. McPartland has previously authored 2 books and more than 65 scholarly articles on autism and related topics. He is on the editorial board of the *Journal of Mental Health Research in Intellectual Disability* and is an Associate Editor for the *Journal of Autism and Developmental Disorders*. He has served in the Executive Committee of the American Psychological Association's Division of Intellectual and Developmental Disabilities and is the Treasurer of the International Society for Autism Research.

Brian Reichow, Ph.D., BCBA-D. is Director of Research at the AJ Pappanikou Center for Excellence in Developmental Disabilities and holds a joint appointment as an Assistant Professor of Community Medicine and Health Care and Pediatrics at the University of Connecticut Health Center. Dr. Reichow is also an Assistant Professor-Adjunct at the Yale Child Study Center, where he completed his Postdoctoral Training and served on faculty prior to leaving for UConn. He completed his doctoral studies in Special Education at Vanderbilt University, where he received M.S. and Ph.D. degrees. Dr. Reichow completed his undergraduate training in Elementary Education and Psychology at the University of North Carolina at Chapel Hill, and was a public school teacher for children with autism spectrum disorders for many years with Durham Public Schools. Dr. Reichow's primary research interest centers around the identification of evidence-based practices and the translation of research-based techniques to clinical and practical applications in everyday settings. Dr. Reichow has also been involved in scale-up efforts with colleagues at the World Health Organization to increase capacity for the identification and management of neurodevelopmental disorders in low-resource settings. Dr. Reichow was the recipient of the 2010 Council for Exceptional Children Division of Research Early Career Publication Award. Drs. Reichow and Volkmar are Editors of *Evidence-Based Practices and Treatments for Children with Autism*, also published by Springer.

Fred R. Volkmar, M.D. is the Irving B. Harris Professor of Child Psychiatry, Pediatrics, and Psychology at the Child Study Center, Yale University School of Medicine. An international authority on Asperger's disorder and autism, Dr. Volkmar was the primary author of the DSM-IV autism and pervasive developmental disorders section. He has authored several hundred scientific papers and has co-edited numerous books, including *Asperger Syndrome*, the third edition of *The Handbook of Autism and Pervasive Developmental Disorders, A Practical Guide for Autism: What Every Parent, Family Member, and Teacher Should Know,* and Evidence-*Based Practices and Treatments for Children with Autism*. He has served as Associate Editor of *The Journal of Child Psychology and Psychiatry*, the *American Journal of Psychiatry*, and the *Journal of Autism and Developmental Disorders* of which he is currently Editor-in-Chief. He is also the Editor of the five volume *Encyclopedia of Autism,* published by Springer.

Contributors

M. John Bankart University of Leicester, Leicester, UK

Lauren Bishop-Fitzpatrick University of Pittsburgh, School of Social Work, Pittsburgh, PA, USA

Mary E. Van Bourgondien TEACCH Autism Program, University of North Carolina, Chapel Hill, NC, USA

Jane Thierfeld Brown University of Connecticut School of Law, Hartford, CT, USA

Traolach S. Brugha University of Leicester, Leicester, UK

Lillian Burke The Redpath Centre, Toronto, ON, Canada

Staci Carr Rehabilitation Research and Training Center, Virginia Commonwealth University, Richmond, VA, USA

Paul K. Cavanagh Vocational Independence Program, New York Institute of Technology, Central Islip, NY, USA

Frank Cicero Eden II Programs, Staten Island, NY, USA

Sally Anna Cooper University of Glasgow, Glasgow, UK

Tamara Dawkins TEACCH Autism Program, University of North Carolina, Chapel Hill, NC, USA

Whitney J. Detar University of California, Santa Barbara, Santa Barbara, CA, USA

Carolyn A. Doyle Department of Psychiatry, Indiana University School of Medicine, Indianapolis, IN, USA

Christian Sarkine Autism Treatment Center, Riley Hospital for Children, Indianapolis, IN, USA

Shaun M. Eack University of Pittsburgh, School of Social Work, Pittsburgh, PA, USA

Western Psychiatric Institute and Clinic, University of Pittsburgh, School of Medicine, Pittsburgh, PA, USA

Ruth Ellingsen University of California, Los Angeles, Los Angeles, CA, USA

Megan Farley Waisman Center, University of Wisconsin, Madison, Madison, WI, USA

Amanda Fox University of California, Santa Barbara, Santa Barbara, CA, USA

Peter F. Gerhardt The McCarton School, New York, NY, USA

Robert L. Koegel University of California, Santa Barbara, Santa Barbara, CA, USA

Lynn Kern Koegel University of California, Santa Barbara, Santa Barbara, CA, USA

Sarah Kroesser Boston University, Boston, MA, USA

Elizabeth A. Laugeson University of California, Los Angeles, Los Angeles, CA, USA

Lee Marcus TEACCH Autism Program, University of North Carolina, Chapel Hill, NC, USA

Johnny L. Matson Louisiana State University, Baton Rouge, LA, USA

Erik Mayville Institute for Educational Planning, Milford, CT, USA

Christopher J. McDougle Department of Psychiatry, Harvard Medical School, Boston, MA, USA

Massachusetts General Hospital, Lurie Center for Autism, Boston, MA, USA

Bill McMahon University of Utah School of Medicine, Salt Lake City, UT, USA

Sally McManus NatCen Social Research, London, UK

James C. McPartland Yale Child Study Center, Yale School of Medicine, New Haven, CT, USA

Nancy J. Minshew Western Psychiatric Institute and Clinic, University of Pittsburgh, School of Medicine, Pittsburgh, PA, USA

Brian Reichow AJ Pappanikou Center for Excellence in Developmental Disabilities, University of Connecticut Health Center, Farmington, CT, USA

Sir Michael Rutter Institute of Psychiatry, King's College, London, UK

Carol Schall Rehabilitation Research and Training Center, Virginia Commonwealth University, Richmond, VA, USA

Fiona Scott University of Cambridge, Cambridge, UK

Kimberly A. Stigler Department of Psychiatry, Indiana University School of Medicine, Indianapolis, IN, USA

Christian Sarkine Autism Treatment Center, Riley Hospital for Children, Indianapolis, IN, USA

Kevin P. Stoddart The Redpath Centre and University of Toronto, Toronto, ON, Canada

Nicole C. Turygin Louisiana State University, Baton Rouge, LA, USA

Freya Tyrer University of Leicester, Leicester, UK

Ernst O. VanBergeijk Vocational Independence Program, New York Institute of Technology, Central Islip, NY, USA

Pamela Ventola Yale Child Study Center, Yale School of Medicine, New Haven, CT, USA

Fred R. Volkmar Yale Child Study Center, Yale School of Medicine, New Haven, CT, USA

Paul Wehman Rehabilitation Research and Training Center, Virginia Commonwealth University, Richmond, VA, USA

Julie M. Wolf Yale Child Study Center, Yale School of Medicine, New Haven, CT, USA

Lorraine E. Wolf Boston University, Boston, MA, USA

Marc Woodbury-Smith McMaster University, Hamilton, ON, Canada

Chapter 1
Autism Spectrum Disorder in Adolescents and Adults: An Introduction

Fred R. Volkmar, Brian Reichow, and James C. McPartland

Introduction

This chapter reviews the current state of the science and best clinical practice in research and service for adolescents and adults with autism spectrum disorder (ASD)[1] and serves as an introduction to the volume as a whole. Subsequent chapters cover these topics in detail. In this introduction, we provide an overview, aiming to highlight current understanding of ASD in adolescents and adults, as well as gaps in knowledge. In 1983, Schopler and Mesibov's earlier book on this topic addressed topics relevant to adults, such as education, medical care, behavior problems, sexuality, family issues, and independent living. At that time, most knowledge was based on case reports, clinical experience, anecdote, and occasional open intervention studies. In the three decades that have elapsed since its publication, methods and the overall volume of research in ASD have dramatically improved, but adolescence and adulthood in ASD remain rather poorly understood. Much of the research and clinical work has centered on young children and those of primary school age; although developmental change is maximal in early years, in this volume we emphasize, as much as possible, that important development continues through adolescence and adulthood while simultaneously emphasizing that adolescents and adults do, of course, have unique and important concerns. While the number of adolescents and adults with autism and related disorders has increased over the last several decades, research on this age group has not correspondingly increased.

[1] Note that unless otherwise specified we use the terms autism and autism spectrum disorder interchangeably.

F.R. Volkmar, M.D. (✉) • J.C. McPartland, Ph.D.
Yale Child Study Center, Yale School of Medicine, New Haven, CT, USA
e-mail: fred.volkmar@yale.edu; james.mcpartland@yale.edu

B. Reichow, Ph.D.
AJ Pappanikou Center for Excellence in Developmental Disabilities,
University of Connecticut Health Center, Farmington, CT, USA
e-mail: reichow@uchc.edu

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This has reflected a field-wide focus on very young children and, to some extent, an emphasis on genetics and siblings at-risk. As we discuss subsequently, earlier diagnosis and provision of effective intervention programs has significantly improved prognosis, with more individuals being able, as adults, to lead self-sufficient, independent, or semi-independent lives. Unfortunately, many adolescents and adults, particularly those with higher levels of cognitive ability, lose entitlements and services as they enter adulthood. It is our hope that increased understanding of the unique challenges of this understudied segment of the population of individuals with ASD will improve service quality and, consequently, quality of life for older individuals with ASD. We envision this text to follow on Schopler and Mesibov's initial book on adulthood, enriching their work with the accrued clinical and scientific understanding of 30 years of research and clinical practice.

What Do We Know (and Not Know) About Autism in Adolescents and Adults?

In the seven decades following Kanner's initial description of the syndrome of early infantile autism (Kanner, 1943) much progress has been made. We now understand that ASD is an early-emerging, usually lifelong neurodevelopmental disorder that significantly impact social, communicative, cognitive, and adaptive skills and has a strong genetic basis (Rutter, Kim-Cohen, & Maughan, 2006). There is now an extensive literature of peer-reviewed, scientific papers focused on ASD, and multiple studies on adult outcome have been published (for a review, see Howlin, 2013). As Howlin notes, however, these focus almost exclusively on outcome in young adulthood and information on older individuals is limited (Piven & Rabins, 2011), with almost no research focused on aging (Perkins & Friedman, 2012). Of the studies focused on outcome, most have studied individuals with classic ASD, or "Kanner's" autism and "outcome" is essentially confined largely to early adulthood.

Several factors have contributed to the paucity of research on issues specifically germane to adolescents and adults with ASD. As noted previously, the research literature varies tremendously by age group. Much more work has been done with infants and preschool children than older populations, especially older adults. This disproportionate body of work reflects an increased interest, especially over the last 15 years, in early identification and treatment with the hope of improving long-term outcome (National Research Council, 2001). This goal has been effectively advanced, but a consequence has reduced interest in and research support for work with older populations. Improvements in care for children make likely an increasing proportion of adults on the spectrum with higher levels of independence and self-sufficiency. Historically, it was often presumed that individuals with ASD would require residential, full time, care. It is now recognized that an increasing proportion will require less substantial support, but there has

been limited information gather about how to support these individuals in achieving full or semi-independence (Howlin, 2013).

Another complication for treatment research relates to an intrinsic difficulty in research funding. Treatment studies of all kinds (behavioral or pharmacological) are difficult to design and carry out for all age groups. For these reasons, it is often more challenging to procure research funding to complete them. Complexities arise in sample selection, in selecting comparison treatments, and insuring that the sample sizes are sufficiently large (and the treatment effect significantly robust) that robust differences between groups can be detected with confidence. As a practical matter, treatment studies significantly lagged behind other areas in funding and in peer-reviewed publications over the past two decades (see Volkmar, Reichow, & Doehring, 2011 for a discussion of this topic and a review of the range of evidence-based treatments now available). To some extent, this reflects the nature of ASD, in that it is a disorder with a marked range of outcomes and in which services are provided by many different disciplines. Moreover, access to services can vary dramatically within region and country as well as across countries. In the USA, separate service systems are in place for children under 3 years of age, for children from 3 years to young adulthood (e.g., age 21), and for older individuals. In many states, adults with cognitive disabilities are provided services by a state department of developmental disabilities while more cognitively able individuals receive services (if at all) from the mental health and social support systems. In other countries, the system is not as fractionated, although supports for adults are also often lacking (e.g., Stoddart et al., 2013). This heterogeneity in both the disorder itself and in service delivery, render it a complicated landscape for the study of intervention and outcome (Volkmar et al. 2013; Reichow & Volkmar 2011).

Changes in nomenclature and diagnostic taxonomy have also complicated interpretation of research over the years and of identification of older individuals on the autism spectrum (see Gibbs, Aldridge, Chandler, Witzlsperger, & Smith, 2012; Mahjouri & Lord, 2012; Matson, Belva, Horovitz, Kozlowski, & Bamburg, 2012; McPartland, Reichow, & Volkmar, 2011for varying views of the issue). The concept of autism has changed over time with variable emphasis on broader versus narrower definitions of the disorder (i.e., "lumping" versus "splitting"). For the past two decades, the DSM-IV (APA, 1994) and ICD-10 (WHO, 1993) approaches have been virtually identical. The 2013 publication of the DSM-5 (APA, 2013) combines subdiagnoses into an overarching class, "autism spectrum disorder." The potential for divergent American and International diagnostic systems could result in increased complexity for international research (Rutter, 2011; Tsai, 2012). The potential for significant change in diagnostic assignment further complicates longitudinal, follow-up, and epidemiological study interpretation in particular.

Despite the important limitations of the research literature, it does appear that on balance outcome has, and is continuing, to improve. The gradual change in outcome over time likely reflects early detection and intervention, entitlements to programs, and evidence-based treatments. In her recent review, Howlin (2013) observes that, overall, many adults now are able to achieve independence; she also rightly

emphasizes that even for this most able group knowledge remains limited and needs remain high. As she notes in much of the outcome literature (indeed almost entirely so), outcome is assessed in young adulthood with little or no attention to issues of needs after that point in time (or potential changes with age).

For adolescents and young adults, the outcome literature in young adulthood is reasonably extensive. As first noted by Kanner, Rodriguez, and Ashenden (1972), some individuals with autism make noteworthy gains in adolescence while a minority appear to lose skills (Howlin, 2013). In up to 50 % of cases, there are overall gains in communication and adaptive skills as well as reduced symptom severity; this is most likely if overall IQ > 55. For those individuals losing skills in adolescence, the onset of seizure disorder and mental health comorbidities may pose difficulties in adolescence. Transition issues themselves (from school-based to adult-focused vocational and educational programs) can pose major challenges. For example, more individuals with ASD are now entering college and post-secondary programs, resulting in increased opportunities for adult self-sufficiency and higher levels of occupation. As discussed in Chap. 7, this has also posed a challenge to both these individuals and to post-secondary programs in confronting unique special support needs (Stoddart et al., 2013, Wolff, Brown, & Bork, 2009) The relationship between severity of early symptoms of autism and ultimate outcome remains unclear, with at least a few studies suggesting that the severity of social skills impairment is the most significant outcome predictor (Howlin, 2013). This and many other questions regarding changes in outcome remain to be discovered.

Past young adulthood the literature becomes quite sparse. In one review of autism, research studies conducted between 2000 and 2010 only 23 (of an estimated 11,000) were focused on adult services (Shattuck et al., 2012). Despite this recognized paucity of research (Howlin, 2013; Mukaetova-Ladinska, Perry, Baron, & Povey, 2012; Piven & Rabins, 2011), extant evidence suggests that support services/networks can significantly influence outcome and quality of life. There is also some suggestion that more supportive communities are associated with better outcome (e.g., Farley et al., 2009). The data available suggest that most individuals as adults live with parents/family and that a minority is employed. Increased mortality is observed, and this is often related to seizures and accidents in more severely impaired individuals (Gillberg, Billstedt, Sundh, & Gillberg, 2010). Even for the more cognitively able individuals, challenges remain around issues of adaptive skills (Volkmar et al., 1996).

These issues have been investigated through several studies employing survey data. They indicate serious reasons for concern about the status of adults with autism. In one recent report, 480 individuals (adolescent to middle-aged adults) (Stoddart et al., 2013) in the province of Ontario were surveyed, documenting a dramatic shortage of support services and high rates of anxiety (45 %) and depression (27.9 %) with nearly one third of cases indicating they believed they had an undiagnosed mental health condition. Of those receiving medications, over 80 % received more than one medication. Educational attainment was improved relative to historical conditions, with nearly 45 % attending some post-high school educational program (a potential bias for under sampling the less cognitively able was

noted). Even for the most able adults, however, limitations in social interaction, in adaptive/daily life skills, and occupational status were striking, with nearly 60 % of cases continuing to live with their families. About one third of the sample had had romantic relationships and in a few cases had been married (sometimes with offspring). Most of the sample reported major limitations in social connections (with many having one or fewer social encounters outside their living situation each month). Although studies based on survey data have notable methodological limitations (e.g., reliance on self or caregiver report both for diagnosis and perceived needs with limited information on early characterization and diagnosis), these provocative data emphasize the critical need for further study.

While overall outcome for many has improved, not all individuals make comparable gains. Sometimes, even in receipt of appropriate intervention, lifetime costs of care remain very high indeed (Ganz, 2007; Knapp, Romeo, & Beecham, 2009). Although most individuals with autism continue to exhibit features of the condition throughout life, the pattern of syndrome expression changes. Those who make gains became motivated to adapt socially and to achieve independence. As detection and intervention have improved, there appears to be a noteworthy shift in outcome with many young adults now able to attend college or to be independent and self-sufficient (Wolff et al., 2009). Sometimes cases no longer meet diagnostic criteria. For example, Seltzer and colleagues examined the issue of current versus lifetime symptoms using the ADI-R and noted improvement in all three domains with nearly half their sample not meeting cut-offs using scoring based on current functioning (Seltzer et al., 2003). Unfortunately this does not always occur and a substantial number of cases remain in need of considerable support throughout their lives. While behavioral difficulties are strongly related to overall cognitive ability, the relationship of severity of autism symptoms to outcome remains incompletely understood (Howlin, 2013). Even among those who display significant progress, difficulties with social interaction and social isolation often persist, with increased risk for mood problems (particularly depression) and anxiety (Howlin, 2013). However extensive data on these issues are lacking or absent. For example, rates of suicidal ideation and para-suicidal behavior have not been studied in ASD. Anxiety and depression may well be exacerbated by social isolation, experiences of bullying, and difficulties with employment in more cognitively able persons. As Howlin notes (2013), appropriate measures of life quality should account for the point of view a person with ASD (see also Billstedt, Gillberg, & Gillberg, 2007, 2011). For example, the frequency and import of social contact may vary according to the social motivation of the individual.

Overview of This Volume

As emphasized throughout this volume, ASD has significant impact on function in everyday life regardless of cognitive ability. This impairment often leads to a situation in which an individual's family will be responsible for their lifelong care.

Although this has been long recognized, little empirical research has examined this impact. In Chap. 2 Van Bourgondien, Dawkins, and Marcus discuss the impact of autism in adolescence and adulthood on families and provide pertinent information that all families should know for caring for their son or daughter with ASD. The chapter initially discusses the changing role a parent plays from being the main provider of support and advocacy to serving as ancillary support to a more independent adult. This is a similar role change that parents of children without autism encounter, but a key difference is often that the young adult with ASD will continue living with or need considerable amounts of care from the parents (whereas in typical development, the care is weaned more dramatically). The authors review historical accounts of familial relationships in ASD and reflect on improvements in quality of life for both families and adults with ASD over time. They then discuss common concerns parents face, including future planning, guilt, guardianship, transition planning, post-secondary education, living situations, and issues associated with day services/employment. Having a child with autism is associated with increased family stress, especially for the mother who often plays a more significant role in the continued care of the child. Van Bourgondien and colleagues offer an overview of factors associated with increased stress and highlight the importance of managing this stress to decrease the likelihood that other mental health problems develop in parents or other children. The chapter ends with a brief description of the TEACCH program for families of adults with ASD, one of the few intervention programs with a longstanding history of serving adults and of incorporating families into their treatment.

In Chap. 3, Schall, Whman, and Carr provide an overview of the transition from high school to adulthood for adolescents and young adults with ASD. As Kanner (1971) noted in his follow-up of his original series of cases, adolescence is a time when some individuals make considerable gains while others, unfortunately, seem to lose skills. For many individuals making gains, the transition from a more supportive educational setting to more challenging post-secondary and vocational programs presents a range of novel challenges for the individual and his or her family.

Laugeson and Ellingsen provide a cogent overview of what is known regarding treatment of social skills for adolescents and adults with ASD in Chap. 4. Given that social impairment is the defining feature of ASD (Volkmar, 2011) and is, of course, particularly important in the many challenges adults face in holding down a job, socializing, and navigating daily life, effective methods for ameliorating the social deficits found in autism are essential. As discussed in the chapter, limitations in social skills have the potential detriment overall quality of life. Therefore, intervention programs that teach socially appropriate behaviors and skills are a necessary component of any treatment plan or program. Laugeson and Ellingsen review the types of social deficits individuals with ASD face (over/under initiation, poor communication skills, an overall lacking of comprehension of common social norms, verbosity, concreteness in a constantly changing world, and limitations related to theory of mind). A discussion of effective delivery methods follows, highlighting the treatment techniques (behavioral modeling, behavioral rehearsal, coaching and

feedback, social stories and scripts, multimedia software, video modeling, and self-monitoring) that can be used to achieve best outcomes. They then provide an overview of the key elements (treatment manuals, adequate duration of treatment, use of small groups, didactic instruction, caregivers/parental involvement, ecologically valid, opportunities for practice with typical peers, and homework) that programs and interventionists must consider when designing treatment. The chapter concludes with practical suggestions for moving the field forward to address existing limitations in our knowledge base.

In Chap. 5, Koegel, Detar, Fox, & Koegel address the complex aspects of sexuality and romantic relationships in individuals with ASD. As they note, issues of severity of symptomatology, living arrangements, and skill levels are complexly interweaved in determining capacities for relationship development and sexuality. Different approaches to education around these issues are needed, as compared to the typically developing population. Sadly, they note a general lack of education on these topics is the rule rather than the exception only making difficulties with relationships and sexuality more likely. As they also observe, these issues are wide ranging having to do with a range of topics including the experience of bodily change at puberty and social conventions regarding privacy and aspects of sexuality. Given their social disabilities, adolescents and young adults have an even greater challenge than typically developing peers, e.g., with fewer serious relationships and challenges in communication around such relationships. The lack of research in the area is particularly unfortunate and Koegel and colleagues rightly focus on the need for setting a new research agenda in this area.

In Chap. 6, Gerhardt and colleagues addresses the issue of support services and employment for adults with ASD. In the context of rising ASD diagnoses, new generations are being confronted with the challenge of providing lifelong services for affected individuals. The challenges focused on in Chap. 6 are systemic—they are a function of the current poor infrastructure for adults with ASD, not of the disorder itself. There is an undisputed lack of supported employment programs that are documented to be effective. This chapter discusses and compares a variety of different employment options for adults with ASD, from competitive employment to sheltered workshops, and addresses the issues that these programs face. Suggestions are provided for future approaches to improve the system of services and employment.

Access to college education is an important pathway to employment that is increasingly available to individuals with ASD. Wolf, Brown, and Kroesser address the important transition issues for more cognitively able students with ASD as they move from high school to other settings in Chap. 7. Major differences in legal entitlements and expectations for personal independence raise many challenges. At the same time, and as with the rest of the population, having some post-high school education likely has a very significant positive impact on long-term earning potential. Their chapter highlights the many concerns that remain to be addressed and some of the steps that can readily be taken to anticipate, and meet, the needs of students with ASD in college and post-secondary school settings.

Adaptive behavior refers to the skills necessary to adequately function in the environment and community in which one lives. As outlined by Turygin and Matson in Chap. 8, it has historically had a very broad definition and encompasses many areas including life skills, leisure skills, and vocational skills. Given the deficits many individuals with ASD have in adaptive skills regardless of the level of cognitive functioning (Volkmar & Klin, 1994) addressing and treating adaptive behavior is of paramount importance as greater independence and self-determination has been shown to improve quality of life. Moreover, the ability to develop good adaptive behavior skills is hindered by the deficits in socialization, communication, and repetitive and restrictive behaviors, i.e. the core deficits for individuals with ASD. As Turygin and Matson indicate, poor social–communication skills limit the number of opportunities to practice and become fluent in this area and likely have a cascading effect on the acquisition of daily living skills. The chapter summarizes the challenges of intervening and treating these important skills including the need to address environmental concerns, the challenges associated with the broad spectrum of cognitive abilities in ASD and the relation between cognitive ability and adaptive skills training, and choosing appropriate and functional target behaviors. The chapter then provides an overview of the three most common assessment methods and an overview current knowledge of best practices (treatments) focusing on three areas: using the many facets of applied behavior analysis to teach adaptive behaviors, the TEACCH program's focus on vocational and life skills training, and the emerging uses of assistive technology and specifically high-tech devices.

The risk for mental health problems in adolescents and adults with ASD is high. In their chapter on mental health comorbidities, Doyle, Stigler, and McDougle (Chap. 9) focus on psychopharmacologic treatments for these conditions. Several classes of drugs can be considered in the context of treating adolescents and adults with ASD. Medications with serotonin reuptake blocking properties hold promise as treatment for repetitive behaviors, with better efficacy in adults compared to children. Tricyclic antidepressants have also demonstrated some effectiveness in managing repetitive thoughts and behaviors but have shown poor tolerability. Antipsychotic medications have been found to be most effective for treatment of irritability in individuals with ASD. Medications traditionally used to treat symptoms of attention-deficit/hyperactivity disorder (ADHD) have also been studied as potential treatment for hyperactivity and inattention in individuals with ASDs. Mirtazapine is discussed as a possible treatment for hypersexual behaviors in individuals with ASD, however, despite promising findings for both the core symptoms of ASD and comorbidities, double-blind, placebo-controlled studies are needed.

In Chap. 10, Cavanah and VanBergeik provide an overview of residential programs and opportunities for individuals with ASD. As they note, a general guiding principle in this area has been provision of a "Least Restrictive Environment," i.e., in fostering as much independence and self-sufficient (and community integration) as possible. Even for more cognitively impaired individual's inclusion in the process of decision-making is important. This chapter reviews the range of options

available and potential predictors of successful placement. The range of supports and potential of maximizing independence and self-sufficiency are emphasized.

In Chap. 11, Farley and McMahon address the range of outcomes for adults with ASD in middle to later life. Outcomes are difficult to characterize; generalizations about adult outcomes lose validity as diagnostic criteria and social, educational, and therapeutic practices change over time. Furthermore, the lack of revised tools designed for the systematic diagnosis of adults and uniform institutions (e.g., schools), which would provide behavioral and performance data to evaluate adult populations, limits a comprehensive understanding of the life course of ASDs. This chapter examines adult prevalence studies, prognostic variables for adult outcome in ASD, most importantly childhood IQ score and communicative phrase speech, and predicted developmental trajectories for adults with ASD, specifically a reduction in autistic symptoms over time. In addition, the concept of "recovery" from ASD, mortality and causes of death with ASD, and selected outcome studies are discussed. This chapter also focuses on several areas of concern for adults with ASD, such as persistent difficulties processing sensory information, inability to maintain long-term romantic relationships, low levels of employment, limitations in academic achievement beyond high school, and direct medical and direct nonmedical costs as a result of the ASD and limitations. Directions for further research to elucidate the progression of ASD across the lifespan are discussed.

In adolescents and adults, the autism spectrum experiences a wide range of medical and health problems. In some cases there are clearly increased risks, e.g., for seizures disorders and also difficulties with anxiety and depression, as compared to the general population. These medical and psychiatric disorders can unfortunately greatly impact quality of life but frequently go either unrecognized or undertreated. The lack of research in this area mirrors a general lack of services for this population. As Burke and Stoddard summarize in Chap. 12, some risk factors have been identified. Although the focus of the chapter is on more cognitively able individuals much of what is said applies to the entire population of individuals with ASD. While the lack of information (and services) for adolescents and adults on medical are issues is unfortunate, it is the case that guidelines for care are increasingly available (National Institute of Clinical Excellence, 2012).

Adolescents and adults with autism and related conditions are at significantly increased risk for becoming involved with the legal system. As Woodbury-Smith notes in Chap. 13, legal entanglements arise from several sources including being victims of crimes, witnesses of crimes, or as perpetrators of alleged illegal activities. Somewhat paradoxically, it is the case that at times they're over adherence to learned rules/norms (with little latitude for making exceptions) can lead to involvement with the criminal justice system. The latter is often poorly prepared to cope with a person who seems "normal" and who has, if anything, good verbal skills but, to the untrained observer, significant social vulnerabilities. Even for more intellectually challenged individuals, lack of awareness can lead to arrest or incarceration as a result of "zero tolerance." As Woodbury-Smith highlights, many of the published descriptions of legal difficulties range back to Asperger's original description of boys with significant social difficulties but good verbal skills (Asperger, 1944) and

much of the available work focuses on this topic. Woodbury-Smith emphasizes that there is a need for a better understanding of potential risk for individuals with ASD, their family members and supporters, and to members of the legal and mental health system.

Issues of assessment and treatment planning for adults are addressed in Chap. 14 by Wolf and Ventola. Their chapter notes the importance of basing treatment plans in adulthood on comprehensive assessment that continue to address areas of strengths and weaknesses as well as the common comorbidities with ASD, such as mood and anxiety disorders. When diagnosing adults, it can be especially difficult to distinguish ASD from many other disorders (e.g., ADHD and schizotypal personality disorder) and from its comorbidities. In addition to differential diagnosis, the chapter focuses on the evaluative process itself, including neuropsychological, psychiatric, and speech assessments. Finally, the authors offer advice on various treatment and transition plans tailored to assessment results.

In Chap. 15, Brugha and colleagues provide a helpful overview of epidemiological considerations and prevalence estimates relative to ASD in adulthood, which is timely given the many undiagnosed cases in this population. First, the chapter examines the creation, administration, and findings of surveys designed to accurately assess the percentage of adults on the spectrum. The second half of the chapter uses correlated information from the surveys to discuss the livelihoods of the identified population of individuals with ASD. Such topics include data on ASD adults' social tendencies, socioeconomic status, and services received.

As highlighted throughout this book, there has been much less research on adolescents and adults with ASD than other age groups. This is especially true regarding intervention services, where little evidence exists from which to make treatment and programmatic recommendations. Although there is less, the field is not void of research, and the systematic review by Bishop-Fitzpatrick, Minshew, and Eack, published in the *Journal of Autism and Developmental Disorders* and reprinted in Chap. 16 provides an overview of psychosocial interventions for adults with ASD. Systematic reviews (and when applicable meta-analyses) are becoming an important tool in the determination of evidence-based practice, thus this timely contribution has the potential to make an important contribution in outlining what we know about psychosocial interventions for adults with ASD. Their review found only 13 studies of psychosocial intervention for adults with ASD, with mostly small sample sizes focused on a narrow range of outcomes. While they reported positive findings for using applied behavior analysis to increase functional skills or decrease undesirable behaviors and for social cognition training to help adults learn new skills, the small number of studies and significant methodological limitations does not permit strong conclusions about the efficacy of psychosocial interventions for adults with ASD at this time. Given the rising number of children and adolescents that will enter adulthood and receive adult services in the upcoming decade, it is imperative that rigorous research be conducted to ensure that adults with ASD are provided with evidence-based interventions that increase community participation leading to improved overall quality of life for the adults with ASD and their families.

Final Thoughts

Over three decades have elapsed since Schopler and Mesibov's seminal work on adulthood in autism. In that time, the diagnostic construct has evolved; new subdiagnoses have been introduced from the DSM and subsequently removed. Once considered a rare disorder, the prevalence of ASD has grown and is now estimated to approximate 1 in 88 children. The biological and genetic bases of ASD have been recognized, and, in this context, the availability of research funding and public interest in studies of ASD has grown dramatically. Significant amounts of federal and private dollars have been channeled into autism research and the resulting volume has expanded into a literature of thousands of articles spanning basic science to applied clinical practice. Paradoxically, despite increasing numbers of individuals with autism in adulthood and massive volumes of research being published, little remains understood about the development of ASD into adolescence and adulthood and the unique associated challenges presented to individuals, families, and public health systems. It is our hope that this volume, integrating the contributions of field leaders in their respective areas of expertise, will render accessible the body of knowledge available to-date and will foster additional research on this critically important topic for individuals with ASD and the society in which they exist.

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Chapter 2
Families of Adults with Autism Spectrum Disorders

Mary E. Van Bourgondien, Tamara Dawkins, and Lee Marcus

Overview and Introduction: Roles and Responsibilities of Parents

The roles and responsibilities of parents of children with autism shift as their children age and move from early childhood through the various developmental stages of life (Marcus, Kunce, & Schopler, 2005). Although there are a variety of factors that influence the amount and type of involvement (e.g., the child's level of functioning, adaptive skills, stage of adulthood, degree of independence, availability of services), there are common threads across these and other factors.

Parents have commented on how they have to become more of a *supportive parent* and less of a *smothering parent* (*their own words*). By smothering, they are reflecting on a natural tendency to make decisions for their child, do for them what the child might be able to do for himself, and unintentionally impede the growth towards independence. Parents of adults realize that their role has to be a guide and facilitator, to help their adult child to self-advocate as much as possible. Parents are well aware of their diminishing strength and energy and the ability to be "on-call" 24/7 as well as the realization that others are inevitably going to have to assume supervisory or other supportive roles in the future. Helping the adult son or daughter learn to make decisions and choices, no matter how small, to effectively communicate his or her needs, and show good judgment becomes the focus for parents.

While following the path of increased independence, the adult with autism continues to need the parent as an advocate, a role most parents have had to play from the early years since diagnosis. The arena in which advocacy is required differs from the preadult years where the main advocacy takes place in the schools where services are mandated and the rules are clear. For parents who have been effective

M.E. Van Bourgondien (✉) • T. Dawkins • L. Marcus
TEACCH Autism Program, University of North Carolina, Chapel Hill, NC, USA
e-mail: mary_van_bourgondien@med.unc.edu; tamara_dawkins@med.unc.edu; lee_marcus@med.unc.edu

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advocates in the schools and have spent years working with other parents to either develop programs or improve services for their child and others, the transition to advocacy for adults should be seamless. However, without entitlement the task is more challenging. Parents can no longer rely on the public education law of Individuals with Disabilities Education Act (IDEA) and usually the parent support groups they have been a part of have dissipated or their peer group dispersed, so they often may feel that they are back to "square one." In addition, the complexities of the mental health, social security, vocational rehabilitation, and other agencies can be overwhelming. The uncertainty of public funds coupled with the bureaucratic challenges of the multiple systems can lead to discouragement and a kind of paralysis. At a time that most parents of typical adults can move on in their lives without worrying about their child, parents of adults with autism are essentially starting over and readjusting and shaping their advocacy skills to deal with new challenges.

Although parents of children with autism are encouraged to think about the future, more often than not serious planning gets postponed until their child becomes an adult. Issues such as estate planning (with special needs trusts), guardianship, and wills now have to be addressed. Even higher functioning adults who may appear to need less support require similar consideration with regard to long-term planning. Partial guardianship or other strategies for these individuals, especially concerning financial oversight, require careful decision-making by the parents.

Parents, unfortunately, often assume the role of "social outlet" or "social planner" for their adult child with autism who lacks natural peers and the desire to leave the house. Parents worry about their adult child not participating in social or recreational activities, so are forced to seek out appropriate community experiences, find a "peer buddy" or provide entertainment at home.

In the end, parents often have no choice but to accept these multiple roles at an age and time of life when they are entitled to taking care of themselves.

This chapter will review the many roles parents of adults play in their offspring's life, the concerns they have for their child's future, and the impact and stress these responsibilities cause for both parents and siblings. While intervention programs for families of adults with autism are rare, we will describe the model of services for families of adults provided by the TEACCH autism program in North Carolina.

Historical Context

The history of families of adults with autism somewhat parallels the history of families of children with autism in that the understanding of the nature and causes of autism has changed dramatically over approximately the last 50 years. Although it is now widely accepted that parents of children with autism should be supported and considered part of a treatment planning team, as recently as 40 years ago parents were viewed as part of their child's problems (Schopler, 1971). Parents were largely blamed for the idiosyncratic and difficult behaviors seen in their children, whose

condition was considered an emotional disturbance, not the biologically based disorder that research and practice have shown today. As difficult as it was for parents to raise and cope with these challenging children, dealing with the added burden of blame and guilt was grossly unfair and harmful. Parents who were able to survive through sheer determination, courage, and single-mindedness of purpose still were scarred by their negative experiences with professionals. Others, who were unable to deal with a critical and markedly unhelpful professional community, gave up their struggle, placing their children in institutions. In some instances, parents were told early on to give their child up, partly because of the lack of available services and also because pediatricians and others failed to understand the parent perspective. Professionals today need to be aware of and appreciate what this earlier generation of parents went through and how the professionals of that era contributed to the stress of these parents. In the past decade, the rise in the diagnosis of forms of autism with fewer cognitive impairments, described as either high functioning autism (HFA) or Asperger's Syndrome, has coincided with identification of these cases in adulthood. Parents of these individuals have not had the benefit of an early diagnosis and support from the autism community and now are faced with the realization that their adult child with autism may require some degree of long-term support and services.

Focusing on the experience of families of adults, although the issue of causation of autism has been more or less resolved over the past 25 years, the interest and awareness of the needs of adults with autism has trailed behind those of children, especially young children. Compared to early childhood, relatively little has been written about autism in adulthood, beyond outcome studies (Howlin, Goode, Hutton, & Rutter, 2004), parental narratives (e.g., Park, 2001), and aspects of treatment and care (Howlin, 2004). More recently, autobiographies of high functioning persons with autism have become popular and have highlighted coping and adjustment problems in this subgroup (e.g., Tammet, 2006). What is known is that the problems of autism continue to some extent, that impairment in cognitive and social adaptation persists, and that the needs for long-range sheltered care and supervised employment pertain to the majority. The assistance that families require is consistent with that required during the preadult years, but the ability of most families to continue to take the initiative in procuring services can be compromised by their declining strength.

Historically, by adulthood most autistic individuals had been institutionalized; however, the recent efforts at deinstitutionalization is likely to all but eliminate that option, and the responsibility of the home and community to arrange for residential care and vocational opportunities has become more prevalent. Expertise in how to help adults with autism has been sorely lacking. Even where there are programs and services, the concern for parents and other family members is less than for families of young children. Ironically and sadly, many parents from earlier decades who struggled to be heard and advocated for services for their young children remain on the sidelines, while the newer generations of parents have seen the proliferation of programs for their children.

Concerns of Parents

Future planning. As soon as parents of a young child receive the diagnosis of an autism spectrum disorder (ASD), among the first questions they ask are "what will happen when my child becomes an adult?" "Will he/she be able to live independently?" "Go to college?" "Get a job?" "Will he/she get married?" Concerns for the future, with the parents throughout their child's life, reemerge as their child goes through the developmental phases from childhood to adolescence and then again as they transition to becoming an adult.

As the child becomes an adolescent and then an adult, most parents of typically developing children find that their role changes from being the primary caretaker, educator, and financial supporter to having a more removed role in their child's life. However, for parents of children with disabilities this change may not occur. In fact, for many families of adults with ASD, they may find that they are spending more time caring for children. In 1973, Kanner reported that the majority of 96 individuals who he first saw as children, and were now adults were highly dependent and living with their parents. More recent follow-up studies (Howlin et al., 2004) also show that parents in many instances continue to be the primary caregivers and/or main sources of support for their adult offspring. Mothers are more likely than fathers to be the caregiver with fathers helping with supervision rather than physical care or domestic tasks (Holmes & Carr, 1991). Limited support for caregivers coupled with limited opportunities for the family member with autism to socialize outside the family, be employed, or receive residential support adds to the burden of aging parents (Graetz, 2010).

Surveys of parents of adults indicate that their needs are quite varied (Eaves & Ho, 2008; Hare, Pratt, Burton, Bromley, & Emerson, 2004). The needs of parents of adults are generally comparable to those of parents caring for children with ASD (Bromley, Hare, Davison, & Emerson, 2004). The overriding concern for parents is about future planning including where they will live, where will they work or spend their days, and who will care for them when "I am no longer here." As their children become young adults, parental dreams change from thinking about whether their child will go to college and get married to hoping that their child will have a happy and meaningful life. In addition to concerns about finding services and planning for the future, parents who are caring for their adults with ASD also need respite and breaks from the day-to-day responsibilities (Hare et al., 2004).

Guilt. When parents first get the diagnosis of autism or any other developmental disability, another frequent response of parents is that they feel guilt and worry that there is something they did or did not do that caused their child's difficulty (Shea, 1993). It's important to note that as their children grow up, this sense of guilt never totally disappears. In fact, at each new transition in development the parents once again have concerns that they are not doing everything they need to do to insure their child's well-being and continued development (Morrell & Palmer, 2006; Van Bourgondien & Griffin, 2011). For parents of adults, the often heard message of the importance of early intervention and the often implied or sometimes directly stated

belief in a critical window for intervention during the preschool years can add to their sense of guilt and concern for their child's future. Many parents recognize that their adults with autism are in fact lifelong learners, yet the relatively limited information about adult issues and interventions adds to the parents of adult's sense of lack of support (Van Bourgondien & Griffin, 2011).

Guardianship. When adults with ASD reach 18 years of age, in the United States, parents no longer automatically have the legal right to make decisions for them regardless of the individual's level of intelligence or the ability to care for themselves. The parent needs to make a formal legal petition to be appointed the adult's guardian. Depending on the laws and statutes in the state, the parent or sibling or another responsible adult can be given full guardianship (usually involving financial, medical, and all decision making) or partial guardianship (responsible for some aspect of care such as health issues, but the adult maintains some rights, e.g., to vote). The decision to seek guardianship of their adult may seem clear cut for parents of individuals who clearly have an intellectual disability and autism. For parents of more able individuals on the spectrum, this decision is more complex. As parents try to respect their children's desire for adult status, they are also acutely aware of their children's vulnerability and problems with judgment. Unchecked credit card spending or other poor judgments regarding managing a budget put parents in the difficult dilemma of trying to protect their children while not taking all their rights and decision making away.

Transition planning. In the United States, the federal law IDEA requires that a transition plan be put in place by the time a student with an Individual Education Plan is 14 years of age. Unfortunately, not everyone has a meaningful transition plan developed, and the transition plan is only as good as the available community resources for individuals with ASD as they transition from school between 18 and 22 years of age. A 2008 online survey conducted by the University of Miami/Nova Southeastern University CARD program (Gerhardt & Lanier, 2011) of approximately 200 families of transition age and adults with ASD in Southern Florida found 67 % of families surveyed had no knowledge of available transition programs and settings. The majority (83 %) relied on family members as their primary source of transition planning.

Blacher, Kraemer, and Howell (2010) in a study of parents of 246 young adults (18–26 years of age) with a variety of learning and developmental disabilities found that parents of young adults with autism were significantly more worried about various aspects of transition than were parents of children with Down syndrome, cerebral palsy, or individuals with intellectual disabilities. This concern seems justified given the frequent lack of autism-specific information (Hare et al., 2004) and the results of outcome studies (Howlin et al., 2004) that show the majority of adults with ASD unable to do well in work, personal relationships or independent living. Almost 1/3 of families in a Canadian study (Eaves & Ho, 2008) reported lack of supports, work or an awkward transition to adult funding sources. Adding to the anxiety for parents is the movement from the educational entitlements available up to age 22 into the adult services world with no guarantee of services. At a time when

in most families of typically developing youngsters their children are leaving home and becoming more independent, for families with children with disabilities they may actually be spending more time with their adult children because of lack of services (Seltzer & Krauss, 1994). Shattuck, Wagner, Narendorf, Sterzing, and Hensley (2011) reported in a study of children with ASD leaving high school that most children lived with their parents (79 %) and most had a reduction in services as they left school. The odds of not receiving services were significantly higher for African American children and for youth from low income homes. For parents, the adult services world can be more confusing with the greater number of people involved, different agencies and amount of paperwork (Morrell & Palmer, 2006). Hare et al. (2004) cautions service providers that longstanding psychological distress together with social economic disadvantages not only reduce families capacity to provide care, but also affect the parent's ability to negotiate effectively with the service systems and to take and act on advice.

Clara Park (2001) in writing about her daughter's transition from childhood to becoming an adult titled her book "Exiting Nirvana" which is descriptive of Jesse's changes as well as the transition process itself. Coping with their "children's" development into "adults" presents families with new challenges in finding services, at the same time they experience the familiar guilt and fear that they may not be doing the right thing for their children (Van Bourgondien & Griffin, 2011). For some families their sense of guilt may also make them tenacious advocates for services as they are concerned about not doing everything possible to meet their adult's needs.

One of the most fundamental challenges of the transition process is what some parents refer to as "Letting go" (Morrell & Palmer, 2006). Regardless of whether it is a parent of a classic individual with autism and intellectual disabilities or the parent of a college bound individual with Asperger's Syndrome or HFA, the role of the parent changes and the adults with ASD take on a bigger role in advocating for themselves. Professionals working with adults, while still involving family members in some aspects of decision making, develop more direct relationships with the adult. In the ideal situation, the adolescent with autism has been involved in the Individualized Education Plan (IEP) process during high school so that they are taught how to identify their strengths and needs and to learn to ask others for the accommodations they needs.

Post secondary education. A growing number of children with autism especially those with Asperger's Syndrome or HFA are going on to attend community colleges or 4 year degree programs (VanBergeijk, Klin & Volkmar, 2008). For families, who have been actively involved in their children's education through public school and the IEP process, they are used to meeting with teachers and school officials to share information about their child's learning style and to advocate for accommodations and services. In post secondary education, this responsibility falls completely on the individual with ASD. The college student needs to be the person who contacts the college Disability Services program and to be able to talk with the professor about individual learning needs and accommodations. This change in responsibility for advocacy takes preparation for both the individual (young adult) with ASD and their parents (Palmer, 2006). In addition due to the student's difficulties in organizational

skills, interpersonal skills and general self care, families find themselves focusing more on how to help their children with the non-academic aspects of college living (Palmer, 2006) or else some college bound students continue to live at home with parental support in order to only change one aspect of their life at a time. For most typical students, it is often the indirect aspects of the college experience that prepares them for a job after graduation (Van Bergeijk et al., 2008). These skills include communication skills, work habits, team building, time management, and problem solving skills. Parents of individuals with ASD often have to recognize and then help their college bound children understand the difference between having a degree and having the skills needed to do a job.

Day services/employment. Parents hope that their child will have fulfilling work that is meaningful to them (Morrell & Palmer, 2006). Unfortunately, the data indicate that most adults with autism are either underemployed or unemployed (Gerhardt & Lanier, 2011; Howlin et al., 2004). In the 2008 CARD Center online survey (Gerhardt & Lanier, 2011) only 19 % of parents reported being familiar with agencies or professionals who can help with job development. Individuals with ASD and intellectual disabilities may be provided with day services in the form of a sheltered workshop or day program that may include some combination of work, volunteer, leisure activities or chores (Gerhardt & Lanier, 2011; Howlin et al., 2004; Saldana et al., 2009), though the availability of these services varies greatly upon the person's location and available funding sources. Lack of day services puts stress on families as parents end up staying home to care and supervise their adult offspring with the possible loss of income from the parents not being able to work (Hare et al., 2004; Saldana et al., 2009). In their study of 26 families of adults in England, Hare et al. (2004) found a significant positive correlation between formal support, family's weekly income, receipt of autism-specific day care and families' total satisfaction scores with day services.

Living situations. One of the top concerns of families is finding an appropriate living situation for their adults with ASD. Outcome studies have shown a wide range of variation in the number of individuals with autism who have left home to live independently, in a group home, or some supported living arrangement. A number of studies have shown that the majority of young adults continue to live at home with their parents. Shattuck et al. (2011) reported 79 % of adults with ASD aged 19–23 still lived at home with their parents in the few years after completing high school. The CARD program in their online survey found 85 % of adults still lived with their families. In a Spanish study, Saldana et al. (2009) reported 87 % of adults out of 74 lived with their families. In one of the few studies that showed a majority of adults with ASD leaving home, using data obtained from the State Mental Retardation Developmental Disabilities agencies in New York ($n=7{,}941$) and Massachusetts ($n=1{,}198$), Seltzer, Krauss, Orsmond, and Vestal (2000) reported that only 1/4 to 1/3 of the adults with ASD lived at home which was lower than those with other intellectual disabilities.

The reaction of mothers to the out-of-home placement of their adults with autism is very complex. Families who seek an out-of-home living situation for their adults, often experience anxiety and guilt about their decision. On the one hand, they worry

that no one will be able to care for their son or daughter as well as they do, at the same time they are afraid that their child's behavior will be so problematic that they won't be able to remain in the placement. The guilt feelings are often a result of feeling that as parents they should not be placing their son or daughter outside the home (Lehmann, 2009; Morrell & Palmer, 2006; Sullivan, 1997). There does not seem to be a single answer or a particular living situation which is right for all adults with ASD and their families. Kraus, Seltzer, and Jacobson (2005) compared maternal impressions of the positive and negative consequences of adults with autism living at home with their families versus placement in a residential setting. The main perceived benefits for the out-of-home placement were for the adult with ASD with fewer benefits for the family. For the adult with ASD, the mothers perceived more opportunities for learning and growth experiences in a residential program, but a greater likelihood of quality care and security in the family home. For other family members, having the adult with autism stay with the family provided the benefit of peace of mind for the parents and the enjoyment of their child's company. While out-of-home placements resulted in a calmer, more typical family life with less stress and more free time for the parents. Parental concerns about finding the right living situation are no doubt complicated by these competing benefits for the individual with autism and for their families. Some parents of adults have reported that they would never place their adult child with autism outside of their family home if they could guarantee that they would outlive their son or daughter. Since this is an unlikely outcome, many families pursue out-of-home placement in order to facilitate this process while they are still around to advocate for their offspring. The parental concerns for the future care of the individual with ASD continue no matter where the person lives.

Regardless of whether an adult with ASD lives at home or in a group home, supported living, or independent living situation, research and clinical experience suggest that they continue to be highly dependent on their parent's support (Howlin et al., 2004). This need for continued parental support crosses the entire spectrum of individuals with autism. In a Swedish study of individuals with Asperger's Syndrome and HFA, all of these more able adults, whether living at home or elsewhere, continued to be in need of their parent's support (Cederlund, Hagberg, Billstedt, Gillberg, & Gillberg, 2007). In fact, people with ASD without intellectual disabilities may have greater difficulty qualifying for funding for living supports than individuals who have both ASD and intellectual disabilities when funding is based on the severity of the disability. Even when adults with autism live outside the family, their families especially their mothers have extensive contact and involvement in their care. Kraus et al. (2005) reported that 50 % of families visited their adult with autism at least weekly and an equal number of adults came weekly to visit at their mother's home. The role parents play in the life of their adult child who is living away from home can vary from social outlet to being an integral member of a treatment team. Many residential programs/group homes have Medicaid funding which requires an Individual Habilitation Plan (IHP) for their residents (Gerhardt & Lanier, 2011). These IHPs like the Individual Education Plan (IEP) for students are developed by a team and parents are instrumental members of these teams.

Issues for Parents That Cross Settings

In addition to the concerns about where will their adult children live and how will they spend their days, parents of adults have concerns that cross all aspects of their offspring's life.

Provider knowledge of autism. A frequently voiced concern among families about providers of adult services is the lack of knowledge about autism, the learning style of an individual with autism, and specific intervention techniques that will enable the individual with autism to be successful as an adult. Hare et al. (2004) reported significant positive correlations between receipt of autism-specific day care and families total satisfaction scores. While residential, work, and recreational programs for adults with disabilities are growing in many places, programs specifically designed for individuals with ASD or have staff training in understanding autism continue to be insufficient (Gerhardt & Lanier, 2011; Hare et al., 2004; Kraus et al., 2005; Van Bourgondien & Schopler, 1990). While many intervention programs for adults have required training programs for staff members, the core of these training programs are typically generic trainings on first aid, CPR, medication management, client rights, and confidentiality with less required training on specific intervention techniques related to autism. It is interesting to note that many families are not aware of specific intervention techniques that may be used for adults with autism (Hare et al., 2004). This is a sharp contrast to parents of young children who often request by name a specific intervention technique.

Parents continue to want the adults with autism to be actively engaged in learning new skills (Kraus et al., 2005; Morrell & Palmer, 2006; Van Bourgondien & Griffin, 2011). Speech and language interventions and other skill-building activities continued to be valued by parents of adults (Ellison, Clark, & Langford, 2005). Yet few adults appear to receive this intervention (Hare et al., 2004). Learning new skills or even maintaining the skills and the degree of independence acquired during school years require that adults be able to participate in activities outside their parent's home with staff members who understand the learning style of individuals with ASD.

Staff retention. Complicating the staff training issue is the issue of staff recruitment, retention, and ongoing supervision (Hare et al., 2004; Kraus et al., 2005). The turnover rate of staff members in programs that serve adults with disabilities has been reported to be as high as 50 % with ongoing staff vacancies of 10–11 % (Gerhardt & Lanier, 2011). Both families whose adult children are living at home and receiving support and families whose adults are living in a residential program are concerned about staff turnover and lack of consistency. The lack of consistency in caregivers creates difficulty for parents who rely on support within their home and for the individual with autism who seeks predictability. The frequent turnover also makes staff training critical yet in a way very ineffective. For the family, it always appears that they are starting at step one in interventions as the new staff member is getting to know the adult with ASD and his/her learning style and intervention programs. The progress for the person with autism seems to be determined more by the

staff's training and experience and less by the readiness level of the adult. The families find that they can never truly relax and feel certain that someone will be there for their son or daughter next month, let alone when the parent is no longer present. For families the turnover rate in staff members adds to their concerns about their adult's future. Many parents have had the experience of having worked with the same teacher, resource teacher, speech therapist, occupational therapist, psychologist, etc. for an extended period of time when their child was younger. Now that there is an adult with a lifetime ahead of them, this relatively shorter time frame for providers fuels concern for the future. Eaves and Ho (2008) found that when parents of adults report what has been most helpful to them over the years they mention specific people—family members (52 %) or individual teachers, social workers, etc. (50 %) and not a specific treatment approach or program. It is therefore not surprising that the lack of stability in care providers is an area of great concern to families.

Health and safety concerns. The protection and safety of their children with autism continues to be a high priority for families as their children become adults (Hare et al., 2004; Ivey, 2002). Within the home even if the behavioral difficulties of most children with ASD decrease with age, those who are aggressive as adults are bigger and stronger and harder to manage. Families can struggle to find the right balance between giving their adult increasing independence and responsibility while worrying about their ability to truly care for themselves and protect themselves from harmful behaviors from others. Parents of adults with autism with behavioral difficulties are more likely to give in to their children's demands compared to parents of adults with Down syndrome who can more readily say no to their children (Holmes & Carr, 1991). Another concern is that if being mistreated by another person, their son or daughter may not have the communication skills to tell others. For parents of more able adults, determining when they are truly ready to drive, live independently, or even navigate chat rooms on the Internet are areas of concern.

For the parents of the nonverbal adults, there is also the concern that other caregivers may not know when they are sick in order to seek medical attention (Kraus et al., 2005; Lehmann, 2009). Medical care in itself can be challenging for some families of adults with disabilities (Eaves & Ho, 2008; Hare et al., 2004). Most physicians who are trained to work with individuals with disabilities are pediatricians, pediatric neurologists, or child psychiatrists. It is much more challenging to find a provider for adults who also understand developmental disabilities or autism. Finding a gynecologist for a female with autism or a GI specialist for an adult with gastric distress can be difficult.

Social outlets. In examining what parents report as unmet needs, Eaves and Ho (2008), found that 75 % of 48 families reported a need for more social outlets whether that be in the form of a specific social program or a friend or support persons who could take their adults with ASD out to do things. Again, this lack of social outlets increases the time many adults with ASD spend with their parents or siblings, therefore decreasing the ability of family members to pursue their own

lives. With typical adolescents and adults, one way they assert their independence is in their desire to do things with someone outside of the family. It is harder for adults with autism to find these outlets.

Financial security and estate planning. A recurring theme in parents of adults support groups is the question about what resources will be there when I am gone to help support my child with a disability. Based on our clinical experience, there are families who try to assure their child's future by purchasing them an apartment/house that they can live in or possibly share with a roommate. Unfortunately, the bricks and mortar or capital expense of having a home is often the easiest part of developing a long-term living situation for the adults with ASD. Funding the supports the person needs, the ongoing operational costs is far more important and costly. Many families rely on state or federal funding through a combination of Medicaid, social security, and state dollars to pay for the supports and interventions their offspring require. These funding sources while supporting personnel costs and some room and board do not typically pay for all of the individual's clothing or leisure materials or activities. Many families continue to provide these material needs for their children. So families, who have some resources, plan for the day when they are gone by looking for how to establish trust funds or other financial arrangements that will leave some source for funds to supplement the care of their offspring with ASD without jeopardizing their eligibility for state or federal funding. Organizations and lawyers who specialize in estate planning are an important resource to families who are thinking of the future. Some advocacy organizations in addition to managing a trust will also agree to provide an advocate to make sure the individual with ASD's needs continue to be met.

Stress and Coping in Parents

The stress of being the parent of an individual with autism is associated with higher reported levels of depression, anxiety, and exhaustion than parents of typically developing children, other disabilities, or chronic illnesses such as cystic fibrosis (Abbeduto et al., 2004; Bouma & Schweitzer, 1990; Dumas, Wolf, Fisman, & Culligan, 1991; Montes & Halterman, 2007; Seltzer et al., 2010). In addition, parents of a child or adolescent with a diagnosis of autism are more likely to report lower levels of perceived social support and hold less positive views of their child (e.g., Donovan, 1988, Koegel et al., 1992). Both symptom, severity and maladaptive behaviors in the child or adolescent with autism, have been identified as main contributors to maternal and family stress (Hastings et al., 2005; Lecavalier, Leone, & Wiltz, 2006). For example, elevated stress levels were shown to decrease in families without problem behaviors, but remain elevated in families where children, adolescents, or adults exhibited externalized behavior problems (e.g., Gray, 1994, Gray & Holden, 1992; Smith, Greenberg, & Seltzer, 2012). The daily health of mothers also appears at risk given increased reports of physical symptoms (e.g., head and

backaches, muscle discomfort, and fatigue) when compared to mothers of children without disabilities during childhood, adolescence, and adulthood (Smith, Seltzer, & Greenberg, 2012).

Parents of children, adolescents, and adults with autism also report an increased number of daily stressful events (e.g., Hastings, 2003; Smith et al., 2010). Specifically, mothers of adults with autism report engaging in arguments as well as avoiding arguments, stressful events in the workplace and at home, and stress from family members or friends more often than mothers of typically developing adults (Smith et al., 2010). Furthermore, mothers of adolescents and adults with autism experience lower positive affect, higher negative affect, more fatigue (almost triple the percentage of daily intrusions at work than mothers of children without a disability), more time engaged in child caring and maintaining the household, and less time spent in leisure activity (Smith et al., 2010). For some mothers, their child's transition to adolescence is associated with increased levels of behavioral disengagement (a form of emotion-focused coping where one reduces efforts to deal with stressors) and higher levels of anger than mothers of toddlers (Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008). Among mothers, the use of poorer coping strategies during the adolescent years may be a sign of the typical stressors associated with parenting an adolescent but might also reflect an accumulation of stress from years of parenting a child with autism or an increasing sense of limited parenting control of a larger adolescent with autism than a small toddler (Smith et al., 2008).

In an unpublished study of mothers and fathers of adolescents and adults with moderate to severe autism, Reichle and Van Bourgondien (1995) found that both mothers ($n=36$) and fathers ($n=25$) reported high levels of stress related to parenting an adult with autism. Adults with autism who exhibited more maladaptive behavior were perceived as more stressful by both mothers and fathers. This increased stress was significantly related to depression and marital adjustment for mothers and fathers, though mothers reported significantly more depressive symptoms than fathers with 44 % of the mothers being at risk for depression.

The challenge of raising an adolescent or adult with autism is enhanced with the presence of siblings who themselves present with behavioral difficulties. There is increased risk of cognitive, social, linguistic, and psychiatric problems even among adult siblings of persons with autism in comparison to the general population (Piven et al., 1990), which increases the likelihood of difficulties surrounding family adjustment. When compared to mothers who have one adult child with a disability (i.e., autism), the mothers of multiple adult children with disabilities (where one has autism) report higher levels of depressive symptoms, higher anxiety, and poorer family functioning as evidenced by lower adaptability and cohesion among family members as they struggle to meet every individual's needs (Orsmond, Lin, & Seltzer, 2007).

Consistent with the subjective report of increased levels of stress by mothers of persons with autism, mothers also show physiological evidence of chronic stress. Cortisol is a hormone released in the body during times of acute stress with lower blood cortisol levels found among persons who experience chronic stress.

Seltzer et al. (2010) found lower daily levels of cortisol in mothers of adolescents and adults with autism. In addition, the authors found that mothers whose children had subclinical histories of behavior problems showed increased cortisol levels the morning following a day of multiple behavioral incidents while mothers of children with significant histories of behavioral issues did not. So families who have not had a history of dealing with behavioral difficulties with the corresponding chronic stress are more likely to show an acute stress reaction to specific behavior incidents in their adult children. While the reasons for lower cortisol levels in persons with chronic psychological stress are unknown, increased fatigue appears to be a negative consequence (Smith et al., 2010). Considering the relation between behavior problems in the individual with autism and maternal stress, direct intervention to reduce these behaviors may have positive benefits for the psychological and physical well-being of mothers.

The limitations associated with the behavioral characteristics of autism can greatly affect the day-to-day activities of the family. Behavioral difficulties and lack of flexibility in the individual with autism may limit the family's frequency of outings and the ability to partake in family vacations. Further, the additional needs of the person with autism necessitates greater intensity of caregiving and intervention resulting in less time for fun family activities, increased stress for mothers faced with decisions regarding whether or not to maintain employment, pursue activities outside the home, stress on the job of fathers, and overall stress between spouses (Gray, 1994; Hutton & Caron, 2005; Montes & Halterman, 2007).

Several factors have been reported in the literature that can buffer the stress associated with parenting an adult with autism. Psychoeducation plays a vital role in helping parents cope when they have a child with autism and is associated with decreased levels of depression among mothers (Bristol, Gallagher, & Holt, 1993). Continued psychoeducation is a beneficial pursuit for parents of adolescents and adults with autism as new challenges emerge with each stage of development. In addition, parents should encourage extended family members to participate in psychoeducation regarding the needs of persons with autism and to learn ways to support their relative with autism since lower levels of depression and anxiety are found among parents of children with autism who have family members who can provide assistance with care giving (Sharpley, Bitsika, & Efremidis, 1997). Finally, coping strategies can help parents adapt to the stress of parenting an individual with autism. Smith et al. (2008) compared the coping strategies of mothers of toddlers or adolescents with ASD and found that mothers of toddlers or adolescents with autism who more often engaged in problem-focused coping strategies (i.e., direct attempts to reduce the stressor) had a higher general well-being regardless of their child's level of symptomatology, when compared to mothers of who used more emotion-focused coping strategies (e.g., venting or denial).

Smith, Greenberg, Seltzer, 2012 assessed the contribution of social support to psychological well-being among mothers of an adolescent or adult with autism. Mothers who had a larger social network reported decreasing levels of depressive symptoms, higher levels of positive affect (e.g., vigor, friendliness, and elation), and

lower levels of negative affect (anxiety, anger, fatigue, and confusion) over an 18-month period. The quality of social support was also predicative of well-being among mothers. More specifically, mothers who received negative support (e.g., placing blame, criticism or excessive demands on the mother) were more likely to show increased rates of depression and negative affect as well as decreased rates of positive affect over time. Interestingly, positive emotional support (e.g., having a confidant or someone to talk to) was not predictive of psychological well-being suggesting that mothers will find most benefit from a social network with limited negative support.

Marital status is also associated with coping among parents of adults with autism. Lower rates of maternal depression are observed in families where spouses provide direct assistance with care as well as overt expressions of love and caring towards their wife (Bristol, Gallagher, & Schopler, 1988). There is mutual benefit for parents of persons with autism to provide support to one another, as depression among one parent is more likely to result in marital discord and reduced coping mechanisms. Outside the home, support groups offer the opportunity for sharing of information. In person meetings and electronic groups through email-lists and online networks are ways in which parents of children with autism are able to have contact with other parents and receive support. Support groups are particularly effective among mothers of adults with autism who more often than mothers of typically developing children offer and receive emotional support (Smith et al., 2010).

Siblings

In typically developing children, frequent positive sibling exchanges are associated with greater psychological well-being in the developing child. In general, interactions between siblings in early childhood are beneficial for cognitive, social, and emotional development. During adolescence, a period of development where individuals increasingly seek out social relationships outside of the nuclear family, siblings endorse decreased satisfaction with the sibling relationship. With the onset of adulthood, brothers and sisters report increased satisfaction and contact with their siblings (Cicirelli, 1994; Kim, McHale, Wayne Osgood, & Crouter, 2006; Scharf, Schulman, & Avigad-Spitz, 2005). The relationship between typically developing siblings has been extensively studied; however, very few studies have been conducted in order to investigate the interactions and quality of relationship between siblings when one has autism.

For a typically developing sibling, the influence of having a brother or sister with autism is associated with higher rates of behavioral and emotional concerns (Constantino et al., 2006; Fisman, Wolf, Elllison, & Freeman, 2000; Giallo & Gavidia-Payne, 2006; Hastings, 2003; Ross & Cuskelly, 2006) and fewer prosocial behaviors towards their sibling with autism in some studies (Hastings, 2003; Knott, Lewis, & Williams, 1995), and appropriate psychological and social-emotional adjustment in others (Hastings, 2007; Kaminsky & Dewey, 2002; Mates, 1990;

Verté, Roeyers, & Buyesse, 2003). Further, several studies report no adverse effects of having a sibling with autism (Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004; Rodrigue, Geffken, & Morgan, 1993). Despite the communication, social, and behavioral challenges associated with a diagnosis of autism, some children who have a sibling with autism endorse both admiration for, and satisfaction with their brother or sister with autism (Kaminsky & Dewey, 2001; Rivers & Stoneman, 2003; Roeyers & Mycke, 1995). However, others report a lack of closeness and loneliness (Bägenholm & Gillberg, 1991), a limited number of interactions within the family and with their siblings in particular, and thoughts that their sibling with autism is a burden (Bägenholm & Gillberg, 1991; Knott et al., 1995) in comparison to the typical siblings of children with other disabilities. The inconsistencies across studies are thought to be due to differences in the methodology used such as reliance on indirect assessment of the social-emotional adjustment of the typical sibling through parent or teacher reports and small sample sizes. In addition, within some studies, children and young adults have been grouped in the same sample even though changes in the sibling relationship occur from childhood into adolescence and again during the transition from adolescence to adulthood.

Several factors have been identified that mediate the relationship between typically developing children and their sibling with autism. With regard to the family environment, increased levels of parental stress and marital discord were identified as indirect contributors to negative perceptions among typical siblings of the relationship they have with their siblings with autism (Benson & Karlof, 2008; Fisman et al., 1996), while increased size in the family unit improves acceptance and satisfaction with the brother or sister with autism given that the experience of stressors and responsibility is distributed among more family members. Finally, maternal depression can negatively affect the mental health of the typically developing sibling. The risk of maternal depression increases with the degree of impairment in the child with autism (e.g., Davis & Carter, 2008). In general, maternal depression has adverse consequences for children as exposure to the negative behaviors, cognitions, and affect of depression is associated with elevated risk to adjustment (Goodman & Gotlib, 1999). Shared genetic risk for depression between mothers and their children may also contribute to increased risk.

Although much of the literature focuses on the behavior and characteristics of the individual with autism, factors within the sibling of the individual with autism also influence sibling adjustment and psychological well-being. The siblings of persons with autism have greater genetic vulnerability for cognitive, social, linguistic, and learning difficulties than the general population (Ben-Yizhak et al., 2011; Gamliel, Yirmiya, Jaffe, Manor, & Sigman, 2009). In addition, siblings may also have subclinical manifestations of the communicative, social, and behavioral traits characteristic of persons with an autism spectrum diagnosis (e.g., broader autism phenotype; Bauminger & Yirmaya, 2001). Higher levels of broader autism phenotype predict poorer adjustment among siblings of the child with autism between the ages of 2 and 18 years (Meyer, Ingersoll, & Hambrick, 2011) and have been found to interact with negative life events to predict depression and anxiety among adolescent sisters of children with autism (Orsmond & Seltzer, 2009).

The early childhood experiences of siblings have consequences for the quality of interactions with their brother or sister with autism during adulthood; however, additional circumstances related to the transition to adult life continue to influence the sibling relationship. First, as the communication, social and behavioral challenges of autism have been shown to decrease in severity over the course of development (e.g., Seltzer et al., 2003), the likelihood that these changes are also associated with improvements in the sibling relationship increases (Orsmond, Kuo, & Seltzer, 2009). Nonetheless, the adaptive functioning or daily living skills of the brother or sister with autism may continue to influence the relationship as typical siblings of brothers or sisters with lower levels of functional independence report lower levels of closeness with their sibling (Orsmond & Seltzer, 2007). Second, during the transition to adulthood, individuals move away from their immediate family due to personal, educational, and professional pursuits. Within the literature, higher levels of education of the typically developing sibling as well as living at a distance from their sibling with autism have negative consequences for their perceptions of the sibling bond (Orsmond & Seltzer, 2007). Overall, siblings of adults with autism report less contact with their brother or sister, lower levels of positive affect in the relationship, and lower expectations for their sibling's future outcome in studies comparing the perceived quality of relationship between siblings among adults with a sibling with Down syndrome and those with a sibling with autism (Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007). These differences highlight the unique quality of the sibling relation for persons with autism.

An association between the frequency of sibling interactions in relation to the gender of siblings has also been assessed. Similar to the differences observed among children, Orsmond et al. (2009) found that the gender of both the typically developing sibling and brother or sister with autism has implications for the perceived quality of the sibling relationship in adults. Within the sibling dyads assessed, brothers of an adult sister with autism report the fewest shared interactions with sister's of a sister reporting the most shared interactions.

The trajectory of the sibling relationship may be improved by preventative measures including an emphasis on adaptive coping strategies and parental support that enhances the perceived quality of relationship between typically developing children and their brother or sister with autism. Researchers have contrasted the use of coping strategies among adolescents and adults. Problem-focused coping strategies involve the active seeing of solutions to problems or ways to reduce the effect of stressors versus emotion-focused coping strategies with which persons seeks to control or diminish the unwanted emotions associated with stressors. Adult siblings who employ the more adaptive problem-focused coping in which they determine ways to directly address the problem, rather than using avoidance, report a closer relationship with their brother or sister with autism (Orsmond & Seltzer, 2007). Among adolescents, support is provided by parents and friends. In the adult years, although significant others (e.g., partners or spouses) play the greatest role in helping the adult cope with stressors associated with their brother or sister with autism, parents continue to play a vital role (Orsmond et al., 2009). The quality of the

relationship between siblings and their adult brothers or sisters with autism is enhanced when parents are supportive (Orsmond et al., 2009).

Many young children, both anecdotally and empirically, report concerns that as adults they will shoulder the responsibility of caring for their sibling with autism when their parents are no longer able to do so. For adult siblings of individuals with autism, the necessity of maintaining their own personal and professional lives in addition to supporting their sibling with autism presents a challenge. However, increased sibling involvement is noted when the adult with autism has fewer behavioral challenges and when parents can support the relationship between siblings. Furthermore, although the frequency of interactions may decrease with the onset of adulthood, ratings of the quality of the sibling relationship do not (Orsmond & Seltzer, 2007). Even when adult siblings desire to have a role in their sibling's future, many do not want or are not able due to their own family's needs to take on all the roles and the intensity of involvement that their parents and especially their mother's play in their sibling's life. It is important for parents and siblings to talk directly and openly about the future needs of their family member with ASD and to decide which roles if any of the siblings can play.

Many parents are concerned about the impact on their typically developing children when living with a sibling with autism. Parents may find comfort in knowing that the majority of adults report that the relationship with their parents did not suffer as a result of having a sibling with autism, in fact, they state that having a sibling with autism had a positive effect on their relationship with their parents and with their mothers specifically (Orsmond & Seltzer, 2007).

Spouses of Individuals with ASD

As the population of higher functioning individuals with autism ages, a new area to consider will be the nature of the relationships and the stress and coping in spouses and children of adults with ASD. Today, older high functioning adults with autism are likely to have been diagnosed with autism as an adult. In fact, many individuals are referred as adults after a child of theirs has been diagnosed as having autism or Asperger's Syndrome. There is limited research on the spouses of individuals with ASD. With the increasing knowledge and identification of high functioning men and women, there is a growing awareness that a portion of adults with ASD do enter into long-term relationships with others (Howlin, 2003; Renty & Roeyers, 2006; Van Bourgondien & Powell, 2012). However, there is limited empirical data about the nature of these relationships. There are popular books that describe marital issues in couples where at least one partner is presumed to have autism. Some of these describe a single couple's experience (e.g., Newport & Newport, 2002), while another may describe a therapist's clinical practice where there is no diagnostic confirmation that a member of the couple does in fact have autism (Aston, 2003). Renty and Roeyers (2007) examined marital adaptation of 21 men with confirmed

diagnoses of ASD and their spouses. In all cases there was also a child with ASD in the household. The best predictor of positive adaptation for both spouses was informal support from the spouse, other family members, and friends. While the severity of ASD did not affect men with ASD's adaptation, it was inversely related to their spouses' marital adaptation. That is to say, the greater number of symptoms of ASD in the husband, the lower the wife's marital adaptation. Future studies will need to look more at the relationships of both women and men with ASD, and at the impact of having a parent with ASD on children.

Interventions for Families of Adults with ASD

There is limited research literature and very little written about interventions for families with adults with ASD. To provide a framework for future directions, we will describe the services for families of adults with autism provided by the TEACCH autism program at the University of North Carolina at Chapel Hill. The TEACCH autism program, established in 1972 by the North Carolina legislature and built upon the principle of partnering with families of individuals with autism (Schopler & Reichler, 1971), expanded its focus to include adults with autism in 1978. Including parents in the treatment process remained a core component with the adult population. In fact, the move to expand TEACCH services to address the needs of adults with autism was largely initiated by parents in the program whose children had aged into adolescence and adulthood. TEACCH shifted from its emphasis on childhood to the entire age spectrum while maintaining its commitment to the intervention principles of careful diagnosis and assessment, working with parents as co-therapists, community integration, practical information, and emotional support.

While many of the cases seen at TEACCH have received their ASD diagnoses as young children, in recent years with the expansion of the spectrum increasing numbers of adults are being referred for a diagnostic evaluation for autism or Asperger's Syndrome for the first time. Most cases have had previous diagnoses such as ADHD or any number of mental health-based conditions such as depression or an anxiety disorder. From the parent perspective (the focus of this chapter), their child, now an adult, has had a lifetime of behavioral, cognitive/learning and/or social/emotional problems with treatments based on these diagnoses. Yet, from their experience and point of view, the interventions and explanation have never quite captured the essence of their child's difficulties. Obtaining an accurate ASD diagnosis later in their adult child's life helps the family get redirected in what will hopefully be a more productive path. At the same time, parents understandably worry about the negative impact of prior misdiagnoses and the time perceived lost in treatment that did not address the core autism condition. On the other hand, most parents of adults receiving this diagnosis for the first time welcome the new information, especially

when coupled with appropriate services. They already have known that their child was not likely to live a normal life, so that expectation was abandoned well before ASD was considered. So having the correct diagnosis is viewed mainly as a new opportunity to help their adult child have a better future.

Parents are integral to the evaluation process, providing critical information about early history, a chronology of school performance and past interventions, and identifying areas of current and future concern. The adult with autism may or may not be a reliable source of information, adding even more value to the parent report. The interpretive conference is held either jointly with the adult and parents together with staff or concurrently in separate rooms, or can be a combination of both. The key to a successful conference is making sure everyone has an accurate understanding of the results and the meaning of the diagnosis as well as participating in and agreeing to a plan of action. Explaining the information in language (whether spoken or written) to the adult with ASD that makes sense requires knowledge and experience of the staff clinician. On occasion, the adult and parents may need more than one session to review the results because of the relatively complicated nature of the diagnosis (after years of operating under different assumptions), as well as the range of recommendations which takes time to process.

TEACCH provides a number of interventions, informational and support services that include parents as well as the adult with ASD. Consistent with the parents-as-co therapists' model originally developed by Eric Schopler for children, parents of adults are part of the team that focuses on the needs of the adult client. While one staff therapist is providing the adult with counseling on identified goals, another therapist meets with the parents helping with their issues of being a parent of an adult with ASD. Not every case is handled the same way; in some instances, parents meet less frequently than the adult client does. With young children in this model, parents are expected to carry out home teaching activities, teach self-help and other skills, whereas with adults, parents need to figure out where community supports can be found to provide direct service for their adult child. TEACCH's role tends to be consultative, using our knowledge of resources, navigating the family through the maze of agencies and potential opportunities and pitfalls.

There are two specialized programs which primarily serve adult clients, but involve parents. The Supported Employment program provides vocational assessments, helps the individual locate and acquire a job, and support clients in appropriate jobs, while including parents in the assessment process and remaining in contact after job placement, as needed. The Carolina Living and Learning Center is a residential–vocational program for 15 adults who function at a moderate-to-severe level of impairment. Close relationships with the parents are a high priority even though their adult children are no longer living at home.

Parents are offered support through the Parent Mentor program where the family of the newly diagnosed adult is matched with an experienced parent who has volunteered and trained to be a mentor. The Mentor, who has gone through similar life experiences, contacts the matched parent and offers to share his or her perspective,

guidance, and knowledge of resources. Like all parents of newly diagnosed children, having a peer to speak or meet with helps to offset the feeling of being alone and to validate their perceptions. For the Mentor, taking on this role is a way of "giving back" to the program as well as enhancing their sense of building community through helping others.

Support groups for parents of young children with autism are fairly common and a useful adjunct to other services. They are less common for parents of adults (as, frankly, are most services). TEACCH established such a support group close to 20 years ago in response to an unaddressed need. The Parents of Adults group meets monthly from September to June and has a topic for each session. Certain topics seem more relevant for parents whose children range in age from 18 to early 50s, for example, Estate Planning (future financial planning), Dealing with Difficult Behaviors, Finding Social Outlets for Your Adult Child with Autism, and Developing Independence.

The group structure and process involved a leader/facilitator and everyone is encouraged to speak. Members of the group have adult children with a wide range of autism, from severely intellectually impaired individuals with autism to high functioning individuals with autism. Some live in group homes or supervised apartments; others live at home. Most have jobs or work in a sheltered situation. Some of the parents have been actively involved in autism services in North Carolina since the late 1960s or early 1970s and continue to advocate for their adult child. Other parents have had a more recent diagnosis.

As with other support groups, parents attend this group for information and mutual support. Some of the information can be quite practical, such as getting the name of an attorney who can help with drawing up a will. For some parents, these meetings serve as a social opportunity, especially if their adult child continues to live at home and requires ongoing supervision. Family members, who have been parenting a child with autism for 30 or 40 years, continue to request updates on research that helps us better understand the nature of autism as well as the treatment approaches. Another benefit of this group has been the development of some services that were first discussed in the group. For example, a number of years ago the group was concerned about the lack of an appropriate day program specifically for adults with autism. Several meetings were devoted to this topic until some of the members raised the issue with the Autism Society of North Carolina. Eventually a task force was established and a program developed. Although the support group spent only a few hours on this topic, those discussions led to action and an important new service.

Parents of adolescents and adults with autism are always looking for more information that will help them better understand and to continue to guide their adult children. To meet this need, periodic workshops specifically for parents of adolescents and adults are offered on age relevant topics. Transitioning to life after school is over, sexuality, and self-determination are among the topics most requested by parents of adults.

Summary

In this chapter, we reviewed the concerns and roles of families of adults with ASDs, and the impact of the stress these responsibilities have on family members. In reviewing this information and working with families of adults, it is important to recognize that there are unique subgroups among the families of adults who carry different histories and experiences in relation to those who deliver services. Older parents whose children were first diagnosed at a time when parents were thought to be the cause of the disorder, first were blamed for the difficulties in their children and many went on to be the pioneers advocating for appropriate services for children when there were none. Many of these families were called upon once again to be pioneers and advocates for adult services as their children aged out of educational mandates. Another group are families whose children were viewed as having mental health disorders or carried no diagnosis at all as children, although they had clear difficulties both at home and at school, but, as autism has become more recognized and the spectrum expanded, they have been diagnosed as adults having ASD. This group has faced a different set of challenges and frustrations in finding services for their children. And then there are the parents of young adults whose children may have had early intervention services and relatively less difficulty throughout their child's life getting the supports and services their child needed. This group carries a different set of expectations and may actually experience a greater contrast between their previous experiences and the challenges of adult services.

Parents, siblings, and most likely spouses are affected by the long-term impact of having a family member on the autism spectrum. The research suggests that the role of families does not significantly diminish as the individual with ASD reaches adult status, and therefore issues related to stress and coping do not end or necessarily diminish. To address the needs of family members of adults, we need to start by providing quality vocational, residential, social, and recreational services for adults with autism. If funding levels decrease due to economic concerns and a push for "natural supports," those most affected are likely to be family members who experience an increase in their parenting responsibilities with age and not the expected decrease most parents experience. However, the research suggests that even when their adult with ASD does leave home, they clearly do not leave the family. Families of adults with autism continue to play a central role in supporting their son or daughter regardless of where they are on the spectrum and regardless of where they live or work. Interventions for adults with autism need to recognize the vital role that families can play in not just the transition to adult services, but in the long-term success of living and work settings. Parents of adults continue to know their children the best and as long as their health allows they are likely to be their best advocates.

Finally, family members of adults benefit from interventions and supports that are aimed at giving them both the information they need to problem solve about the issues they face as well as the support they need to positively cope with the stresses they face as a parent or sibling of someone with an ASD. As more models of adult

services are developed, the ones where professionals are sensitive to the value of family involvement and the needs of families are likely to be the most successful. With the increased awareness and services for individuals with ASD and their families, the next generation of families is more likely to have the supports they need to have a high quality of life for themselves and for their family member with autism.

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Chapter 3
Transition from High School to Adulthood for Adolescents and Young Adults with Autism Spectrum Disorders

Carol Schall, Paul Wehman, and Staci Carr

Transition from High School to Adulthood for Adolescents and Young Adults with ASD

Our society considers graduation from high school as a key turning point in the lives of young people. Not only does it mark the transition from high school into college or the workforce, but it also symbolizes the transition from adolescence to adulthood (Kline & Williams, 2007; Pyle & Wexler, 2011). For many adolescents, finishing high school marks the start of autonomous decision-making in daily life. In their path of practicing "adulthood," students use high schools and experiences associated with it as a "rite of passage experience" (Collinson & Hoffman, 1998). Students appreciate being trusted with greater responsibilities while still needing guidance from adults. Teachers, parents, and other professionals working with adolescents should encourage them to begin taking on adult responsibilities as well as providing them with guidance during this transition period (Elias, 2009). Unfortunately, far too many students do not receive an education that adequately prepares them for life after high school. Many schools focus on academic progress and pay little attention to the development of other skills that are essential for adult life. Consequently, many students leaving high school are inadequately prepared to handle adulthood (Conley et al., 2010; Floyd, Costigan, & Piazza, 2009; Kline & Williams, 2007).

C. Schall, Ph.D. (✉)
Rehabilitation Research and Training Center, Virginia Commonwealth University,
P.O. Box 842011, Richmond, VA 23284, USA

VCU Autism Center for Excellence, Virginia Commonwealth University,
P.O. Box 842011, Richmond, VA 23284, USA
e-mail: cmschall@vcu.edu

P. Wehman, Ph.D. • S. Carr, M.Ed.
Rehabilitation Research and Training Center, Virginia Commonwealth University,
P.O. Box 842011, Richmond, VA 23284, USA
e-mail: pwe2hman@mail2.vcu.edu; secarr@vcu.edu

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This is particularly true for youth and young adults with autism spectrum disorders (Schall & McDonough, 2010; Taylor & Seltzer, 2010; Wehman, Smith, & Schall, 2009). Recent reviews of outcomes for individuals with ASD through the National Longitudinal Transition Study-2 (NTLS2) have indicated that, as a group, individuals with ASD have low rates of employment, independent living, and lifelong friendships (Newman, Wagner, Cameto, & Knokey, 2009). This longitudinal study followed 11,000 transition-aged students with disabilities from 2001 to 2009. The age range of youth and young adults included in this study were between 13 and 26. This sample included 922 students with autism spectrum disorders. Outcomes recorded for this sample included the following findings (Hendricks & Wehman, 2009; Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011; Taylor & Seltzer, 2010; Wehman et al., 2009, 2012):

- 32 % of this sample attended post-secondary education of one type or another
- Only 6 % achieved competitive employment
- 21 % had no job or post-secondary education experiences at all
- 80 % continued to live with their parents
- 40 % reported having no friends
- 9 % had no form of health insurance

Taylor & Seltzer also found that, of a sample of 66 young adults with ASD, the majority attended sheltered workshops, day activity centers, or had no structured day activities at all (2010). Taken as a whole, these data indicate that, largely, individuals with ASD do not currently experience the autonomy or independence expected of youth transitioning to adulthood. On the contrary, individuals with ASD continue to be dependent on their families for providing basic needs, financial support, housing, day supervision and support, and companionship. Finally, Shattuck, et al., completed a follow-up comparison of outcomes for individuals with ASD to those identified with intellectual disabilities (ID, formerly categorized as mental retardation), speech language impairment (SLI), and learning disabilities (LD; 2012). These findings showed that individuals with ASD had poorer outcomes in employment and post-secondary education when compared with the other three disability groups. While outcomes improved over time, the ASD group still lagged behind their peers in the other three disability groups for nearly 7 years post-graduation. Specifically, at approximately 7 years post-high school graduation, 35 % of young adults with ASD had no employment or post-secondary education compared to 26 % of young adults with ID, 7 % of young adults with SLI, and 3 % of young adults with LD.

While these reported outcomes portray a bleak picture, there is evidence that individuals with ASD can learn to live, work and become contributing members of their communities (Hurlbutt & Chalmers, 2004; Schall, Target, Cortijo-Doval, & Wehman, 2006; Wehman et al., 2012; Wehman, Targett, & Richardson, 2012). Thus, it is important to understand how the characteristics of ASD affect the adolescent and the critical components of transition educational programs that result in better outcomes for individuals with ASD. In this chapter, we will review the impact of ASD on the adolescent, specifically as it relates to achieving better outcomes

upon transition from high school to higher education and work. Additionally, we will discuss transition to independence in community integration and living as well as collaboration with adult services agencies to provide the necessary supports and services to ensure better outcomes for individuals with ASD.

Critical Transition Issues for Youth and Young Adults with ASD

Consider the following scenarios describing youth with ASD.

> Daniel likes to talk about trains; including train schedules, types of train engines, changes in trains throughout history, and various train systems across the world. He likes to talk about this so much that he includes information about trains in every conversation he has. In his English class, while discussing *Romeo and Juliette*, Daniel started talking about the Trenitalia, (the Italian train system) and its schedule in Verona, Italy. Rather than being a part of the conversation, it is as if Daniel is giving a lecture about trains. His peers audibly groaned and rolled their eyes. Daniel continued to talk about Italian train schedules until the teacher stopped him.
>
> Whenever another student in his high school attempts to work with Jim in partner or team assignments, Jim turns from them and walks away while whining and flapping his hands. The other students think that Jim does not like them and, consequently, do not include him in their activities. In fact, Jim is just responding to a social interaction that is spontaneous, thus surprising and unexpected.
>
> At school, Jane overheard another student, Susan, talking about how ugly a third student, Emily's clothing was. Jane, a youth with Aspergers disorder, agreed with the assessment that the clothing was not attractive for Emily. Therefore, feeling that it was wrong to gossip about another person, Jane proceeded to tell Emily that the outfit she was wearing was unattractive on her. When Emily burst into tears at the confrontation, Jane was shocked to learn that Emily was offended by her honesty. In fact, during a meeting with her guidance counselor, Jane expressed her dismay with Emily's response. She said that she was following the 'rule of friendship' that states, 'Real friends will tell you the truth.'
>
> Justin was completing his math at his desk when his teacher stopped to observe him work the problem for a moment. He noticed that Justin was completing the problem incorrectly and said while he bent down to correct him, 'Let me help you with this one.' Justin said in a loud monotones voice, 'I am doing it right! Back off!'

In each of these three scenarios, these students are demonstrating the very characteristics of ASD that will act as a barrier to independence in employment, higher education, and community integration (Billstedt, Gillberg, & Gillberg, 2005; Hendricks & Wehman, 2009; Hurlbutt & Chalmers, 2004; Schall, Wehman, & McDonough, 2012). Specifically, in each case, these students demonstrate social communication challenges that make it difficult for them to interact with others. In fact, it is frequently social and communication challenges, more often than insistence on rituals or routines, that create challenges in the workplace.

In a school setting, these behaviors seem eccentric and perhaps annoying. In a workplace, however, these behaviors could lead to contention, disagreement, and reduced productivity among co-workers. Eventually, employers become less tolerant of such behaviors that cause a breakdown in teamwork among employees.

Employers may reduce the hours of the worker with ASD and eventually may seek to lay off such an employee. Employers view these seemingly subtle social communication errors as much more problematic in the workplace. Yet, educators may not know how to intervene to change these patterns of behavior or, even worse, may not identify these as requiring intervention at all. Consequently, it is important for researchers to identify and teach educators to implement evidence-based practices to address these social communication challenges (Schall et al., 2012).

In addition to these social communication challenges, youth and young adults with ASD are not adept at a number of coping skills that might mitigate these challenges. When Justin tells his teacher to "Back off," he is not accepting correction. When Jane tells Emily that she doesn't look good in her outfit, she is not suppressing information that should be kept private. When Daniel talks endlessly about trains, he is not attending to his listener's verbal and nonverbal cues about their interest in the topic. When Jim runs from peer interaction, he is not engaging with peers to complete assigned tasks. Educators can analyze all of these skills, break them into smaller skills, and teach them systematically to mastery and fluency. These scenarios demonstrate some of the issues that individuals with ASD face in transition to adulthood. That is, they frequently lack the social and communication skills to interact with others in collaborative work or social situations.

These primary challenges often lead to behavior problems at work or in school settings. When Justin yells, "Back off!" he may be considered difficult at work or in higher education classes. Jane's interaction with Emily may be seen as insulting or rude. When Daniel talks on and on about trains, his employer may see him as uninterested. These challenges may escalate to arguments in the workplace and, thus result in verbal or physical altercations with co-workers or employers. This is precisely the kind of issues that result in employees with ASD's suspension from work or university due to failure to follow policy. Consequently, it is critical for transition teams to address these eccentric behaviors from the perspective of future employers or professors.

Making this shift from addressing characteristics of ASD that impact the current school environment to anticipating and addressing behaviors that may become challenging in a work or university environment requires careful transition planning and shifting individualized education plan (IEP) priorities. In fact, much of the educational planning process for students with ASD tends to be deficit focused in the early years of school. Through preschool and into elementary school, IEP teams frequently review a list of missing skills or behaviors and write programs to address these deficit areas. At the point that the individual student with ASD in preparing for his or her transition to adulthood, however, the priority must shift from skills that the student cannot currently perform to skills that the individual will require in adulthood. To be specific, if a student with ASD had not mastered mathematics skills to the fourth grade level by the time he or she reaches the age of 14, it is time to move on and leave those early mathematics skills behind. Instead, the team must refocus on the math, reading, and independent skills that the student can complete in order to be successful as an employee, friend, and active community member (Wehman & Kregel, 2012). Thus, instead of teaching such a student the procedure

for long division, it is more important to teach the student the procedure for taking public transportation from one point to another. Note that we are not suggesting that the IEP teams leave all academic skill development behind. In fact, a person who is taking public transportation from one point to another has to read the schedule and signs around him or her, provide payment for the use of the transportation, maintain safety while interacting appropriately with others, and observe their community to identify their stops. All of these activities involve academic skills that are embedded in functional tasks. Thus, a key issue for transition-aged students with ASD is to embed literacy in functional skill tasks.

Consider the needs of students with ASD who are academically more able. Consider someone like Daniel or Jane. Both of these students appear to have grade level or above academic skills. Shouldn't their IEP teams continue to focus on academics and not shift the focus of their curricular activities to functional skills? In order to answer this question fully, consider again the impact of their behavior at work or in school. Would Daniel and Jane be successful in adulthood demonstrating their current array of behavior? The answer is no. Jane would eventually lose friends and alienate co-workers, while Daniel would have difficulty remaining on task. These students also require a shift of focus from academic skills to the future social and communication skills necessary to make them successful adult workers.

The major issues individuals with ASD face when transitioning from school to young adulthood are related to the nature of the disorder and its impact on social communication and interaction with others. At the same time, however, these characteristics are not immutable. With careful planning and implementation of an individualized curriculum and evidence-based practices, individuals with ASD can learn to cope with their social communication challenges and manage their own behavior. The next section will review the literature related to important skill sets that are necessary for a successful transition to work, community living, and post-secondary learning.

Pivotal Skills for Transition-Aged Students with ASD

The major issues confronting high school students with ASD then are related to their future independence at work, in university, in their community, and in their home life. ASD affects the individual in every aspect of their life. In order to increase their success in life, it is critical that parents, teachers, and adult support service providers recognize the impact of the disorder in employment, university and/or employer learning situations, community, and home settings. IEPs and other transition planning processes must include skills the person will need as he or she enters adulthood. The challenge in meeting this requirement though is that there is not one pathway to adulthood. There is not a common curriculum of skills necessary in adulthood. A person who is going to a large university will need social and communication skills unique to that setting, while another person who intends to work will need a different set of skills. However, some pivotal skill sets have been

Table 3.1 Pivotal curriculum areas for transition-aged persons with ASD

Pivotal curriculum	Definition	Skills included
Self-determination (Wehmeyer, Agran, & Hughes, 1998)	Fluency in these skills results in the ability to make choices and decisions regarding one's quality of life	Making choices Making decisions Setting goals Solving problems Advocating for self and others Instructing self Demonstrating self-awareness
Self-management (Southall & Gast, 2011)	Fluency in these skills results in the ability to monitor and adjust one's own behavior based upon the situation. It also increases one's ability to learn new behaviors and self-monitor problem behavior	Self-monitoring Self-evaluation Self-recording Self reinforcement
Independence (Wehman & Kregel, 2012)	Fluency in these skills results in the ability to manage one's own health and safety in community settings	Personal care and hygiene Transportation Banking and financial management Recreation Home living Community participation Peer relationships Health and safety
Career development (Schall & Wehman, 2009)	Fluency in these skills results in a person who is aware of and able to match personal strengths to desired careers	Career awareness Career exploration Career preparation Job placement

associated with success in adulthood. These skill sets are pivotal because, when mastered to fluency, they allow the individual to adjust to various situations and contexts. These pivotal skill sets include career awareness, self-determination, self-management, and independence. Table 3.1 provides a description of each skill set.

Skill sets such as self-determination, self-management, independence, and career development are critical curriculum areas for individuals with ASD and are discussed in the next sections.

Self-Determination and ASD

Self-determination describes a set of skills that result in an individual's ability to make life decisions and solve problems related to life goals (Wehmeyer & Powers, 2007). A person is "self-determined" when they can make their own choices and decisions, solve life problems, set goals, and implement actions to achieve those

goals (Martin & Marshall, 1995). There are impressive research findings developing around the topic of self-determination for students and adults with disabilities (Martin, Dycke, D'Ottavio, & Nickerson, 2007; Thoma, Williams, & Davis, 2005). This literature indicates that students and adults with disabilities who receive education and training in self-determination have higher academic productivity, better employment outcomes, and better problem-solving skills (Goldberg, Higgins, Raskind, & Herman, 2003; Konrad, Fowler, Walker, Test, & Wood, 2007; Wehmeyer & Powers, 2007). These findings demonstrate the importance of teaching the component skills that result in self-determination to students with disabilities (Wehmeyer, Gragouda, & Shogren, 2006).

At the same time, individuals with ASD may have difficulty mastering self-determination due to the nature of their disability. Specifically, mastery of self-determination requires the development of communication and social interaction to assure that the individual is able to self-advocate and self-direct his or her own life. These are also core deficits in ASD. The fact that these challenges are present neither diminishes nor negates the importance of self-determination in the life of a young adult with ASD. Rather, it behooves transition educators and support providers to address these deficit areas from the perspective of self-determination. That is, when teaching communication, it should be through the lens of self-determination. Educators of students of all ages can accomplish this task by teaching persons with ASD to communicate the essential functions of behavior. Rather than focusing on labeling items or objects, educators encourage self-determination when they teach students with ASD to communicate their choices, ask for help, request a break from difficult tasks or environments, and request attention from those with whom they want to interact. By focusing on these types of messages, educators support self-determination in their students.

This holds for students across the spectrum of ASD. For those with more significant communication challenges, the link between communication and self-determination is clear. For those who have Aspergers disorder, though, the same holds true. In the previous scenario where Justin told his teacher to "back off!" this may appear, on the surface to be "self-determined." Realistically though, this is a rough attempt at expressing his need for a break. He will likely find more success if he learns to monitor his behavior and express his needs in a way that draws those who would help to his cause. Improving his social communication skills would also improve his ability to become self-determined.

Self-Management

Self-management is a specific skill within the self-determination curriculum that bears special mention for individuals with ASD. All of the scenarios described above involve behavior that ranges from mildly inappropriate to fully unacceptable. While these types of behaviors may be more manageable in the context of school, they can be extremely disruptive in a workplace or community location. Thus, it is

essential that educators mindfully move from providing direct behavior support for individuals with ASD to teaching them to monitor their own behavior and access their own supports.

Self-management is an empirically based procedure that individuals with a variety of disabilities, including those with ASD, have used to change their own behavior (Cooper, Heron, & Heward, 2007; Couglin, McCoy, Kenzer, Mathur, & Zucker, 2012; Sheffield & Waller, 2010). Self-management is an effective technique to increase targeted replacement behaviors, adaptive social skills, communication skills, and school and vocational skills (Southall & Gast, 2011). When an individual is adept at self-management, they are frequently able to generalize behaviors between contexts, adjust behavior based upon situations, and develop behaviors to cope with difficult situations (Lee, Simpson, & Shogren, 2007). As Lee, Simpson and Shogren demonstrate in their meta-analysis of self-management for students with ASD, "Self-management strategies empower students to control their own behavior instead of relying on parent or teacher prompts or external interventions…" (2012, pp. 2–3). For transition-aged youth and young adults with ASD, the use of self-management is essential due to the frequent lack of access to continuous support in work, university, or community settings (Getzel & Wehman, 2005; Schall, 2010). As students enter high school, educators should rapidly move from externally cued behavior supports to self-management.

Independence in Functional Skills

Andre is a 32-year-old man who was diagnosed with Aspergers disorder at the age of 28 years old. He was seeking therapy for long-term unemployment and underemployment. Although he had successfully completed a bachelor's degree in chemical engineering, he struggled throughout his life interacting successfully with others. In fact, his peer interaction skills were so poor that he lost numerous jobs due to a failure to "work as a team player" or "get along with co-workers." Co-workers reported that Andre was rude, abrupt, disorganized, and frequently came to work disheveled without having showered or even brushed his teeth. His personality and lack of personal hygiene skills made others at work avoid him. He reported that his supervisors said he could "do the work well and was rarely, if ever, absent, but he was too offensive to other employees to be successful." Andre's story is unfortunately all too often the case for adults with ASD (Hurlbutt & Chalmers, 2004; Shogren & Plotner, 2012). His story also illustrates a little acknowledged challenge for persons with ASD. Specifically, regardless of the individuals intellectual abilities, individuals with ASD frequently struggle with every day functional skills. According to Wehman et al., functional skills are those skills that make it possible "for students to participate in current and future environments" (2012, p. 6). Andre and many others with ASD may be able to function in the structured and predictable environment of school, but struggle to function successfully in employment, relationships, or community environments. Therefore for all transition-aged students

with ASD, even for those students with ASD who have average or above average academic abilities, it is important to provide structured instruction in the essential functional skills the person will need in the next stage of life (Wehman et al., 2009).

Given the learning needs of individuals with ASD, it would be nearly impossible to teach these skills in the vacuum of high school. The rules and consequences in a school environment are contrived and do not reflect the real risk associated with problem behaviors in work and community environments. Additionally, individuals with ASD have difficulty generalizing skills between settings. Thus, all students across the ability spectrum require experiences in community, employment, and higher education environments while in high school to the degree that these experiences are a part of their vision for their future (Schall & Wehman, 2009). The best way to accomplish this is through internships in employment and dual enrollment in community college or university programs while in high school (Getzel, 2005). Some exemplary programs that offer such experiences include Project SEARCH, a community-based employment emersion model, and Mason Life and ACE-IT, integrated college experiences for young adults with intellectual disabilities including ASD (ACE-IT in College—Programs—VCU Partnership for People with Disabilities, 2012; Mason, 2010; Schall, Target, & Wehman, 2013). Programs such as these offer students the opportunity to experience work or college life while still receiving publicly funded special education services. This provides two advantages. Firstly, the students learn skills they will need in their future in the environments where those skills are needed. Secondly, special educators supporting those students learn about their skill needs in future environments. Such experiences lead to better futures planning for both the students with ASD and their IEP team (Schall, 2009).

Career Development

Career development is a lifelong process where individuals with or without disabilities discover and gradually gain skills to become employed in a chosen career. For most individuals without disabilities, this process starts as early as preschool when children pretend to work the careers of admired adults around them. Career awareness leads to career exploration through middle and early high school when youth without disabilities begin to work odd jobs and complete household chores. Finally, by high school and through post-secondary educational training youth and young adults engage in career preparation when they gain the skills necessary to obtain a job in the career of their choice (Wehman et al., 2012). For students with ASD, however, this developmental sequence from pretend play to exploration to career preparation is frequently absent (Schall & Wehman, 2009). These critical developmental experiences are missing or practiced to a lesser degree. Thus, students with ASD have difficulty identifying suitable career choices by the time they reach transition age (Seltzer, Shattuck, Abbeduto, & Greenberg, 2004).

The purpose of including career development activities in the high school curriculum is to increase the person's ability to match their strengths, preferences, and

Table 3.2 Pivotal curriculum areas and suggested educational activities

Pivotal curriculum area	Suggested educational activities
Self-determination	• Provide multiple choices across the day to teach choice-making skills • Have students set and evaluate their progress toward daily and weekly goals • Plan a daily problem (i.e., lock the classroom keys in the room, forget to bring lunch) then have the students help solve the problem • Have students volunteer to help another group in the school or community • Have students develop their own learning activities to teach others in the classroom • Assist students in identifying and keeping a log of their own strengths, preferences, and interests
Self-management	• Have students define required behaviors in various setting in the school or community • Teach students to collect data on their own behavior • Teach students to reinforce themselves when they have accomplished a difficult task or mastered skill
Independence	• Build an ample array of community activities into the school program to practice community independence • Teach students to develop a personal budget • Have students participate in school stores and after school activities to practice functional skills
Career development	• Develop a rich array of exploratory and embedded internship experiences that allow students to learn about careers • Encourage internships for all students with ASD, even college-bound students • Encourage dual enrollment in university or community college coursework for all students with ASD, even students seeking employment • Establish formal collaborative relationships with vocational rehabilitation offices and community services agencies who can provide additional opportunities for students to experience employment and community supports

interests to a chosen career path. When students with ASD graduate from high school or college without these experiences, they have a very immature understanding of work. This then may lead to repeated failures as the individual with ASD attempts to "catch-up" in their understanding of their personal strengths and match them with a desired career. By that point, the person with ASD, like Andre, has encountered so much failure at work that they are increasingly less likely to attempt employment. In order to change this pattern, educators must provide a rich array of community-based experiences to help the person with ASD learn about himself or herself as a worker and use that experience to inform their career choices. Yet again, this set of curricular experiences applies across the ability spectrum of ASD. Table 3.2 presents each of these pivotal curriculum areas with suggested experiences to support their learning.

Those knowledgeable about ASD and curricular components of educational programming may be wondering where the curricular description for communication

and social skill development is located in this discussion. In fact, each of the pivotal areas described above include significant doses of communication and social skills embedded in the related tasks. When a person with ASD learns to advocate for himself or herself, they are practicing and communicating their needs in a socially assertive manner. When a youth with autism implements a self-management program, he or she is practicing social skills to replace problem behavior. Likewise, learning community skills that will increase independence and focusing on career development activities will result in identifying essential social and communication skills to increase the person's future success at work and in his or her community.

Educators can ensure that students with ASD are college or career ready upon graduation from high school by teaching and providing rich curricular experiences in each of these four pivotal areas. While this will address much of the challenges students with ASD encounter because of their disability, it does not ensure that adequate individualization occurs in planning or implementation of the educational program. The next section will discuss the transition process and the components of an exemplary transition program for students with ASD.

Elements of Exemplary Transition Programs for Students with ASD

The previous section discussed essential curriculum elements that teach the necessary skills for success in employment and college. While these skill areas are necessary, they are not enough by themselves to increase success of young people with ASD in adulthood. In addition to an excellent series of curricular activities and experiences, an exemplary program requires a number of other elements. They include:

- Strength-based assessment and person-centered planning
- Collaboration with the person with ASD, their family, and relevant adult services agencies
- Intensive, behaviorally based teaching strategies in generalized environments

Each is described in the next sections.

Strength-Based Assessment and Person-Centered Planning

Through elementary school and middle school, educational planning for students with ASD tends to be deficit based. That is, assessments designed for students with ASD focus on deficit skills or missing developmental milestones (cf: Sundberg, 2008). While this approach may be appropriate for younger children, once the individual enters transition age, it is time to move from a deficit focus toward a futures planning focus (Schall & Wehman, 2009). Such a shift in focus frequently results in the eventual selection of a career path.

As students with ASD enter high school, it is time to focus on those skills and abilities that increases the individual's employment and college readiness (Sitlington,

Neubert, Begun, Lombard, & Leconte, 2007; Wehman, 2011). For individuals with more significant disabilities, this might mean a strong shift from an academically focused curriculum to a functional skills curriculum (Wehman & Kregel, 2012). For college-bound students, this should include dual enrollment, community and work experiences to increase the students' ability to make informed career selections (Getzel & Wehman, 2005). Thus, assessments at this age must also shift from a focus on deficits to a focus on strengths and employable skill sets. Sitlington et al. define transition assessment as "an ongoing process of collecting information on the student's strengths, needs, preferences, and interests as they relate to the demands of current and future living, learning, and working environments" (2007, pp. 2–3). Schall recommends that transition teams rely on community-based structured observations over standardized tests or interest inventories due to the challenges of individuals with ASD generalizing skills and engaging in imaginative interactions with others (Schall, 2009). Such tools would include community-based vocational assessments, community-based observations, ecological inventories, and situational assessments.

Once an assessment is complete, transition planning should focus on the use of person-centered planning processes. Person-centered planning describes a set of values and derived processes that make every effort to include persons with disabilities in life planning to mitigate barriers such as communication difficulties and self-consciousness sharing personal dreams and goals in the presence of others who may minimize them. Person-centered planning strives to assist individuals with disabilities in planning processes that lead to persons with disabilities experiencing self-directed lives. One of the goals of person-centered planning is to include the person with disabilities as a partner in planning his or her own supports and services (Sax, 2002). Some person-centered tools that have been used for this purpose include:

- Planning Alternative Tomorrows with Hope (PATH) (Forest & Pearpoint, 1992)
- Personal Futures Planning (Mount, 2000)
- Personal Lifestyle Planning (Smull, 2005)

Such tools are likely to result in a sound transition plan that results in outcome-based goals and action plans that move the team toward accountability.

Collaboration with the Person with ASD, Their Family, and Relevant Adult Services Agencies

Individuals in transition from school to adulthood also require the support and services of a wide array of adult services providers. In addition, youth with ASD in transition to adulthood required a skilled team that can help them move into the adult world of work and/or higher education (Grigal, Hart, & Migliore, 2011). In fact, involving community agencies and organization that can support individuals in transition is consistently identified as a core practice for successful transition to adulthood (Schall et al., 2012). Schall et al. note that the transition team must

include the person with ASD and their parents as well as an interdisciplinary team of individuals with a variety of skills (2013). Those skills include teaching communication and social skills, coordinating with community agencies, analyzing behavior and developing instructional and behavior support plans, connecting the individual with potential employment, and/or post-secondary education, teaching functional skills, and facilitating person/student-centered planning (Schall et al., 2013). They note that these skill sets and activities should be shared among a team of people during transition planning meetings (Schall & Wehman, 2009).

Intensive, Behaviorally Based Teaching Strategies in Generalized Environments

According to IDEA, transition planning is meant to be an outcomes-oriented process. In fact, IDEA 2004 define transition services as follows:

The term "transition services" means a coordinated set of activities for a child[1] with a disability that:

- Is 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 post-secondary education, vocational education, integrated employment (including supported employment); continuing and adult education, adult services, independent living, or community participation.
- Is based on the individual child's needs, taking into account the child's strengths, preferences, and interests.
- Includes instruction, related services, community experiences, the development of employment, and other post-school adult living objectives, and, if appropriate, acquisition of daily living skills and functional vocational evaluation [34 CFR 300.43 (a)] [20 U.S.C. 1401(34)].

By definition, high school students with or without disabilities are preparing to generalize and apply skills learned throughout their school careers to new community or higher education environments. As educational teams contemplate this process for students with ASD, it is important to consider the learning challenges faced by individuals with ASD and apply that knowledge to the transition process. Table 3.3 lists the learning challenges faced by individuals with ASD and their impact on transition to adulthood.

All of the learning characteristics described in Table 3.3 indicate the need for highly structured, intensive teaching strategies that occur in natural environments. The following strategies have been identified as evidence-based practices that would

[1] Author's note: The 2004 reauthorization of IDEA changed the term "student" to "child." Throughout this chapter, we will refer to transition aged individuals as "students" and not "children." In this case, however, we are quoting the regulations as written.

Table 3.3 Learning challenges for individuals with ASD and their impact on transition

Learning challenge	Impact on transition
Requires high frequency of learning opportunities to master skills	Individuals in transition accelerate learning and apply skills in work and educational environments. Individuals with ASD require more practice to learn and acquire skills
Difficulty generalizing skills from one environment to another	Individuals in transition must generalize skills learned in multiple settings across time to new environments. Individuals with ASD frequently require direct training in new environments to generalize skills
Requires learning to be taught precisely as it will be displayed with materials and equipment exactly as it will be used (high salience)	Individuals in transition are able to display skills across different sets of materials and equipment. Individuals with ASD frequently require a much higher "salience to stimuli" in order to become independent on acquired skills
Once skills are mastered, may need more practice and time to achieve fluency	Fluency is a critical component in work and post-secondary education (e.g., production rate). Individuals with ASD require additional practice to achieve fluency of skills

meet this criterion (Briefs/autismpdc.fpg.unc.edu, n.d.; Wehman, Schall, & McDonough, 2013):

- Modifying the environment, antecedents, or setting events to prevent the need for challenging behavior or increase the use of adaptive behavior.
- Using tablet computers or applications to teach academic, social, and communication skills.
- Indentifying the function of a specific problem behavior through the functional behavior assessment process (FBA).
- Providing cues, prompts, and instruction in natural environments to elicit and reinforce communication and social behaviors.
- Strengthening desired behaviors by providing a consequence that increases the likelihood that the behavior will occur again.
- Teaching the individual to identify, monitor, and self-reinforce desired behaviors while tracking and eliminating undesired behaviors.
- Providing practice of social skills and social interactions in a group with an adult facilitator.
- Teaching skills with many steps a few steps at a time with reinforcement following each step.
- Providing an array of information in visual formats including the daily schedule and steps to complete a task, social behaviors, communication supports, and how to transition between activities.

Finally, and perhaps most importantly, transition-aged students with ASD benefit tremendously when these practices are applied to teaching skills in natural settings

where they will be used. Thus, intensive internship experiences (i.e., Project SEARCH or through dual enrollment in university classes while still in high school), represent the final critical element in exemplary transition programs (Schall, 2010; White, Ollendick, & Bray, 2011).

This section of the chapter reviewed the characteristics of exemplary transition programs. Yet, even with all of these elements available to youth with ASD, it is likely that such individuals will struggle with transition to employment or post-secondary education. The next section of this chapter, then will discuss the exact services and supports available through adult service agencies.

Adult Services and Supports

Youth in the transition process have potential access to a variety of community training, employment, and support programs. These programs offer an array of service coordination assistance, employment services, and funding possibilities; however, they operate under different federal, state, and local laws; regulations; policies; and service arrangements. The key to a successful transition outcome is early involvement with these programs during the planning process.

Becoming fully educated about the resources and service relationships that characterize community framing, employment, and support programs available to individuals in transition is a critical first step for students, families, and transition teams. Next, team members should identify the primary community agencies and work to incorporate these programs into transition IEP. The primary case management/service coordination resource among the agencies should be identified. This role might be taken on by different agencies depending on the nature of an individual's disability and core service needs and/or local eligibility requirements. Early transition planning can help to establish these key relationships with community agencies and establish the primary and secondary-level participation needed by each to support a successful employment outcome.

State Vocational Rehabilitation Services

The Rehabilitation Act of 1973 (PL 93-112), as amended in 1998 (PL 105-220), provides federal grants for states to operate comprehensive programs of VR services for individuals with disabilities. VR is a cooperative program between state and federal governments that exists in all 50 states, the District of Columbia, and the US territories. It should be a core transition resource for youth with disabilities throughout the transition process. VR provides an array of services and supports

focusing specifically on achievement of an employment outcome, including but not limited to the following:

- Assessment for determining eligibility for VR services
- Vocational counseling, guidance, and referral services
- Vocational and other training, including on-the-job training
- Personal assistance services, including training in managing and directing a personal assistant
- Rehabilitation technology services
- Job placement services and supported employment services

A VR agency also provides direct services, such as counseling, guidance, and job placement assistance, and it will be usually arranged with other community providers to obtain services such as rehabilitation technology and supported employment. The ability of a VR agency to reach into the community for individualized services is one of its key strengths. VR agencies are well positioned to serve as the service coordination hub for employment-oriented community services for eligible youth with disabilities.

Community Rehabilitation Programs

Community rehabilitation programs (CRPs) are usually not-for-profit or for-profit private agencies that assist people with disabilities in obtaining and maintaining competitive employment. Specific services offered by providers will vary; many offer career counseling, assessments, benefits counseling, job placement, and supported employment services designed to assist individuals with disabilities to live and work in the community. Since many CRPs obtain much of their funding through contractual arrangements, access to their services can require a funding authorization from an agency such as VR.

CRPs can provide a variety of employment-related services such as assistance with exploring potential job and career options, job preparation, job development, and job placement services. Staff might assist individuals with job interview practice, job-seeking skills, resume preparation, guided job searches, and negotiations with employers. For example, perhaps an employer has an available job that includes multiple duties. Some of these duties match well to the abilities of the job applicant with a disability; others are a poor match for the applicant. The employment consultant, with the permission of the applicant, might work with the employer to negotiate a customized job carved out of the original job description that is a good match for the individual with a disability. Once the job match is completed, the employment consultant can assist with training at the job site, help the worker with a disability adjust to job demands, and provide ongoing support as needed to help maintain the job or assist with a job change.

One Stop Career Centers

The Workforce Investment Act (WIA) of 1998 (PL 105-220) created One Stop Career Centers (or "One Stop Centers") as a key employment resource in the community. The One Stop Centers have core services that are available to anyone in the community who needs help in locating employment. These core services mainly involve access to self-directed job searches through an information center that contains information on available job openings in the community. For those individuals who are eligible for more intense services through the One Stop Center, a variety of individualized services are potentially available, including access to vocational training and assistance with job placement.

Youth and young adults with disabilities are targeted for services through One Stop Centers. Therefore, One Stop Centers can serve as a significant resource for youth with disabilities and transition teams in the development of the transition plan. One Stop Center staff, such as plan managers and disability program navigators, can assist in planning employment-related services, including reaching into the community to identify and acquire other needed transition services. By design, One Stop Centers frequently serve as a home base for many community partners, such as VR and representatives of CRPs that colocate staff within the One Stop setting.

One Stop Centers have job listings identifying available employment opportunities. Information from interest inventories can help guide a job search. For individuals who need accommodations to access job information through, for example, computerized job search resources, One Stop Center workstations are frequently equipped with accessibility kits that accommodate a variety of disabilities (Gervey, Gao, & Rizzo, 2004). One Stop Centers offer job clubs, where an individual looking for employment can get support and information from peers and a group facilitator. Some One Stop Centers have employment resource staff who will represent the job interests of an individual with a disability to a potential employer and help negotiate a job opportunity (Targett, Young, Revell, Williams, & Wehman, 2007). Additional employment services of potential value to youth in transition include paid and unpaid work experiences, occupational skills training, job placement, and follow-up services after employment to help with job retention and career development. Funding for employment services through a One Stop Center occurs frequently through the center's direct links with the other community agencies that fund employment services, such as VR and CSBs.

Conclusion

As evidenced by the dismal outcomes currently experienced by transition-aged youth with ASD, the need for improved transition services that result in employment and success in post-secondary education is past due. The material in this chapter has discussed critical issues, described pivotal curriculum skills, characteristics

of exemplary programs, and essential adult services and supports. It is time now, for educators and adult services staff to implement exemplary transition services and supports for this able group of individuals.

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Chapter 4
Social Skills Training for Adolescents and Adults with Autism Spectrum Disorder

Elizabeth A. Laugeson and Ruth Ellingsen

Introduction

Deficits in social skills are the common impairment shared by all individuals on the autism spectrum, regardless of cognitive or intellectual functioning. It is widely known that individuals with autism spectrum disorder (ASD) typically have great difficulty in the social arena; in fact, Laushey and Heflin (2000) have even proposed that poor social functioning is the most profound and defining issue for individuals with ASD. While social difficulties are certainly present in childhood, adolescents and adults with ASD face increasingly complex social situations and higher expectations for social adeptness that may make their social challenges even more pronounced and profound.

Despite the pervasiveness of social deficits commonly experienced among individuals with ASD, social skills are comparatively much less studied than other aspects of ASD and research examining social skills interventions for adolescents and adults with ASD are especially rare. In a best evidence synthesis of 66 studies of social skills interventions for individuals with ASD published between 2001 and 2008, only three studies contained adolescent or adult participants (Reichow & Volkmar, 2010). Fortunately, the annual publication of peer-reviewed studies examining social skills interventions for individuals with ASD is steadily increasing (Reichow & Volkmar, 2010). Nevertheless, while progress is being made, there are several limitations in ASD social skills research that need to be considered, including areas in which to target treatment.

E.A. Laugeson (✉) • R. Ellingsen
University of California, Los Angeles, Los Angeles, CA, USA
e-mail: elaugeson@mednet.ucla.edu; RuthEllingsen@ucla.edu

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Social Deficits in Adolescents and Adults with ASD

Social deficits are typically a major source of impairment for individuals with ASD, regardless of cognitive or language ability (Carter, Davis, Klin, & Volkmar, 2005). However, the considerable heterogeneity in the level of cognitive functioning and language ability among individuals with ASD may affect the presentation of social deficits. For example, Bauminger, Shulman, and Agam (2003) found that higher-functioning adolescents initiate social interaction with peers more frequently than do their lower-functioning peers; yet, their interactions are often awkward and sometimes even intrusive or offensive. In fact, high functioning adolescents may be no less affected by social deficits than those with cognitive limitations; rather, their heightened self-awareness and false appearance of being less impaired may actually increase the severity of their social limitations and motivation, perhaps increasing the likelihood of peer rejection and neglect. Consequences of poor social skills often manifest in the form of peer rejection, peer victimization, poor social support, and isolation. Consequently, individuals with ASD generally report higher levels of loneliness and poorer quality of friendships than same aged typically developing peers (Bauminger & Kasari, 2000; Capps, Sigman, & Yirmija, 1996; Humphrey & Symes, 2010). Thus, the importance of social skills training for individuals across the spectrum cannot be underestimated.

When considering the impact and relevance of social skills training, it is important to consider the specific social deficits often shared by individuals with ASD, which contribute to poor social outcomes. Broadly, social deficits often observed across the spectrum and throughout the lifespan include poor social communication, impaired social cognition, and lack of understanding of social cues. These deficits do not appear to improve as a result of development or maturation alone (White, Keonig, & Scahill, 2007); in fact, they may increase as children with ASD enter adolescence, when the social milieu becomes more complex and demanding.

Poor social communication is often exhibited through one-sided conversational patterns, in which the individual with ASD may perseverate on specific topics of personal interest (usually restricted interests), exhibiting difficulty changing conversational topics (Elder, Caterino, Chao, Shacknai, & De Simone, 2006). This inability to carry out a bidirectional conversation and take turns in conversations (Church, Alisanski, & Amanullah, 2000; Klin & Volkmar, 2003) makes it difficult for adolescents with ASD to trade information with social partners and find common interests (Laugeson & Frankel, 2010). One consequence of this failure to identify common ground with peers is that it becomes difficult to form friendships, particularly since friendships are often based upon common interests (Laugeson & Frankel, 2010). Consequently, enhancing social communication might be considered an essential element of social skills training for individuals with ASD, particularly upon reaching adolescence when the social demand for conversational skills increases.

The tendency to be overly verbose in conversations with peers is yet another social error often exhibited by individuals with ASD (Elder et al., 2006), with

conversations typically focused on the restricted interests of the person with ASD, paying little regard to the interests of the other person. Poor speech prosody, which includes the natural rising and falling of voice pitch and inflection that occurs during speech, has also been identified as a communication deficit in individuals with ASD (Starr, Szatmari, Bryson, & Zwaigenbaum, 2003). This atypical pattern of speech can often manifest itself in the adolescent or adult with ASD sounding robotic and somewhat pedantic in their manner of talking. Parents often describe their adolescent or adult child as sounding like a robot or a computer (rather than a person), which can be rather odd and even jarring to the listener, making it difficult to interact with neurotypical peers. While atypical patterns of speech might be more appropriately addressed through speech and language therapy, one might argue that remediation of hyper-verbosity and focus on restricted interests in conversations is an appropriate and necessary element of social skills training for adolescents and adults with ASD.

Individuals with ASD are also known to think in very concrete and literal terms, which may impact their social functioning in a variety of ways. Research indicates that youth with ASD often have difficulty understanding and using humor appropriately (Winter, 2003), for example. Social challenges may include difficulty in understanding punch lines to jokes (Emerich, Creaghead, Grether, Murray, & Grasha, 2003) or telling jokes that are socially immature (Van Bourgondien & Mesibov, 1987), often with little regard to the reaction of the audience. Other forms of nonliteral language such as understanding sarcasm, analogies, metaphors, and figurative use of language have also been shown to be problematic for those with ASD (Kerbel & Grunwell, 1998; Starr et al., 2003). Therefore, targeted interventions to teach social skills to adolescents and adults with ASD might address the appropriate use of humor, while avoiding the use of figurative language during instruction.

Impaired social cognition, also known as Theory of Mind, is another hallmark feature of ASD and often includes difficulties in expressing emotions, understanding the feelings of others, and empathizing (Baron-Cohen, 1995; Frith, 2004; Klin & Volkmar, 2003; Krasny, Williams, Provencal, & Ozonoff, 2003; Travis & Sigman, 1998), as well as an overall lack of understanding of social causality (Baron-Cohen, Leslie, & Frith, 1985). Such deficits make it very difficult to make sense of or predict the behavior of others. Consequently, incorporating perspective taking into social skills training is critical to improving social cognition.

Lack of understanding of social cues is another hallmark feature of ASD and manifests in many ways, including difficulty understanding the value and meaning of nonverbal elements of social interaction (Volkmar & Klin, 1998). For example, the use of social touch, gestures, and eye contact are often impaired in adolescents with ASD. Inability to interpret these social cues, assess the formality of social events, and act accordingly also appears to be in deficit (Griffin, Griffin, Fitch, Albera, & Gingras, 2006). Thus, social skills training programs would do well to include the interpretation of nonverbal forms of communication as a target of intervention.

Although most social skills training programs tend to focus on children with ASD (and to a lesser extent on adolescents), deficits in social communication, social cognition, and understanding of social cues remain prevalent for adults with ASD and may even exacerbate, leading to problems with friendships, romantic relationships, skills of daily living, and vocational success (Barnhill, 2007; Howlin, 2000). Although research suggests that social and behavioral symptoms may improve with some consistency in children and adolescents with ASD (Shattuck et al., 2007), this progress tends to slow as these individuals enter adulthood (Taylor & Seltzner, 2010). In fact social challenges specific to ASD may be greatest upon entering adulthood, possibly due to the greater salience and complexity of peer relationships, growing drive toward identity exploration, lack of availability and knowledge about appropriate services, and uncertainty about the balance of responsibility between the individuals themselves and those who support them (Tantam, 2003). Accordingly, adults with ASD often present with more depression and anxiety than their adolescent counterparts (Shtayermann, 2007). Interestingly, higher-functioning adults with greater intelligence and less autistic symptomatology tend to experience more depression, anxiety, social isolation, withdrawal, and peer victimization (Shtayermann, 2007; Sterling, Dawson, Estes, & Greenson, 2008) than lower-functioning individuals. This may be due in part to greater social expectations often placed on higher-functioning adults occurring as a result of placement in less protective and more inclusive settings. With higher-functioning adults with ASD often giving the appearance of seeming more "odd" than disabled by their peers, these individuals may be more susceptible to peer rejection, and consequently greater negative socioemotional outcomes like depression and anxiety. Furthermore, greater self-awareness about peer rejection and "differentness" more likely found in higher-functioning adults with ASD may also contribute to greater depression and anxiety (Sterling et al., 2008). Although outcomes for higher-functioning adults may be less optimistic, research does suggest that having good social skills and adequate social support relate to better quality of life in adults with ASD (Jennes-Coussens, Magill-Evans, & Koning, 2006; Wing, 1983). Thus, the need for effective social skills training programs is of great importance for this highly vulnerable population.

Having good social skills may not only improve quality of life and lessen the risk of depression and anxiety, good social functioning may also predict the ability to form romantic relationships for individuals with ASD, whose romantic functioning generally compares unfavorably to neurotypical peers (Stokes, Newton, & Kaur, 2007). Even though individuals with ASD report sharing similar interests in forming intimate relationships as typically developing individuals, those with ASD often lack the social skills knowledge and competence to appropriately pursue and engage in successful romantic relationships (Mehzabin & Stokes, 2011). For example, individuals with ASD have been known to naively behave in an intrusive manner with potential romantic partners, which may even be perceived as stalking behavior (Stokes et al., 2007). Consequently, instruction in appropriate dating behavior would be an important treatment priority for adults and older adolescents receiving social skills training.

Social Skills Interventions for Adolescents and Adults with ASD

Given the pervasive social deficits seen among adolescents and adults with ASD, it is not surprising that social skills training is an increasingly popular method of treatment for this population. Although typically developing individuals often learn basic rules of social etiquette through observation of peers and/or through instruction from parents in nonclinical settings (Gralinski & Kopp, 1993; Rubin & Sloman, 1984), adolescents and adults with ASD often require additional support and assistance.

Before examining the growing literature base in social skills training for adolescents and adults with ASD, perhaps it is wise to explain why there is such a desperate need for effective social skills interventions. Social skills are an important component of an individual's behavior, affecting multiple areas of functioning. Orsmond, Krauss, and Selzter (2004) found that adolescents and adults with ASD who possessed well-developed social skills were more likely to participate in various social and recreational activities; the benefit of which includes access to peers and potential friends. The development and maintenance of friendships should not be undervalued. Having one or two close friends may positively impact later adjustment, buffer the impact of stressful life events (Miller & Ingham, 1976), improve self-esteem, and decrease anxious and depressive symptoms (Buhrmester, 1990). On the other hand, poor interpersonal skills are linked with academic and occupational difficulties, rejection by peers, delinquency, early withdrawal from school, and later mental health and adjustment problems (Buhrmester, 1990; Howlin & Goode, 1998; Myles, Bock, & Simpson, 2001; Tantam, 2003). Despite their apparent social difficulties, individuals with ASD often desire friendships and even express concern about their peer relationships (Church et al., 2000), which typically lack closeness and security, often leading to extreme loneliness (Bauminger & Kasari, 2000). Thus, there is a great need for adolescents and adults with ASD to learn the skills necessary for developing and maintaining relationships and to build the social competence required to function successfully in broader social contexts. Given that adolescents and adults with ASD typically desire social interactions, but are lacking the appropriate proficiency, training in appropriate social skills is a logical and necessary approach.

While social skills training has been utilized for decades and is not a particularly unique or novel treatment for individuals with ASD, the research literature suggests that these approaches have not been tremendously effective in improving the social functioning of individuals on the autism spectrum (Rao, Beidel, & Murray, 2008; White et al., 2007). However, certain empirically supported methods of treatment delivery have been identified, which may lead to more successful treatment outcomes. Targeting interventions to focus on common social deficits shared among individuals with ASD, while using evidence-based methods of social skills instruction, may make intervention more effective with this population. Treatment focusing on areas such as social communication, social cognition, friendship skills,

understanding social cues, and strategies for handling peer rejection and conflict would fill a large gap. Within these targeted areas, crucial skills for adolescents and adults with ASD might include:

- Reciprocity in conversations in order to develop meaningful relationships and maintain gainful employment.
- Promoting skills to expand the individual's social network.
- Abating the effects of the individual's negative reputation within the current peer group through instruction in the rules of social etiquette.
- Instructing how to promote more successful peer interactions leading to higher quality relationships.
- Avoiding continuing provocation from peers by improving the individual's competence at handling peer rejection and conflict.
- Enhancing the individual's understanding of verbal and nonverbal social cues through behavioral feedback.
- Teaching perspective taking to improve social cognition and emotion recognition.
- Improving emotion regulation in order to more effectively handle social conflict, frustration, and rejection.

While these are just a few of the targeted areas in which social skills instruction might be focused, the level of functioning, cognitive abilities, and treatment goals of the individuals must also be considered when identifying an appropriate social skills program. Above all else, the skills that are taught through social skills instruction should be relevant to the population being served, and the skills must be ecologically valid.

Ecologically valid social skills are those behaviors that are naturally exhibited by socially accepted adolescents or adults in a given social context. Far too often, social skills instruction includes rules of social etiquette deemed appropriate by adults, clinicians, or researchers, rather than those rules established by the dominant peer group. The problem with this method of social skills instruction is that if the goal is for the adolescent or adult to be accepted by the dominant peer group, teaching the wrong set of social behaviors is futile and ineffective. For example, consider the strategies often taught for handling verbal bullying. What do most adults tell adolescents to do in response to teasing? In our clinical experience, the vast majority of adolescents will say they are told to ignore the person, walk away, or tell an adult. However, if you ask adolescents whether these strategies work, they will often say they do not. Perhaps this is because these strategies are not ecologically valid. Instead, socially accepted teens will often take a very different tactic toward handling verbal teasing. This tactic typically involves giving a short comeback that suggests that what the teaser said did not bother them (Laugeson & Frankel, 2010). For example, the adolescent being teased might respond by saying, "Whatever" or "Anyway" or "Yeah, and?" or "Am I supposed to care?" or any other number of comments that show the teaser they were unaffected. This ecologically valid approach makes the teasing less fun for the teaser and thus, less reinforcing. Consequently, because the teaser finds the experience of teasing less enjoyable, he

or she will be less likely to target this individual after repeated failure to elicit the desired response. This strategy for handling verbal bullying is a good example of the importance of teaching ecologically valid skills during social skills instruction. Teaching strategies for handling challenging social situations simply because the skills "appear" to be appropriate is less likely to result in positive social outcomes. Instead, teaching social skills naturally utilized by socially accepted individuals will be more likely to lead to improved social functioning and peer acceptance.

An example of teaching ecologically valid social skills relevant to adults with ASD relates to handling peer pressure. If you were to ask adults with ASD what they are typically told to do in response to peer pressure, they might say they have been told to *just say no*; a popular catch phrase from the 1980s anti-drug movement, but not particularly ecologically valid. Anecdotally, if you were to inquire as to how adults with ASD often respond to peer pressure, they will often report a tendency to *police* the person offering the unwanted pressure. For example, they might point out the illegality of offering alcohol to a minor, or taking drugs without a prescription. Even worse, they might accept unwanted offers of peer pressure out of naiveté or lack of effective strategies for turning down such offers. Furthermore, instances of peer pressure might actually result in the termination of a friendship, or the gaining of a bad reputation among the peer group. Thus, *just saying no*, *policing*, or accepting unwanted offers are not particularly effective or ecologically valid social skills for handling peer pressure. Instead, if you were to observe the social skills exhibited by socially savvy youth when confronted with peer pressure, you would find a variety of far more effective strategies that would not necessarily result in the termination of a friendship or the acquisition of a bad reputation. For example, effective strategies for declining alcohol or drugs might include (Gantman, Kapp, Orenski, & Laugeson, 2012): making an excuse (e.g., "I have to get up early tomorrow," or "Alcohol makes me feel sick," or "I have to drive," or "My work does random drug testing"); stalling (e.g., "Maybe later," or "Maybe another time"); or in cases of extreme and persistent pressure, reversing the peer pressure (e.g., "Why do you care so much if I drink?").

The bottom line is that whatever skills are targeted for treatment, social skills training programs must be adapted to include instruction in ecologically valid social skills. The practice of therapists designing their own curriculum based on their own personal beliefs about what good social skills should include are not likely to lead to positive outcomes. If the goal is to teach socially motivated adolescents and adults with ASD how to interact effectively in a neurotypical world, then understanding the ecologically valid social customs of the dominant peer group is essential.

Effective Treatment Delivery Methods for Teaching Social Skills

The social deficits that characterize adolescents and adults with ASD should not only influence which skills are taught, but *how* they are taught. Research suggests

that there are several key ingredients needed to successfully teach social skills. Effective treatment delivery methods for teaching social skills include:

- Behavioral modeling and role-playing demonstrations.
- Behavioral rehearsal exercises in which the participants practice newly learned skills.
- Coaching with performance feedback in a small-group setting.
- Use of social stories and scripts.
- Use of multimedia software.
- Video modeling and video self-modeling.
- Self-monitoring and self-management.

Behavioral Modeling and Role-Playing Demonstrations

One critical component to social skills training includes the use of behavioral modeling, or role-playing demonstrations. This method involves acting out certain targeted behaviors. For example, adults with ASD receiving instruction about strategies for handling peer pressure would more successfully synthesize this information by visually observing these tactics in action either in person by two social coaches, or by watching a video demonstration of these strategies (video modeling). This method of instruction is particularly important in social skills training as it brings life to the lesson being taught; making concepts that might be viewed as theoretical or conceptual, more real and concrete.

Behavioral Rehearsal Using Coaching with Performance Feedback

Another important approach to teaching social skills involves the use of behavioral rehearsal with performance feedback through coaching. It is recommended that adolescents and adults with ASD practice newly learned social skills with peer mentors or other group members before practicing these skills outside of the treatment setting. For example, in the case of peer pressure, adults would surely benefit from rehearsal of this newly learned skill in the protective setting of a social skills group, while receiving feedback from trained coaches on their application of the strategies during teachable moments.

There are multiple benefits to in-group behavioral rehearsal. For one, the individual can practice the new skill in a comfortable and supportive environment, thus easing the initial anxiety of using the skill outside of the group setting. Also, it is important for group facilitators to witness the individual's understanding of and ability to implement the skills they have been taught to avoid misunderstanding or misuse of newly learned skills. Providing performance feedback through coaching during sessions is crucial to troubleshoot difficulty with acquisition and application

of skills. Having multiple trainers or coaches in the group to prompt the individual and provide feedback is useful in ensuring that the adolescent or adult does not become dependent on any one person to provide social cues (White, 2011). Given that adolescents and adults with ASD have likely experienced fewer successes in their social lives, it can also be helpful to set up behavioral rehearsals early in the intervention that will guarantee at least some degree of achievement (White, 2011).

Social Stories and Scripts

Another popular method for teaching social skills to younger children with ASD involves the use of social stories. This technique involves describing a social situation or concept in terms of relevant social cues, perspectives, and common responses in a specifically defined style and format (Gray & Garand, 1993). The goal of social stories is not necessarily to change the individual's behavior, but to improve understanding of events and social expectations, which may lead to more effective responses (Gray & Garand, 1993; Swaggart et al., 1995). While social stories are frequently used in social skills interventions for younger children with ASD, the utility of these approaches is fairly unknown for adolescents and adults with ASD. A review of social skills interventions by Reichow and Volkmar (2010) suggested that these visual supports can be effective methods for enhancing social skills in preschool and school-aged children, but the utility of using these approaches with older individuals with ASD is unknown. Thus, more research needs to be conducted on the use of these techniques with adolescents and adults on the autism spectrum.

Multi-Media Software

Scientists are beginning to discover new ways to mesh advances in technology with the implementation and delivery of social skills treatment. For example, Golan and Baron-Cohen (2006) evaluated an interactive systematic guide to emotions, called *Mind Reading* for its effectiveness in teaching adults with ASD to recognize complex emotions in faces and voices. The multi-media software explores over 400 emotions through the use of video clip demonstrations delivered by a wide range of people, along with definitions and stories for each emotion. Results showed that following 10–20 h of software use over a period of 10–15 weeks, users significantly improved their ability to recognize complex emotions and mental states from both faces and voices. While improvement following the intervention was limited to faces and voices taken from the *Mind Reading* software, and not tasks of distant generalization, researchers suggest that longer exposure to the software might increase generalization (Golan & Baron-Cohen, 2006). This research illustrates the potential benefit of teaching particular aspects of social skills through augmentative interventions using multi-media software or other technology-based approaches.

Video Modeling and Video Self-Modeling

While the use of video modeling as a type of intervention for younger children with ASD is becoming more popular as it is easy to incorporate into existing social skills interventions, the benefit of using this approach with older adolescents and adults is still unknown. Video modeling is a form of observational learning in which targeted behaviors are learned by watching a video demonstration and then imitating the behavior of the model. For instance, using the peer pressure example, the adult with ASD might watch a video of a person successfully handling peer pressure, then practice the skill in an imitative manner. Similarly, video self-modeling involves individuals observing themselves performing a targeted behavior successfully on video, and then imitating the targeted behavior. Although a review of video modeling research by Bellini and Akullian (2007) found this type of intervention to be most effective in teaching adaptive skills, they also noted some evidence for targeting social communication and problem behaviors. While visually based learning strategies used in video modeling may be more easily understood by individuals with ASD than material that is presented verbally (Buggey, 2005; Hodgdon, 1995; Quill, 1997), the true benefit and generalization of these strategies with adolescents and adults with ASD is uncertain as video modeling studies are often conducted using single subject designs, resulting in very small sample sizes. Moreover, the use of video modeling and video self-modeling has not been widely tested with older adolescents and adults with ASD. Therefore, assumptions regarding generalization of findings to the broader ASD population (particularly older individuals on the spectrum) are limited, and additional research on these interventions is warranted.

Self-Monitoring and Self-Management

Several studies have shown self-monitoring to be efficacious in increasing social skills in children and adolescents with autism (Koegel, Koegel, Hurley, & Frea, 1992; Morrison, Kamps, Garcia, & Parker, 2001; Newman, Reinecke, & Meinberg, 2000; Strain, Kohler, Storey, & Danko, 1994), though little is known about the efficacy of using this method with adults with ASD. Self-monitoring involves teaching a person to recognize a target behavior and notice and record its occurrence or lack thereof (Kamps & Tankersley, 1996), while self-management involves techniques to modify one's own behavior. For instance, using the strategy identified for handling verbal bullying, the individual might observe and record the frequency and manner in which they handle teasing (self-monitoring), while adapting their teasing strategies to fit the ecologically valid tactic of giving a brief comeback that reflects lack of upset (self-management). Research suggests that self-monitoring followed by self-management can increase independence in individuals with ASD because this method does not rely on continued assistance from parents, educators, and

professionals (Hume, Loftin, & Lantz, 2009). While initial findings for self-monitoring and self-management are encouraging for younger individuals with ASD, the benefit of this method may have limited applicability to a wider range of functioning in that it may be best suited to those with greater self-awareness, as well as higher intellectual abilities.

Other Considerations for Treatment Delivery and Format

Other key features thought to enhance treatment outcome for adolescents and adults with ASD include the use of evidence-based treatment manuals, didactic instruction presented using concrete rules and steps of social behavior, in vivo socialization homework assignments, and structured involvement of parents, caregivers, peer coaches, and/or teachers in treatment (Gantman et al., 2012; Laugeson, Frankel, Gantman, Dillon, & Mogil, 2012; Laugeson, Frankel, Mogil, & Dillon, 2009; White et al., 2007). Yet, the heterogeneity among individuals with ASD, specifically in levels of cognitive functioning, should always be a factor when considering how treatment is to be delivered. Approaches used to teach adolescents and adults with significant cognitive and verbal limitations may require intensive prompting, augmentative communication devices, visually based teaching strategies, and tangible reinforcers. Approaches tailored to higher-functioning adolescents and adults, on the other hand, will likely include verbally mediated strategies, instructor modeling, and self-reinforcement.

Use of evidence-based treatment manuals. The use of evidence-based treatment manuals may help to ensure that adolescents and adults in community settings achieve comparable treatment gains as research participants upon which the evidence is based. Using treatment manuals may also help to standardize interventions, although actual treatment delivery may still vary (Smith et al., 2007). Measurements of treatment fidelity or adherence to original guidelines for delivering the intervention are commonly not reported in ASD treatment research, and may be particularly important for interventions delivered by parents or less experienced or credentialed mental health professionals (Matson, 2007). To minimize variation in treatment delivery, protocols should be in place to ensure treatment fidelity. For example, clinicians might receive training on a particular intervention until they have achieved reliability in their delivery of the intervention. However, this option may not be feasible due to the extensive time and financial costs involved in training clinicians. Perhaps a more practical option for maintaining treatment fidelity would be to have an assistant or coach monitor a checklist of targeted points to be covered during delivery of treatment sessions to ensure that all elements are covered. As long as treatment fidelity is maintained, the use of evidence-based treatment manuals is helpful toward effective dissemination and replication of empirically supported treatments in community settings.

Duration of intervention. Some social skills training interventions involve instruction over a short period of time, such as a couple of weeks, while other time-limited training programs involve instruction for 3–6 months or more. On-going social skills instruction with no predetermined time line is also a popular method of treatment delivery in the community, but has not been studied thoroughly thus far. Little is known about the advantage or disadvantage of time-limited approaches to social skills instruction, but due to the constraints of managed healthcare, it is likely that time-limited social skills interventions for adolescents and adults with ASD will be more widespread and commonplace in the future. Whatever the case may be, duration of intervention is an important consideration to make when designing the format of a social skills intervention, and should be based upon the needs of the individuals under consideration, as well as the aims of the program.

Small group format. Group instruction is an intuitive method for social skills training, as it allows the opportunity to interact with and practice newly learned social skills with peers. Of course, there are several considerations that should be made before conducting group social skills training. First, group facilitators should have a shared understanding of each group member's history and specific needs. This is necessary in order to develop a sense of group cohesion and support. Perhaps most important is considering the level of functioning, including language ability, maturity level, and amount and degree of inappropriate behavior. Heterogeneity of the group should be limited in order to aid learning and group cohesion (White, 2011). Even with these considerations, it is likely that the facilitator will have to deal with some disruption from group members; therefore, a small group size (7–10 group members) is ideal for being able to troubleshoot these issues when they arise. It is further suggested that social skills groups for adolescents and adults only include those members who are motivated to participate in treatment (Laugeson & Frankel, 2010), thereby improving the likelihood of success and reducing the negative impact of treatment resistance and negative group contagion.

Another important consideration when forming social skills groups relates to the gender and age range of the group members. Although gender and age of group members ought to be considered when forming groups, it may be difficult to create groups with equal gender balance given that many more males than females are diagnosed with ASD. Furthermore, the interests of adolescent girls and boys can sometimes be very different, and there is some evidence to suggest that being the only girl in a group for adolescents with ASD can be an uncomfortable and isolating experience (Barnhill, Cook, Tebbenkanmp, & Myles, 2002). However, assuming the facilitator is mindful of gender differences, it still may be useful to have a mixed-gender group, since this reflects the natural setting for most adolescents and adults outside of the treatment setting (White, 2011). It is also helpful to keep the age range of group members as homogenous as possible, with particular attention paid to the context of the social setting. For example, segregating groups based on school or work setting (i.e., middle school, high school, college, or work) would be more advantageous than creating groups based on a specific age range. A 10-year-old boy in grade school and an 11-year-old boy in middle school may share less in common than 11- and 14-year-old boys both attending middle school.

Given the fact that many adolescents and adults with ASD have a history of peer rejection, an environment that provides support and caring among group members and facilitators is particularly important for any social skills intervention for individuals with ASD (White, 2011), and another reason to teach social skills in a group format. Although it should be noted, a group format is not always the most appropriate setting for adolescents and adults who exhibit severe maladaptive behaviors (e.g., severe anxiety, unprovoked aggression) that could make interacting with group members aversive or unsafe (White, 2011).

Didactic instruction. The use of structured lesson plans to teach social skills using concrete rules and steps of social behavior is also key to the development and successful implementation of an effective social skills program. Structured lesson plans ensure that a core set of skills will be taught. Many community-based social skills programs attempt to teach social skills through "process groups" in which individuals are asked to give a recount of their week, while therapists and other group members attempt to troubleshoot potential problems and brainstorm how to behave in a more socially constructive manner. The benefit of these types of process groups is unknown, but the risk of possibly failing to teach a core set of skills necessary to function adaptively in the social world may outweigh any benefits. The use of structured didactic lessons is recommended to ensure that some predetermined core set of skills in learned.

Additionally, when providing social skills instruction to adolescents and adults with ASD, it is important to consider the unique manner in which information is processed. For example, individuals with ASD typically think in very concrete and literal terms. Therefore, it is essential that when providing social skills instruction, didactic lessons be presented using concrete rules and steps of social etiquette, while avoiding the use of metaphors, analogies and other forms of figurative language, which those with ASD often struggle to comprehend (Kerbel & Grunwell, 1998; Starr et al., 2003). This manner of teaching will enhance comprehension of complicated abstract social behaviors in a more easy to understand way. For example, consider how one might teach strategies for entering a conversation. The steps involved in conversational peer entry are complicated and difficult to untangle from abstract thought, particularly for adolescents or adults with ASD. However, when broken down into concrete steps, this complex social behavior becomes more manageable. The three basic steps involved in conversational peer entry include: watch/listen, wait, and join (Laugeson & Frankel, 2010). First, we watch and listen to the conversation. This step involves listening to the conversation to determine what the group is talking about and whether we share a common interest, while watching inconspicuously from a short distance and making periodic casual eye-contact. Second, we wait for a brief pause in the conversation or some sign of receptiveness from the group. This step helps us to avoid being intrusive during peer entry and allows for a more natural and unobtrusive entrance into the conversation. Third, we join the conversation by moving closer and making a comment or asking a question that is on topic. This step involves *joining* the conversation by adding to it, rather than hijacking the conversation by being off-topic. While this sophisticated social behavior related to peer entry might seem abstract at first, when broken down to

its concrete parts, it becomes quite manageable for the individual with ASD, and provides a good example of the necessity for teaching social skills using concrete rules and steps during didactic instruction.

Parent or caregiver-assisted interventions. Parents and caregivers (e.g., grandparents, aunts/uncles, adult siblings, job coaches) can have significant effects upon acquisition of social skills for adolescents and adults with ASD, both in terms of direct instruction and supervision, as well as supporting the development of an appropriate peer network (Gantman et al., 2012; Laugeson et al., 2012; Laugeson et al., 2009). The use of a parent-assisted (also known as parent-mediated) model for social skills training was first introduced by Frankel and Myatt (2003) through the Children's Friendship Training Program (CFT), which has been shown to be effective in improving friendship skills for elementary-aged children with ASD (Frankel et al., 2010). The effectiveness of using parent/caregiver-assistance has also been demonstrated for adolescents and young adults through the Program for the Education and Enrichment of Relational Skills (PEERS; Laugeson & Frankel, 2010), an evidence-based social skills intervention, targeting friendship and relationship skills for individuals with ASD (Laugeson et al., 2012; Gantman et al., 2012, Laugeson et al., 2009).

Parent or caregiver involvement in treatment may be crucial to help adolescents and adults with ASD improve their social skills (Orsmond et al., 2004), as these individuals are often quite dependent on their parents or other caregivers for support. As an example, PEERS incorporates significant parental or caregiver involvement to ensure practice and generalization of social skills outside of the treatment setting. Parents and caregivers assist and monitor adolescents or adults in their completion of weekly homework assignments to practice using social skills taught during previous treatment sessions. Parents and caregivers are also taught to act as social coaches to adolescents and adults when appropriate in order to promote the generalization of skills to other settings such as the home and community. Involvement of parents and caregivers in the intervention is also critical to the expansion or enhancement of a peer social network. Parents and caregivers are taught to work with the adolescent or adult on identifying appropriate extracurricular activities and social hobbies where they might meet potential friends with common interests (Laugeson & Frankel, 2010). Findings from clinical research trials with adolescents and young adults reveal significant gains in social skills across raters and settings, as well as increased frequency of social interactions in adolescent and adult participants (Gantman et al., 2012, Laugeson et al. 2009, 2012). Results of follow-up assessments further revealed maintenance of treatment gains at least 14 weeks after the completion of treatment (Laugeson et al., 2012) and as long as 1–5 years post-intervention (Mandelberg et al., 2014), strongly supporting the use of parents and caregivers in treatment.

While findings from parent and caregiver-assisted interventions are encouraging and suggest generalization of skills and maintenance of treatment gains where others do not, few social skills interventions incorporate a parent or caregiver component. Yet parents and caregivers are arguably the one factor in an adolescent's or adult's life that will remain consistent across time.

School-based interventions. The use of school-based social skills interventions is not uncommon; in fact, many school districts require instruction in social skills through Individualized Education Plans (IEPs) for students with special needs, like those with ASD. Despite the widespread use of school-based social skills instruction, the effectiveness of this approach has been tested very little. Most social skills interventions provided in the schools are taught by speech and language pathologists, special education teachers, and school psychologists, many of whom develop their own programs based on an amalgam of existing interventions. Lack of adherence to evidence-based treatments is most likely due to short supply of empirically supported school-based curricula. However, the use of evidence-based social skills interventions in the school setting has been studied to a limited extent and has been shown to be effective for middle and high school adolescents with ASD (Laugeson, 2014). The notion that teachers can effectively teach social skills in the classroom, much like teaching math or science, is a novel approach, but is slowly gaining research evidence (Laugeson, Ellingsen, Bates, & Sanderson, 2013). The use of teachers as social skills facilitators may be a nice alternative to traditional social skills interventions as this method of treatment delivery has the capacity to reach a greater number of adolescents with ASD, while teaching social skills in a more natural social environment.

Peer-mediated interventions. While peer-mediated interventions have been used for preschool and school-aged children with ASD (Reichow & Volkmar, 2010), there is little evidence supporting the effectiveness of using this method for adolescents or adults. However, given the promising results from younger children with ASD (Reichow & Volkmar, 2010), peer involvement in social skills interventions for adolescents and adults with ASD may be helpful in teaching, modeling, and reinforcing age-appropriate skills. For example, White, Koenig, and Scahill (2010) implemented a social skills intervention for adolescents with a peer tutor component. Peer tutors would perform such tasks as modeling specific social skills and engaging group members as they practiced the newly learned skill. Results indicate that the intervention was helpful for some participants, but the improvement was not consistent across group members. While these early findings are encouraging, efficacy for peer-mediated social skills interventions should be further evaluated for adolescents and adults with ASD in larger randomized controlled trials (RCTs).

Socialization homework assignments. One of the common criticisms of social skills training programs is that the skills taught do not generalize to other settings. To facilitate generalization of newly learned skills, adolescents and adults should be assigned in vivo homework between sessions to practice the skills outside of the treatment setting. For example, in the case of conversational peer entry, the individual with ASD might be given a homework assignment to practice the steps for peer entry (i.e., watch/listen, wait, join) in a more natural environment like school or work. A portion of each session (ideally at the beginning) should also be used to review the completion of homework assignments and troubleshoot any issues that may have come up. Homework review is also a nice opportunity to individualize the treatment to the specific needs of the adolescent or adult with ASD (Laugeson & Frankel, 2010); therefore, considerable time should be allotted for reviewing these assignments.

Limitations of Social Skills Training Interventions

While social skills training has increasingly become a popular method for helping individuals with ASD adapt to their social environment (Laugeson et al., 2012; Attwood, 2000, 2003; Gantman et al., 2012; Krasny et al., 2003, Laugeson et al., 2009; Myles et al., 2001; Tse, Strulovitch, Tagalakis, Meng, & Fombonne, 2007), a review of the research literature suggests there are very few evidence-based social skills interventions for adolescents and adults with ASD (White et al., 2007). With emphasis on early intervention, most social skills treatment studies have targeted younger children on the autism spectrum, with few clinical research trials focusing on adolescents or adults with ASD. Among the limited number of social skills intervention studies conducted with this population, most have not been formally tested in terms of their efficacy in improving social competence or the development of close friendships, nor do they examine the maintenance of treatment gains months or years after the intervention has ended.

Studies investigating the effectiveness of social skills training for individuals with ASD indicate that intervention during adolescence is critical; however, much of the literature on social skills training for youth with ASD has been far from encouraging. In a review of the social skills treatment literature, White et al. (2007) identified 14 studies that used group-based social skills training for children and adolescents with ASD. Among these studies, only one used a randomized control group design (Provencal, 2003), two identified the use of a manualized treatment (Barnhill et al., 2002; Webb, Miller, Pierce, Strawser, & Jones, 2004), and only four focused on adolescents 12 years of age or older (Barnhill et al., 2002; Mesibov, 1984; Provencal, 2003; Webb et al., 2004). None of these studies examined the maintenance or trajectory of improvement in social competency over time, nor did they use parent-assisted or peer-mediated models of social skills instruction to improve outcome.

Even fewer studies have focused on social skills treatment for adults with ASD. To date, only three published studies appear to have tested the effectiveness of a social skills intervention for adults with ASD. Turner-Brown, Perry, Dichter, Bodfish, and Penn (2008) implemented a program developed for adults with psychotic disorders to perform social cognition and interaction training with a group of adults with ASD ages 25–55. The intervention improved participant's social cognition, but not social functioning. Hillier, Fish, Coppert, and Beversdorf (2007) reported that only empathy improved after an 8-week social and vocational program for young adults. Only one intervention study for adults with ASD used a RCT design and found significant improvement in overall social and psychosocial functioning post-intervention (Gantman et al., 2012).

Problems with Defining Social Skills

In reviewing the existing research literature on social skills interventions for individuals with ASD, the difficulty in comparing the efficacy of one intervention to another quickly becomes apparent. Each of the many different groups of

professionals within the mental health field (i.e., psychologists, psychiatrists, psychiatric and pediatric nurses, speech and language pathologists, etc.) may espouse different theoretical orientations and approaches to social skills training, with different goals or frames of reference. Even within a single discipline, such as psychology, researchers may differ significantly according to the specific social skills that are targeted, the method for teaching the selected skills, the measurement of skill attainment, as well as many other factors.

Perhaps the most notable difficulty in comparing one social skills intervention to another is the lack of a common definition of social skills. Although it is widely accepted that a core feature of ASD includes deficits in social interaction and social communication, scientists continue to debate which particular social abilities are impacted in individuals with ASD and which of these social deficits is most debilitating. This has resulted in social skills training interventions targeting a wide range of skills, including initiating social communication and speech, recognizing emotions and/or facial expressions, providing empathic responses, developing friendships, and many more.

Since social skills are quite broad and can range from ordering a meal in a restaurant to developing meaningful and long-lasting reciprocal relationships, providing a definition of targeted social skills is fundamental and primary to any treatment study or clinical intervention. One would imagine that prior to treatment a particular set of social skills would be chosen and targeted for intervention based on the needs of the individuals being served; however, research studies and clinical programs often fail to explain why a particular set of social skills were targeted in a given intervention, and in many cases even fail to specify what these skills include. This not only complicates the identification of treatment goals and priorities, but also compounds the difficulty in properly measuring treatment success in social skills training.

Problems Assessing Treatment Outcome

The method of measuring treatment outcome can vary greatly from one study or clinical program to another. Treatment outcome may involve collecting quantitative measures, such as frequency ratings of a particular behavior, or standard scores on various psychometric assessments, or qualitative assessments, which seek to uncover more in-depth understanding of treatment outcome (often used in single-case designs). Few interventions use valid and reliable standardized assessment measures to evaluate treatment efficacy.

One commonly cited problem with assessments aimed at measuring social functioning is that they tend to be rather subjective. To combat this criticism, more objective methods of measurement might include observational behavior data taken by raters who are blind to research conditions. The use of objective tests using standardized measures of social functioning that include norm-referenced scores, which allow the researcher to compare the scores of a given participant to a larger population, might also be used. Examples of standardized measures of social functioning

include the Social Skills Rating System (SSRS; Gresham & Elliott, 1990), the Social Skills Improvement System (SSIS; Gresham & Elliott, 2008), which is the updated version of the SSRS, and the Social Responsiveness Scale (SRS; Constantino, 2005), which is an autism screening questionnaire that includes assessment of several social domains. Arguably, a good battery of social skills treatment outcome measures should involve a combination of standardized and behavioral ratings from a variety of reporters, including independent rater who are blind to the conditions under investigation (i.e., do not know whether the adolescent or adult is receiving treatment).

Another method of assessing social functioning involves measures of social validity. This includes information regarding how typically developing peers perform in relation to the experimental group following treatment (Matson, 2007). Social validity can be achieved by testing typically developing adolescents or adults on the same target behaviors during post-test assessment, or by calculating the percentage of individuals in the experimental group who score in the "typical" or "normal" range during post-test assessment (Matson, 2007). Although an interesting and useful form of information gathering, researchers often neglect to include measures of social validity in treatment intervention studies.

Another consideration in the assessment of social skills treatment outcome relates to choice in raters. Just as with the measurements themselves, the raters chosen to report treatment outcome can be quite varied. Raters might include the adolescent or adult participants themselves, parents, caregivers, teachers, clinicians, peers, members of the research team, or any combination of others. While no one particular rater is best, the difficulty with including adolescent or adult participants in the measurement of treatment outcome is that there is no guarantee the participant will be a good reporter or free from bias. The dilemma with including parents, caregivers, teachers, clinicians, or peers in the assessment of treatment outcome is that they may be less sensitive to the immediate changes in the social functioning of the adolescent or adult. The problem with including members of the research team in measuring treatment outcome is that experimenter expectations may bias the findings. One way to remedy these difficulties is to include multiple raters in the assessment process.

Although the use of multiple raters would seem to be a logical choice to address some of the issues surrounding the assessment of social skills treatment outcome, few studies use multiple raters to assess treatment efficacy. Among those that do, consistency across raters is often poor, complicating the clinical picture. A recent study showed that although parents and teachers showed moderate agreement on overall social skills rating scores for individuals with ASD, they often rated the individuals differently on specific items, suggesting that certain social skills may be exhibited differently according to the context (Murray, Ruble, Willis, & Molloy, 2009). Although research clearly supports the use of certain standardized instruments with a single rater, such as the SRS (Constantino, 2005), many researchers agree that a more complete picture of an individual's social functioning can be achieved with multiple raters (Rapin, 1999).

Another form of assessment in social skills intervention studies involves the use of blind raters (i.e., those who are unaware of the conditions under investigation). When raters are blind to the treatment condition (control versus treatment), there is a reduced chance of collecting biased ratings. Although it may not be feasible to have parents or caregivers of individuals participating in social skills interventions blind to the treatment condition, researchers coding target behaviors and other individuals (e.g., teachers, peers) who observe the individual's social functioning may represent an unbiased and perhaps more accurate picture of the adolescent or adult if they are kept blind to treatment conditions.

Lack of Randomized Controlled Trials

The use of RCTs is an essential ingredient to testing the efficacy or effectiveness of an intervention. The key distinguishing feature of a RCT is that participants are randomly assigned to receive one or other of a particular treatment after being assessed for eligibility. Method of random assignment varies, but conceptually, the process is like flipping a coin. After randomization, participants are treated in the same manner, the only difference being the treatment they receive. The benefit of using RCTs in the evaluation of treatment outcome is that they minimize selection bias, promote the comparison of equivalent groups, and allow the researcher to examine the true benefit of an intervention with fewer confounding variables. Within the ASD treatment research literature, there is a particular need for more RCTs of social skills interventions. Only 4 of the 14 studies White et al. (2007) included in their review employed a RCT with a control group. In a similar review of social skills training interventions for children and adolescents with ASD, Rao et al. (2008) found that 9 out of 10 reviewed studies did not use a RCT as their research design.

Poor Generalization of Treatment Findings

Another factor that should be considered when evaluating social skills training interventions is generalizability, which is the extent to which the findings from a given study can be generalized to a larger population. Regrettably, most social skills intervention studies are limited in their ability to generalize research findings to other settings and other populations of adolescents and adults with ASD. Two of the biggest offenders to generalization relate to sample size and participant characteristics. Most social skills training intervention studies for adolescents and adults with ASD have small sample sizes (often single-case designs), which may include a very heterogeneous group of individuals with developmental disabilities. The problem with using single-case designs is that it becomes difficult to generalize findings to a larger population; yet, single-case experimental designs with approximately three

or four participants appear to be the most common research design employed within social skills training studies. Consequently, group research designs with larger sample sizes and well-characterized populations are recommended to better assess treatment efficacy and improve generalizability (Matson, Matson, & Rivet, 2007).

Lack of Maintenance of Treatment Gains

Whether or not targeted social skills are adequately maintained over time is another important consideration for social skills training. Assessment of maintenance of skill acquisition is rarely targeted in treatment studies or clinical programs, calling into question how beneficial these programs are over time. A recent study investigating the maintenance of treatment gains for high-functioning adolescents with ASD found that teens receiving the PEERS intervention maintained positive outcomes in the areas of social responsiveness and social skills, frequency of peer interactions, and social skills knowledge 1–5 years post-treatment (Mandelberg et al., 2014). While these findings are promising for maintenance of treatment gains in an intervention utilizing parent-assistance, little is known about the social trajectories of adolescents and adults following other types of social skills treatment.

Conclusions

While deficits in social skills are clearly a hallmark feature of ASD, affecting individuals across the spectrum and throughout the lifespan, literature examining the effectiveness of social skills interventions for adolescents and adults with ASD is relatively limited and not particularly promising thus far. While the field has a long way to go before we can definitively recommend certain interventions over others, there do appear to be effective treatment components and strategies that enhance treatment benefit, which might be utilized with this population. These treatment components include: behavioral modeling or role-playing demonstrations; behavioral rehearsal exercises; coaching with performance feedback in a small-group setting; social stories or scripts; the use of multimedia software; video modeling or video self-modeling; and self-monitoring or self-management.

In order to clarify and build upon limited positive results, recommendations for future researchers conducting social skills intervention studies for adolescents and adults with ASD include: the use of randomized controlled trails as the standard for examining the efficacy and effectiveness of social skills interventions; assessment of treatment outcome using a combination of standardized outcome measures and behavioral observations with multiple independent raters; and long-term follow-up assessment to examine the maintenance of treatment gains over time.

In conclusion, as the empirical support for social skills training for adolescents and adults with ASD slowly develops, the need for evidence-based treatments for

this growing population increases exponentially. With nearly 70 % of currently identified individuals with ASD under the age of 14 (Gerhardt & Lainer, 2011) and soon to enter adolescence, the demand for effective social skills interventions for adolescents and adults has never been greater.

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Chapter 5
Romantic Relationships, Sexuality, and Autism Spectrum Disorders

Lynn Kern Koegel, Whitney J. Detar, Amanda Fox, and Robert L. Koegel

Introduction

Romantic relationships and sexual behaviors among individuals with autism spectrum disorders (ASDs) are complicated matters and involve many personal issues including emotions, values, attitudes, and beliefs—all of which can change constantly in response to interactions, experiences, and education (Koller, 2000). Further, other issues, such as living conditions (e.g., independent vs. residential), extent of symptom severity, and level of communication and socialization may also play a role in relationships and sexuality (Mehzabin & Stokes, 2011). In regard to education and general knowledge, sex education materials and instruction for individuals with autism differ greatly from those provided for typically developing students, with individuals with disabilities receiving far lower levels of support in this area. While almost all parents of individuals with disabilities favor comprehensive sex education for their adolescent/adult children, very few individuals with disabilities receive any type of formal sex education (Koller, 2000), and furthermore, most teachers do not feel confident in their ability to provide sex education to students with ASD (Kalyva, 2010). Logically, then, without education and the communicative skills to gain social support from and interact with peers, individuals with ASD may have more difficulties with relationships and sexuality. The literature also suggests that they demonstrate more challenges with a wide variety of sexuality-related issues, including their bodily changes during puberty, privacy rules and customs, and masturbation. Further, adolescents and adults with ASD have far fewer sexual experiences than their typically developing peers, despite their expressed sexual interest (Hellemans, Roeyers, Leplae, Dewaele, & Deboutte, 2010). Despite these

L.K. Koegel (✉) • W.J. Detar • A. Fox • R.L. Koegel
University of California, Santa Barbara, Santa Barbara, CA, USA
e-mail: lynnk@education.ucsb.edu; wjsmith@education.ucsb.edu; afox@education.ucsb.edu; koegel@education.ucsb.edu

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issues and concerns, there is a paucity of research, literature, and education relating to romance and sexuality in individuals with ASDs, and while the desire for intimate and sexual relationships may be similar to individuals without ASDs, attitudes and practice in this population appear to differ. This chapter will discuss issues related to romance and sexuality in individuals with ASDs.

Privacy Issues and Masturbation

Despite the commonality of sexual behavior in adolescents and adults with ASD, the growth of sex drive that typically occurs during puberty is not accompanied by a corresponding growth in the field of social "know-how" and this can lead to inappropriate behavior (Gabriels & Van Bourgondien, 2007; Gillberg & Coleman, 1992). Adolescents and adults with ASD display more inappropriate sexual behaviors than their peers. For example, without intervention, they may engage in fewer privacy behaviors (such as not seeking privacy for undressing and masturbating), have poorer knowledge regarding privacy rules (such as knocking rather than entering closed doors and not touching oneself in public), and engage in inappropriate socio-sexual behaviors (such as speaking about sexual activities in public) more frequently than their typical peers (Stokes & Kaur, 2005). Masturbation is the most common form of sexual behavior in individuals with ASD, and many studies report inappropriate masturbation behaviors to be common in this population, such as engaging in masturbation in public locations (Hellemans, Colson, Verbraeken, Vermeiren, & Deboutte, 2006; Ruble & Dalrymple, 1993; Van Bourgondien, Reichle, & Palmer, 1997).

Mutual Satisfaction

Another issue related to the sexuality of individuals with ASD is the degree to which the individual with autism is able to engage in a relationship that is mutually satisfying to both partners. In one study, among male adolescents and adults that caressed or cuddled others, approximately one-third reported that they did not care whether or not the other person enjoyed this (Hellemans et al., 2010). Similarly, other researchers have found little overlap in the percentage of individuals with ASD that displayed sexual behavior and the percentage that took into account whether the other person wanted the sexual behavior (Hellemans et al., 2006). Further, of the approximately 17 % of the individuals with ASD that displayed sexual touching, none of them verbally expressed that they cared whether it was enjoyed by the other person (Stokes & Kaur, 2005). It is unclear whether individuals with autism actually care but merely cannot express their feelings well, or if they lack the education to fully understand the physical and psychosocial issues that create a mutually satisfying relationship. In any case, such verbal reports should raise concern.

These types of sexuality issues can greatly impact the family, and research shows that parental concerns are greater for parents of individuals with ASD in comparison to parents of typically developing adolescents (Stokes & Kaur, 2005). Thus, there is a significant and unmet need to address relationship and sexuality issues with students and adults with ASDs.

Victimization and Safety

Another issue that has been discussed in the literature relates to sex crimes, particularly against women with disabilities. While females with ASD are less likely to engage in heterosexual relationships than males with ASD or typically developing males and females, and a greater number report being asexual (Gilmour, Schalomon, & Smith, 2012), an area that cannot be overlooked relates to the fact that individuals with ASD may be at greater risk for victimization (Sobsey & Doe, 1991). This may occur for several reasons. First, these individuals are often considered "perfect victims" because they often have limited communication and therefore may not be able to verbalize experiences of victimization. Second, it is difficult for family members, friends and even professionals to recognize reactions of physical and emotional torment, instead often attributing these reactions to stereotypical or disruptive behaviors. Similarly, psychological symptoms such as acute anxiety, depression, and post-traumatic stress disorder are often overlooked and mistakenly attributed to typical behaviors exhibited by individuals with ASDs. An additional complication that increases risk of victimization in this population is that perceptions of sexual experiences may be very different in individuals with autism and developmental disabilities than those of a typical individual.

In Goodman, Koss, Fitzgerald, Russo, and Keita's (1993) integrative analysis of the most prominent prevalence studies in the field, findings suggest that between 21 and 34 % of women in the United States will be physically assaulted—slapped, kicked, beaten, choked, threatened or attacked with a weapon. Between 14 and 25 % of adult women have endured rape according to its legal definition, which includes acts involving non-consensual sexual penetration obtained by physical force, by threat of bodily harm, or when the victim is incapable of giving consent by virtue of mental illness, intellectual disability, or intoxication (Koss, 1993). These rates of violence against women in the general population probably represent marked underestimates. As Browne (1993) points out, national surveys of violence typically do not include all groups in their samples. Groups not included in the surveys may consist of women who are hospitalized, homeless, or institutionalized, among others. These groups, who are potentially at the highest risk—are typically underrepresented. Presently, there is a gap in existing research regarding prevalence of sexual abuse among individuals with ASD. Due to methodological flaws in sampling and identification practices, it is difficult to obtain accurate rates of prevalence within this group of individuals. However, current research has sought to address this problem through several recent studies that focus on the prevention of sexual abuse and assessment and interventions designed specifically for individuals with disabilities.

Communication and Social Issues

Further adding to the difficulties in addressing this area is that evidence suggests that individuals with autism and developmental disabilities may perceive and/or exhibit emotions in a different manner than is typical. Although it is difficult to assess whether the individuals with ASD actually perceive things differently, or if they merely express them differently because of a communication difficulty, the literature does frequently report different emotional responses from individuals with ASD. For example, Losh and Capps (2006) examined emotional experience in autism through a discourse analytic framework in an effort to identify children's strategies for interpreting emotional versus non-emotional encounters. Participants included 50 children (aged 7–13) 28 of whom were described as "high-functioning" individuals with autism and 22 who were typically developing comparison peers. Children were given a list of simple emotions, complex emotions, and complex, self-conscious emotions, as well as two non-emotions that were presented in random order. The children were asked to provide a definition of each and to tell the experimenter about a time when they experienced each emotion. The children's accounts were analyzed for thematic content and discourse structure. Results indicated that "high-functioning" children with autism were able to discuss contextually appropriate accounts of simple emotions. However, their strategies for interpreting all types of emotional (but not non-emotional) experiences differed from those used by typically developing children. "High-functioning" children with autism were less inclined to organize their emotional accounts in personalized, causal, explanatory frameworks and displayed a tendency to describe visually salient elements of experiences. This was seldom observed among the comparison group. However, "high-functioning" children with autism did produce accounts comparable in length to those of typically developing children. These findings may suggest that children with autism produce less coherent representations of emotional experiences and may use alternative strategies for interpreting emotionally evocative encounters. Despite their apparent ability to distinguish appropriate contexts for the expression of simple emotions, children with autism's script-like emotional accounts, lacking reference to the causes of their emotions, have caused some to question the children's depth of understanding of all types of emotional experiences. Also evident in responses was the overall impoverished structure of their emotional accounts relative to those of comparison children. Again, it is difficult to know how much of these differences are due to the general communication difficulties that are symptomatic of individuals with ASD. Whatever the reason, such results suggest it is likely that such individuals may be especially vulnerable to inappropriate sexual encounters and victimization.

Historically, research has provided some insight into the feelings and coping behaviors of typically developing individuals who have experienced victimization. According to Frieze, Hymer, and Greenberg (1987) typical emotional responses include a loss of a sense of self, a loss of feeling safe, and feelings of inequity or injustice. As part of the healing process, the typical victim tries to understand

how and why a criminal would have violated them and considers how he or she (the victim) may have contributed to the criminal's action. Redefining the victimization experience as occurring for some other purpose is one common, useful coping mechanism. Another reaction is to blame oneself. Given that difficulty with communication may accompany ASD, it may be more challenging for these individuals to report and discuss their experiences and employ valuable coping strategies after victimization has occurred.

Bullying

Other types of victimization include bullying or peer harassment, and because victimization is often more difficult to identify in individuals with autism and developmental disabilities, it is important to recognize the domains in which this population may be most vulnerable. Individuals with ASD exhibit impairments in the social realm. These challenges may put them at greater risk of victimization by peers and adults in social domains. Youth on the autism spectrum seek friendships and relationships, however, this is juxtaposed with difficulties in understanding the subtleties and nuances of social interaction. Unfortunately, this may make them easy targets for ridicule. Humphrey and Lewis (2008) conducted a qualitative study of the views and experiences of 20 students on the autism spectrum who were fully included in mainstream classrooms in four secondary schools. Data were collected through semi-structured interviews and student diaries. Results indicated that social naivety exhibited in the sample appeared to be frequently used for exploitative purposes by other students. According to Norwich and Kely (2004), students with special educational needs are more likely to be bullied than other students. However, it may be argued that the difficulties in communication and interaction experienced by those with ASD place them at an even higher risk for bullying and harassment than other students. Furthermore, these individuals may lack strategies to help them overcome the problems associated with being bullied, and the thought of school, itself, can become distressing (Tantam, 2000). Left unidentified or unaddressed, these experiences may produce a negative cycle in which students experience increasing levels of social isolation (Bauminger & Kasari, 2000).

Technology

As the world becomes more technically advanced, this arena may also present interesting challenges for individuals with ASD. For example, although some individuals with autism may prefer the computerized aspects of social networking, face-to face social interactions can be difficult. These challenges are compounded by the impersonal nature of social networking, where many visible social cues are absent and communication may be more nuanced and difficult to interpret.

Due to recent concerns about possible social networking victimization, several organizations have developed social networking sites specifically for individuals with ASD, which may provide a promising venue for members of the autism community to share insights, opinions, information and engage in social relationships in a more protected manner.

Sex Education

Individuals with autism and developmental disabilities are at increased risk of sexual abuse due to several factors. As discussed earlier, having difficulties with communication makes these individuals more vulnerable to sexual abuse. Secondly, individuals with autism and developmental disabilities are often denied the opportunity to learn about and explore their sexuality. This subject has been wrought with controversy. Some argue that while these individuals have the right to learn about sexuality, others conjecture that this poses risks to both the individuals involved and to society in general. The philosophy of inclusive practice has brought a corresponding increase in social opportunities with peers and the general public. Despite the positive strides these changes have created, they can also be problematic and bring potential risks (Tissot, 2009), particularly in situations where proper supervision and education are not provided. Failing to provide these individuals with opportunities to learn about appropriate and responsible sexuality puts them at greater risk for victimization. For example, many adult individuals with ASD are placed in the care of others for long hours, or may reside in residential facilities. Ideally, these settings provide respite for families and promote independent living skills. However, if not carefully monitored, these settings can provide an environment that facilitates victimization of vulnerable individuals. Again, difficulties in social and communication areas may make it difficult for individuals with ASD to understand and report inappropriate behaviors.

There are, however, some programs that may be helpful in improving the gap in sex education for individuals with various disabilities that may prove to be helpful for individuals with ASD. For example, Hughes et al. (2010) evaluated the effectiveness of a safety awareness program for women with disabilities. The sample included seven women with diverse disabilities (aged 41–58) involved in a community site. Baseline and post-intervention questionnaires were administered to the women who completed *A Safety Awareness Program* (ASAP: A Program for Women). The intervention consisted of eight interactive sessions emphasizing violence-free relationships, respect for personal choice, healing from violence, and empowerment of people with disabilities, and was designed to increase protective factors. Outcome measures included self-efficacy, safety skills, social support/isolation, and safety-promoting behaviors. The results indicated that women who completed the program showed significant increases from baseline to post-intervention on measures of self-efficacy and safety skills. Although this pilot study suffered

from a number of limitations, including a small sample size, the findings suggest that participation in a safety awareness program may improve protective factors and knowledge of safety, which may be an effective means of violence prevention for this population.

In another computer-based program, Robinson-Whelen et al. (2010) sought to investigate the efficacy of abuse and safety assessment interventions. The aim of this study was to evaluate the effects of the *Safer and Stronger Program* (SSP). This computer-based, disability-specific assessment tool was designed to provide an accessible and anonymous method for women with disabilities to self-screen for inter-personal violence by disclosing their exposure to abuse, describing the characteristics of their primary perpetrator, and reporting their use of safety promoting behaviors. The SSP integrates audio and video vignettes of four interpersonal survivors who describe their abuse and survival experiences, offer affirming messages, identify warning signs, and discuss safety-promoting strategies. The sample included 305 women (aged 38–63) with disabilities and used a randomized control group design. The intervention group completed the assessment intervention both at Time 1 and again, 3 months later at Time 2; the control group completed the assessment intervention only once, at Time 2. Analyses compared intervention and control groups at Time 2 and evaluated change over time in intervention group participants. Results indicated that the intervention group had greater abuse awareness than the control group at Time 2, and abuse awareness increased from Time 1 to Time 2 among women in the intervention group, particularly among women who had experienced little or no abuse in the past year. Both abuse awareness and safety self-efficacy were significantly related to safety behaviors. These findings suggest that computerized programs, such as SSP may offer promise as a non-threatening method of conducting abuse assessments among women with disabilities while also serving as an intervention to enhance abuse awareness.

As a whole, the literature suggests that despite advancements in detecting victimization in individuals with autism and developmental disabilities and a few educational programs, we are still faced with the challenges in providing appropriate evidence-based treatments. Again, treatment of sex abuse in individuals with autism and developmental disabilities differs markedly than that of typically developing individuals. Adapted therapy approaches and adapted sexual abuse treatments may be necessary for people with developmental disabilities. Adapted therapy techniques are similar to conventional therapeutic approaches but require that a practitioner adapt the techniques to the person's level of understanding, communication, development, and social adaptability. Individuals with ASD often have challenges with social areas and communication, and these complications may need to be addressed through creative solutions and repeated, targeted interventions. Individuals with ASD may have additional concerns and confusion about their sexuality and their dependency on others may exacerbate fears of retaliation and abandonment. Practitioners need to be aware of the impact of these combined issues for individuals with ASD and recognize that treatment may be more complex than for individuals without developmental disabilities.

Availability of Interventions

In an effort to inform treatment for individuals with autism and developmental disabilities, Mansell, Sobsey, and Calder (1992) conducted a survey of 119 sexual abuse victims with developmental disabilities. Their responses indicated that sexual abuse treatment services for people with developmental disabilities are typically inaccessible, unavailable, and inappropriate. Inadequate treatment services appear to be due to the paucity of qualified professionals in the area of sexual abuse and developmental disabilities, coupled with the slow development of appropriate sexual abuse treatment approaches.

Dating and Sexual/Relationship Satisfaction

In addition to interventions relating to safety and abuse, the particular impairments in individuals with ASD often necessitate specific considerations when designing interventions to address general sexuality issues. In fact, Nichols and Byers (2008) found that participants who were older and had fewer ASD symptoms reported better sexual functioning. Specifically, individuals with fewer ASD symptoms reported greater sexual satisfaction, sexual self-esteem, assertiveness, arousability, and desire. They also reported fewer sexual problems and less anxiety surrounding sexual issues. As such, a sizable population of individuals with ASD is capable of having a satisfying sex life. Research also suggests that intervention to reduce ASD symptoms may result in collateral gains in appropriate sexual functioning and satisfaction.

It is interesting to speculate as to whether pivotal areas could be targeted that would produce widespread gains in sexual functioning and satisfaction in the population with ASD. An impairment in social interaction is a core symptom of ASD (American Psychiatric Association, 2000) and can impact social communication, friendship-making, dating, relationship-building, as well as sexuality. These deficiencies can lead to a decrease in social relationships (Howlin, 2000; Jobe & White, 2007), an increase in loneliness (Howlin, 2000; Jobe & White, 2007), an increase in social isolation, and poor quality friendships (Bauminger & Kasari, 2000; Frea, 1995; Mesibov, Shea, & Adams, 2001; Stewart, Barnard, Pearson, Hasan, & O'Brien, 2006; Strain & Schwartz, 2001). Furthermore, co-morbid diagnoses of other mental disorders are common among this population. Individuals with Asperger's are 5.7 times more likely to develop symptoms of depression in comparison to the typically developing population (McHale, Dariotis, & Kauh, 2003; Stewart et al., 2006). The literature suggests that most individuals with ASDs show a desire for relationships, but experience loneliness because their difficulties with social skills often interfere with friendship formation (Howlin, 2000; Jennes-Coussens, Magill-Evans, & Koning, 2006; Jobe & White, 2007; Jones & Meldal, 2001). Related, a study by Jennes-Coussens et al. (2006) regarding the relationships

of individuals diagnosed with "high-functioning" autism or Asperger's syndrome found that social difficulties were the main reason cited for a lack of success in developing intimate relationships. Furthermore, in a study of "high-functioning" individuals with autism, more than 56 % had never experienced a sexual relationship and only 25 % had dated (Szatmari, Bartolucci, Bremner, Bond, & Rich, 1989). Sadly, a study by Hellemans et al. (2006) reported that approximately half of the individuals with ASD had expressed a need for a relationship and about 21 % of those expressed frustration about not being able to establish or maintain one. Thus, as a whole, studies repeatedly show that although individuals with ASD desire intimate relationships, few actually have them.

Social Communication

An impairment in social communication, including deficits in non-verbal skills, present in ASD (American Psychiatric Association, 2000) must be taken into account when designing interventions to target appropriate sexuality for this population. Specifically, a deficit in interpreting non-verbal social cues may lead to broad misunderstandings. The meanings and appropriateness of body language should be explicitly taught. For example, Emmers and Dindia (1995) demonstrated that physical touch can convey closeness and affection, and individuals with ASD may need to be explicitly taught where, when, and with whom this type of closeness and affection is appropriate. In teaching these skills, individuals with ASD may be able to avoid the negative consequences of misinterpreted inappropriate touch.

Since a sexual relationship is a primary goal in dating for both genders (Clark, Shaver, & Abrahams, 1999; McDaniel, 2005; Mongeau, Jacobsen, & Donnerstein, 2007; Mongeau, Serewicz, & Therrien, 2004; Roscoe, Diana, & Brooks, 1987), professionals and researchers can address appropriate sexual expression in the context of dating interventions for adults with ASD; however, there is a lack of research studies focusing exclusively on improving dating skills in adolescents or adults with ASD. This suggests that we are far from a systematic understanding of the needs regarding dating and sexuality of individuals with ASD. Adding to this challenge is the problem that the topic is generally taboo in our culture. In fact, many researchers have found myths about people with disabilities and their experiences with sexuality to be common (DeMyer, 1979; Dewey & Everard, 1974; Kaufman, Silverberg, & Odette, 2005; Sullivan & Caterino, 2008). For example, many commonly held myths suggest that people with disabilities are not sexual, not desirable, do not need sex education, and have more important things to worry about than sexuality. However, the literature on this topic clearly suggests otherwise.

Despite these myths, a few researchers are focusing on trying to address these issues. For example, Sullivan and Caterino (2008) assert: "We acknowledge that individuals with ASD, and all other disabilities regardless of severity, have a basic right to a sexual life and intimate relationships. As such, we hold that appropriate sexuality education is necessary to promote healthy socio-sexual functioning"

(p. 382). The Sexuality Information and Education Council of the United States (SIECUS) declare in their position statements:

> SIECUS believes that individuals with physical, cognitive, or emotional disabilities have a right to education about sexuality, sexual health care, and opportunities for socializing and sexual expression. Healthcare workers and other caregivers must receive comprehensive sexuality education, as well as training in understanding and supporting sexual development, behavior, and related healthcare for individuals with disabilities. The policies and procedures of social agencies and healthcare delivery systems should ensure that services and benefits are provided to all persons without discrimination because of disability (2009).

Despite the lag in the research on sexuality in individuals with ASD, these positions suggest that all individuals have a basic right to sexuality and appropriate sex education. Again, further research is desperately needed in order to determine the best methods for sex education for the population with ASD that will best promote sexual functioning and satisfaction.

Perhaps sex education programs for individuals with ASD should be informed by the current literature on the effectiveness of sex education programs with typical adolescents. First, abstinence-only sex education has been shown to be ineffective in reducing risky behavior (Underhill, Montgomery, & Operario, 2007). In contrast, a national data set from the Centers for Disease Control and Prevention (CDC) National Center for Health Statistics (Kohler, Manhart, & Lafferty, 2008) suggest that adolescents who received comprehensive sex education were significantly less likely to become pregnant in their teens and marginally less likely to initiate intercourse. Furthermore, despite common beliefs, the researchers concluded that education about contraception does not increase adolescent sexual activity.

The SIECUS states that comprehensive sex education should be "appropriate to students' age, developmental level, and cultural background" and provide "medically accurate information, recognize the diversity of values and beliefs represented in the community, and complement and augment the sexuality education children receive from their families, religious and community groups, and healthcare professionals" (SIECUS, 2009). Sex education programs for individuals with ASD may benefit from using components from these effective, comprehensive sexual education programs that provide in-depth information about sexuality, but are also tailored to each individual student's unique communicative and developmental level.

Materials for sex education programs for this population may need to be developed, as there are very few programs that specifically focus on sex education for adolescents and adults with ASD. Sullivan and Caterino (2008) identified a few programs that exist, including the Treatment and Education of Autistic and related-Communication Handicapped Children (TEACCH) program, which focuses on teaching sex education in a developmental sequence based on cognitive functioning of the individual. The levels include information on appropriate sexual behaviors, personal hygiene, sexual anatomy and functioning, and developing social relationships (Schopler, 1997; Sullivan & Caterino, 2008). Also, the Devereux Centers designed a sex education curriculum covering "body parts and function, social/sexual behavior, sexual life-cycle, dating, marriage, parenting, establishing relationships, abuse awareness, boundary issues, assertiveness, and self-esteem" (Koller,

2000; Sullivan & Caterino, 2008, p. 387). These programs are designed to provide comprehensive sex education for adolescents and adults with ASD, yet systematic measures of their effectiveness have not yet been conducted. A third program, the Benhaven School focuses on self-care and appropriate behaviors, yet masturbation is not considered acceptable (Koller, 2000; Sullivan & Caterino, 2008) in spite of its usual inclusion in most sex education programs. Overall, research is lacking on major issues in sex education, and there is a fundamental and essential need to determine the best methods and curriculum for effective and beneficial sex education for individuals with ASD.

Coordinated and Comprehensive Sex Education

As mentioned above, sex education programs in school or other community settings should be coordinated with home education programs. Preliminary data have been collected on two sex education programs for individuals with ASD that intend to increase comfort of parents and teens in talking about sexuality (Roth & Nichols, 2008; Tetenbaum, Nichols, Blakeley-Smith, Hepburn, & Reaven, 2008). The program by Roth and Nichols (2008) focused on both increasing adolescents and their parents' comfort levels in discussing sexuality and helping teens achieve individualized goals related to sexuality. Topics included changes to expect in puberty, hygiene, appropriate boundaries and personal rights, the difference between public and private behavior, masturbation, friendship, attraction, dating, bullying, safety skills, and preparing for the future (Roth & Nichols, 2008). Teaching was multimodal and included group discussion, role playing, video viewing, clinician demonstration, and social stories. Preliminary results indicate that the program was effective in increasing teens' and parents' comfort in talking about sexual issues. Tetenbaum et al. (2008) conducted a parent education program that intended to increase the parent's comfort independent of their teen children with ASD. The program featured group teaching using visual supports, incidental teaching, role plays, and in vivo and video modeling. Preliminary results indicate that the program was effective in increasing parental comfort in discussing sexuality, puberty, and growing up with their children. While these studies did not measure the teens' actual use of appropriate sexual behaviors, further studies are more likely to be implemented that assess behavioral changes as a consequence of these types of educational programs.

Risks of Not Addressing Sexuality

There are other extreme risks of not addressing sexuality in comprehensive ASD intervention. That is, individuals with disabilities are involved in the criminal justice system at a much higher rate than persons without disabilities (Lord &

McGee, 2001; National Research Council, 2001). Specifically, individuals with ASDs have approximately seven times more contacts with the criminal justice system than the typical population (Curry, Posluszny, & Kraska, 1993; Hall, Godwin, Wright, & Abramson, 2007). As mentioned above, adolescents and adults with ASDs are often victims of crimes such as sexual abuse due social naïveté, vulnerability in sexual situations involving authority figures, difficulties with communication, and a lack of knowledge about sexual issues (Ammerman, Hersen, & Lubetsky, 1988; Hall et al., 2007; Howlin & Clements, 1995; Sobsey & Doe, 1991). This increased frequency of sexual abuse among individuals with ASD puts them at further risk for depression, suicide, and criminal behaviors (Sequeira & Hollins, 2003; Sequeira, Howlin, & Hollins, 2003). However, for many of the same reasons relating to the symptomology of autism, adolescents and adults also have been prosecuted as perpetrators of sexual assault and stalking (Berney, 2004; Holmes, 1998) and some warn that an seemingly harmless obsession by a person with ASD can lead to criminal offending (Berney, 2004). In fact, Berney (2004) suggests that misinterpretation and misjudgment of social relationships, misinterpreting social rules, computer crimes, and stalking may predispose individuals with ASD to criminal offending. Some suggest, however, that violent crime in Asperger syndrome is primarily a symptom of co-morbid psychiatric diagnoses rather than a symptom of ASD itself (Newman & Ghaziudin, 2008). Nevertheless, appropriate sexual expression needs to be included as a target in sex education for adolescents and adults with ASD in order to prevent unintended criminal offences.

Summary and Recommendations

Sexual development in individuals with an ASD parallels typical sexual development, with some differences. Research suggests that sexuality is common among both the typical population and the population with ASD, with individuals with ASD experiencing some sexual behaviors less frequently. Despite the growth of sexuality during puberty among adolescents with ASD, there is not a natural, corresponding growth of sexual knowledge. This often leads to embarrassing and inappropriate behaviors, which can contribute to peer rejection and other poor outcomes.

Sex education is a necessity for this population to combat these poor outcomes; however, the research is lacking in the development of effective and beneficial programs for individuals with ASD. To start, sex education programs could be informed by the current literature on effective programs for other populations with modifications to address the specific impairments in ASD. There are significant risks of not addressing sexual issues in this population, including an increased risk of contact with the law as victims of sexual abuse or perpetrators of sexual crimes.

The current research points to many areas that should be included in a comprehensive sex education program. In addition to issues addressed in sex education

programs for typical developing children, sex education for individuals on the autism spectrum may also benefit from including the following issues the research suggests are particularly relevant:

- Puberty and body changes. Individuals with ASD show more difficulties with body changes during puberty, including growth, erections, pubic hair, and so on (Hellemans et al., 2010). Preparation for body changes in addition to appropriate behaviors for dealing with these situations (e.g., itchy pubic hair, erections) should be addressed in sex education programs.
- Privacy issues. Individuals with autism, particularly those with more significant impairments, have been reported to touch private parts in public, masturbate in public (Ruble & Dalrymple, 1993), and disregard personal privacy issues (Stokes & Kaur, 2005). Explicit instruction regarding social norms and privacy rules is warranted.
- Hygiene. Menstruation and self-care (changing underwear, grooming, washing, and other hygienic behaviors) require attention in regard to sexuality for some individuals with ASD. While there is a range in skill ability in regard to self-care and hygiene (Hellemans et al., 2010), some individuals with ASD have difficulties in these areas and thus they should be addressed in a sex education program.
- Dating. Dating involves a myriad of behaviors and very few programs address these behaviors. Support prior to dates through video modeling, self-management, initiations, practice dates, and feedback can be helpful for promoting healthy and intimate relationships in this population (Koegel & LaZebnik, 2009).
- Social communication. The literature has revealed that persons with ASDs of all ages show an interest in sexuality and a desire for intimate relationships but their poor social and communicative skills may prevent them from succeeding. Individuals with better communication and socialization fare better in the area of relationships, and thus, an emphasis on social standards and communication relating to intimate relationships may be essential in a sex education program. Further, in-depth discussion of social norms, acceptable dating practices, and unacceptable behavior would be likely to decrease accidental and unintentional perpetration and criminal offences. A myriad of effective social communication programs are available in the literature, but very few children with autism receive even minimal intervention programs in this area (Koegel, Fredeen, Koegel, & Lin, 2012). Implementation of such programs is likely to lead to more satisfying and rewarding relationships for individuals with ASD.
- Safety. Understanding risky behavior and recognizing offences and inappropriate behavior are likely to reduce bullying, peer harassment, and sexual abuse commonly experienced by individuals with ASD. Undoubtedly, respect and socially appropriate sexual behaviors also need to be taught simultaneously to typically developing children, adolescents, and adults, so that abuse toward individuals with disabilities is reduced.
- Masturbation. While individuals with autism engage in fewer sexual experiences (Mehzabin & Stokes, 2011), masturbation is high, particularly in males; however

residential settings typically do not allow interpersonal sexual interactions of any type (Van Bourgondien et al., 1997), and masturbation appears to be the most common sexual outlet. Over one-third of individuals living in residential settings express sexual interest in other adults, (e.g., other residents), but are unable to engage in any intimate relationship because of sexual prohibitive policies in these settings (Van Bourgondien et al., 1997). For individuals with ASD who desire an intimate relationship, prohibition of a relationship due to rules of the setting in which the person lives, may not be appropriate. This issue needs to be addressed as a society and in educational programs.

- Mutual satisfaction. Individuals with ASD report that they are un- or less concerned with whether their partner is physically satisfied in a relationship. To improve the likelihood of lasting and mutually satisfying relationships, explicit social skills such as "checking in" with a partner may need to be taught. This should be implemented independent of sexual orientation, as several, but not all studies, suggest that individuals with autism are more likely to engage in homosexual relationships and less likely to engage in heterosexual relationships (Gilmour et al., 2012). Again, difficulties with social communication may interfere with the likelihood that an individual with ASD will express concern about a partner's feelings, but education and instruction in this area has the potential to decrease or eliminate this issue.

While these suggestions are not exhaustive, they provide a start to areas that have proven challenging for individuals with ASD and have impeded the development of successful relationships. There is much controversy regarding the degree, type, and even whether sexuality should be encouraged in individuals with ASD (see parents speak discussion in the *Journal of Autism and Developmental Disorders*, 1985). However, most parents and professionals do agree that an individualized sex education program is important for individuals with ASD. This will require both teacher and parent education to increase comfort levels in addressing the many important behaviors relating to sexuality (cf., Kalyva, 2010). This need is particularly strong, given the fact that teachers and parents feel that sex education is lacking, and individuals with autism report that they, themselves, would benefit from more sex education (Mehzabin & Stokes, 2011). Despite the reported occurrence of inappropriate sexual behavior in this population, researchers assert that individuals with ASD can learn appropriate sexual behaviors (Shea & Mesibov, 2005), and the lack of sex education may be responsible for these inappropriate behaviors. As well, co-morbidity such as anxiety and depression may be greatly reduced if interventions focusing on the development of intimate relationships are addressed. There appears to be a very broad positive impact of improved socialization. For example, there is a relationship between increased number of social activities with peers in college students with ASD and academic success (Koegel, Ashbaugh, Detar, & Koegel, 2013). As discussed above, many individuals with ASD do not develop relationships, despite the desire to do so. In short, further discussion of sexuality, sex education, and research in this area with regard to individuals with ASD is long overdue.

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Chapter 6
Employment and Related Services for Adults with Autism Spectrum Disorders

Peter F. Gerhardt, Frank Cicero, and Erik Mayville

Introduction

The past decade has seen a general consensus regarding an increase in the prevalence of autism and related disorders (ASD) and, subsequently, steadily growing numbers of adolescent and young adults on the autism spectrum. With this increase has come an increased demand for appropriate services for adults with ASD in the post-school years. Unfortunately the employment, day, community, and residential needs of these individuals continue to far exceed the available resources leaving a generation of individuals with autism and their families in a programmatic, financial, and personal limbo (e.g., Parish, Thomas, Rose, Kilany, & Shattuck, 2012; Perkins & Berkman, 2012).

The resulting poor outcomes for adults with ASD, while not unexpected, are also not easily addressed. Among the contributing factors are poorly implemented transition services intended to guide individuals from school to adult life; a general lack of societal understanding as to the potential for adults with ASD to be employed, active, and contributing members of their; a near total absence of coordination between the educational, behavioral, mental health, vocational rehabilitation, and the adult intellectual/developmental disabilities systems; an absence of qualified staff to work with older learners; and the shift from an entitlement services (i.e., IDEA) to nonentitlement services made available as a function of available funds.

P.F. Gerhardt, Ed.D. (✉)
The McCarton School, New York, NY, USA
e-mail: pfgerhardt@gmail.com

F. Cicero, Ph.D., B.C.B.A.
Eden II Programs, Staten Island, NY, USA
e-mail: fcicero@eden2.org

E. Mayville, Ph.D., B.C.B.A.
Institute for Educational Progress, Milford, CT, USA
e-mail: mayville@icpinc.org

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Note that none of these challenges focus on the individual challenges of living with autism. Rather, the potential of individuals with ASD to become employed and engaged adults seems limited more by the failure of the systems charged with supporting them than by the challenges associated with their being on the spectrum. Not surprisingly, the economic cost of these systemic inadequacies is rather far reaching. As Ganz (2007) notes "Autism is a very expensive disorder costing our society upwards of $35 billion in direct (both medical and nonmedical) and indirect costs to care for all individuals diagnosed each year over their lifetimes" (p. 343). Absent a concerted effort on behalf of all stakeholders (i.e., parents, professionals, employers, society at large) to correct these inadequacies, the costs can only be expected to grow in the coming years.

Despite recognition of the complex and lifelong needs of adolescents and adults with autism, the development of appropriate and effective services continues to lag far behind those currently available for persons with less severe disabilities. This disparity between the potential for an integrated and productive life and the lack to services to achieve this potential represents an ongoing challenge to parents, professionals, and adults with autism.

Employment and Related Services

Vocational settings for individuals with developmental disabilities, including individuals with a diagnosis of ASD, are diverse; ranging from segregated day programs to competitive employment without supports. Unfortunately, there is no specific government program or agency that is designed to exclusively meet the needs of individuals with ASD. Adolescents transitioning into the adult vocational world need to choose from a variety of public and private programs designed for individuals with a range of developmental disabilities. The decision on which program to choose is made based on the needs of the individual, his or her transitioning and vocational goals, the nature of his or her disability, the economic resources available, and eligibility requirements amongst the various options (McDonough & Revell, 2010). Currently, possible placements include day habilitation settings, sheltered workshops, supported employment programs, and competitive employment without support.

Many individuals with developmental disabilities are placed in vocational and employment settings through programs that are funded through state run Vocational Rehabilitation agencies (Wehman, Inge, Revell, & Brooke, 2007). Vocational Rehabilitation programs often provide an array of services and supports including assessment of eligibility, vocational counseling, guidance and referral services, vocational on the job training, and supported employment. As part of their services, Vocational Rehabilitation agencies will develop an Individualized Plan of Employment (IPE) for each eligible individual. IPEs outline the support services that are needed in order for the individual to achieve his or her personalized goal (McDonough & Revell, 2010). Research suggests that traditional Vocational

Rehabilitation programs may not appropriately meet the needs of individuals with ASD. Out of 382,221 individuals who received services through vocational rehabilitation programs whose cases were closed in 2005, 4.3 % of individuals with ASD had a case closed to their disability being determined to be too severe to benefit from services as compared to only 2.0 % of individuals with cognitive impairment and 0.4 % of individuals with specific learning disability (Lawler, Brusilovskiy, Salzer, & Mandell, 2009). Despite this finding, Vocational Rehabilitation programs are showing an increase in the number of cases they are receiving with individuals with a primary diagnosis of ASD. It has been found that cases involving individuals with ASD cost more in supports than cases with individuals with other developmental disabilities. Employment outcomes are found to be mixed. Out of all disabilities, individuals with ASD had the third highest rate of successful employment post Vocational Rehabilitation services (only individuals with a diagnosis of sensory impairment or learning disability were found to achieve more successful outcomes), however individuals on the spectrum are found to work fewer hours and earn lower wages than nearly all other disability groups (Cimera & Cowan, 2009).

Segregated day settings, such as day habilitation and pre-vocational programs, continue to be the most popular setting for individuals with developmental disabilities. In 2004, state disability agencies reported a 3:1 ratio of individuals in segregated settings as compared to supported employment settings (Wehman et al., 2007). Day habilitation settings are "community-based programs that provide long term personal and social development opportunities within a structured environment for individuals with developmental disabilities who are unable to function independently in social, recreational or employment settings. Services are available on an hourly or daily basis and may include daily living skills instruction, basic education, recreational and social activities, exercises to improve coordination and other forms of developmental support which help participants develop and maintain the functional skills that are required for community involvement, self advocacy, self care and employment" (Day habilitation, n.d.). Although theoretically designed to lead toward less restrictive vocational settings, day habilitation programs are often inconsistent with independence and community inclusion. In fact, in 2001 the Rehabilitation Service Administration (RSA) of the US Department of Education stated that positive employment outcomes will only be considered those that are within integrated settings (Wehman et al., 2007).

Sheltered employment programs/sheltered workshops are another vocational option for individuals with developmental disabilities. Sheltered employment refers to "employment provided under special conditions (e.g. in a special workshop or at home) for handicapped persons who, because of the nature and severity of their disability, are either totally unable to carry out a job under ordinary competitive conditions or are able to do so only for a very short period of time" (Sheltered employment, n.d.). Individuals in sheltered workshops can either be paid or not paid for their work, which often includes a variety of activities including sorting, collating, assembly and disassembly tasks set up in contracts with local businesses. Although not an integrated setting, the RSA allows the use of Vocational Rehabilitation monies to fund sheltered employment programs as long as the service is being

provided on a time-limited basis in preparation for integrated employment (Wehman et al., 2007).

Initiated in the United States in the 1980s, based upon the 1986 amendment to the Rehabilitation Act in Title VI Part C, supported employment programs were created to enable individuals with disabilities to obtain paid, community-based employment with the addition of necessary supports directly in the job site (Mawhood & Howlin, 1999). Supported employment programs are in accordance with RSA requirements stating that positive outcomes are those where jobs are in integrated settings; "Integrated setting" being defined as a setting typically found in the community where the individual has interaction with people without disabilities, other than those individuals providing supportive services (Wehman et al., 2007). Within supported employment programs, an employment specialist or job coach provides individualized training to the person with a developmental disability. Providing stability and predictability in an independent work environment is the mission of the supported employment paradigm. True supported employment has three main characteristics: paid employment, an integrated work setting, and ongoing support (Garcia-Villamisar & Hughes, 2007).

Outcomes of supportive employment programs seem to be superior to outcomes of sheltered employment and day habilitation settings. Specifically, research has shown greater financial gain for participants, greater social integration, increased worker satisfaction, and savings related to service cost (Mawhood & Howlin, 1999). Ridgeway and Rapp (1998), as cited in Wehman et al. (2007), indicate key employment interventions for effective supported employment. Specifically identified as important elements of supported employment are workplace accommodations, job coaching, supportive counseling, off-site assistance, on-site assistance, support groups linked to community supports, ongoing assessment of support needs after securing a job and ongoing assessment of the job site environment making accommodations as necessary. Bond (2004) outlined six evidence-based principles for successful supported employment, specifically (1) eligibility for the program is based on individual choice, (2) supportive employment is integrated with other services and treatments, (3) the goal of the program is focused on competitive employment, (4) job searching and placement is rapid, (5) job finding is individualized to participant preference, and (6) supports are ongoing and continuous. Programs adhering to these principles showed greater employment outcomes as compared to programs that did not adhere to best practice supportive employment principles.

Mawhood and Howlin (1999) conducted a study to compare employment outcomes of individuals with ASD within a supported employment program to the outcomes of individuals with ASD within nonspecialist day programs. Thirty participants were included in the study, all with a diagnosis of ASD, IQs of 70 or above, able to travel independently and without comorbid psychiatric conditions. Participants within the supported employment group were assessed for their level of functioning and past employment history. Employment specialists were then responsible for indentifying an appropriate integrated job site and providing guidance to the worker on a full-time basis for the first 2–4 weeks of the program. Employment specialists were also responsible for ensuring that the participant

could cope with the social and occupational requirements of the job, educating employers about autism and the focus of supportive employment, and advising coworkers and supervisors on how to deal with problems. The amount of support was faded to weekly visits within the second month and then further faded to occasional visits by the fourth month. Planned meetings continued on a regular basis and the employment specialist was made available at all times in case of an emergency. Results indicated that two-third of participants in the supported employment program obtained competitive jobs as compared to only one-quarter of participants in the control group. Of the supported employment participants who obtained competitive employment, over 80 % of the jobs were in administration or computing. Only one of the jobs in the control group was at this level. Regarding participant satisfaction, high levels of dissatisfaction were reported from control group participants while participants in the supported employment group reported high levels of satisfaction.

In another outcome study, Howlin, Alcock, and Burkin (2005) investigated the efficacy of a supported employment program for individuals with ASD in the UK over an 8-year period. Within the first year of the program, eight individuals were enrolled in paid employment. By the eighth year, paid employment was obtained for 192 cases with 70 % of jobs meeting the UK Department for Work and Pensions job criterion of 16+h per week, sustained for over 13 weeks. Most individuals surveyed were satisfied with their jobs and the pay they received. Almost all individuals reported that the supported employment program was extremely helpful in allowing them to succeed. One problem was that many individuals reported that they did not make friendships in the job site and only seven individuals reported that they met up with coworkers socially after work hours.

Schaller and Yang (2005) reviewed the case closure data for 815 individuals with autism who received services through Vocational Rehabilitation programs in 2001. 55.2 % of individuals had received services to obtain competitive employment and 44.8 % had received supported employment services. Results indicated that individuals who had received supported employment had significantly greater successful closure rates than individuals who had only received competitive employment services. The authors hypothesize that this difference is attributed to the core feature of supported employment which is to provide on the job supports in order to enhance job retention. Although a portion of individuals with autism were able to obtain competitive jobs, without supports they were less likely to retain those jobs over time. In the opposite direction, it was found that individuals who received supported employment earned significantly less wages and worked significantly less hours than individuals who only received competitive employment services. The authors offered two hypotheses for this finding. First, it could be that the range of jobs available for individuals who require supported employment naturally pay less and require less hours than jobs that would be more appropriate for independent workers. Second, it could be that individuals who qualified for supported employment programs needed to earn less pay per year in order to retain Supplemental Security Income (SSI). It is likely that individuals who were appropriate for independent competitive employment were not eligible for SSI support.

Garcia-Villamisar, Wehman, and Diaz Navarro (2002) tracked the outcomes of 55 individuals with autism who were either receiving sheltered workshop or supported employment services. Results indicated a positive relationship between supported employment and improved quality of life; with quality of life being defined by environmental control, community involvement and perception of personal change. In comparison, the quality of life of individuals receiving sheltered workshop services did not change.

Hillier et al. (2007) studied the outcomes of nine individuals with ASD who received supported employment within community-based settings over a 2-year period. Overall, employment levels increased by 78 %. Seven out of nine individuals who were placed in jobs held their first positions for an average of 12.5 months. On average it took 4.5 months to find correct placements based on participant vocational interests, previous experience, and aptitude for particular jobs.

In addition to successfully promoting job placement and retention, supported employment programs have been found to result in increased job satisfaction among individuals with autism (Hillier et al., 2007), increased knowledge of autism among community employers (Howlin et al., 2005), and improvements in standardized test scores related to nonverbal intelligence as compared to individuals in noncompetitive vocational day programs (Garcia-Villamisar & Hughes, 2007). Despite all the evidence showing the benefits of supported employment programs for individuals with ASD, the majority of adults on the spectrum continue to be unemployed, work only to a limited degree or work only within sheltered settings (Lattimore, Parsons, & Reid, 2008).

There is also an economic benefit to supported employment programs beyond the direct benefit to participants. It has been found that supported employment programs cost less per individual in the long run than sheltered workshops or day habilitation programs. Cimera (2008) investigated the financial costs of four adult service agencies providing both supported and sheltered employment services to individuals with cognitive impairments. Results indicated that the cumulative cost of services per individual were significantly higher for individuals served in supported employment settings ($6,618.76 per employment cycle) as compared to individuals served in sheltered workshop settings ($19,388.04 per employment cycle). These numbers indicate that for every one sheltered employee being served, nearly three individuals can be served in community-based supported employment settings. Looking at the trend in cost over time, Cimera (2008) found that supported employment programs showed an initial increase in cost over the first three fiscal quarters followed by a decreasing trend over future quarters. Sheltered workshops, on the other hand, showed an increasing trend in costs over all fiscal quarters.

For individuals whose behaviors or skills prevent them from participating in full time, community-based supported employment, there are some variations to supported employment that might be appropriate alternatives. Lattimore et al. (2008) discuss a procedure whereby individuals with ASD were taught to master skills necessary in community-based jobs through simulated activities within nonintegrated settings. Three supported workers with ASD were introduced to work tasks within simulated teaching sessions that took place within an adult day program setting. Learned skills were then generalized to the job site once mastered. Positive

findings were noted even when equipment and materials used in the simulated sessions were not identical to those which would be encountered in the job site. The authors point out that although simulated training is a concept that is well researched in the general behavioral literature, it is a concept that is unfortunately not included within recommended practices for supported employment. Another variation of traditional supported employment is enclave employment. Enclave employment is when individuals attend a community-based job site as a group and are supervised together by one or more than one employment specialist. In enclave employment models, the employment specialists might fade out their influence, however are always present to provide assistance to individuals and the group as needed.

Another variation to the traditional, job coach/employment specialist model of supported employment is using natural supports in place of or in addition to paid job coaches. Some vocational professionals suggest that the presence of paid job coaches impedes the social integration of individuals with disabilities in the employment setting. Using natural supports inherent in the natural environment, in place of job coaches, might alleviate this problem (Unger, Parent, Gibson, Kane-Johnston, & Kregel, 1998). Natural supports refer to resources that are inherent to the job site such as coworkers, supervisors, friends, family members, and community volunteers. Of 385 supported employment agencies surveyed, 328 or 85.2 % indicated that their agency used natural supports in the delivery of their services. 93.3 % of agencies reported that natural supports were used in the job training; however, only 66.1 % indicated that they used natural supports for participant assessment and only 78.3 % used them for job development. Coworkers were the most often reported natural support used (West, Kregel, Hernandez, & Hock, 1997).

Although individuals with ASD are still often unemployed, underemployed or attending non-integrated vocational or pre-vocational settings, the field is gradually moving away from this model in favor of empirically-based supported employment. Wehman et al. (2007) offers the following five suggestions for increasing the availability of supported employment programs which lead to independent competitive employment: (1) the opportunity to obtain paid work before graduating from state education funded school programs, (2) the presumption of employability which will lead to the imposition of time limits on adult day programs, (3) the availability of work vouchers which will increase funding for placement outside of day programs, (4) self-determination training, and (5) expanding the utilization of Medicaid dollars to support community-based job placements and supports.

Challenges to Effective Employment Programming

There are a number of barriers that complicate the process of helping individuals with ASD find and maintain employment. Several of the most significant are underdeveloped preparation programs (e.g., educational, transition), challenges in finding and keeping appropriate numbers of qualified staff, negative societal attitudes, a lack of coordination with the business community, and economic challenges. An overview of these issues is provided below.

Underdeveloped Preparation Programming

As is the case with persons of all abilities, the degree to which persons with an ASD complete tasks effectively will be in large part a function of instruction, both prior to and after acquiring employment. Given the challenges that persons with ASDs often face in acquiring effective task completion and employee-relevant social skills, a strong case can be made for providing instruction in these domains early in the individual's educational career. In a description of their adult services program, McClanahan, MacDuff, and Krantz (1999) noted that less than half of the funding used for their children's program was effective in maintaining appropriate adult programs, an outcome they attributed to adults receiving science-based education throughout childhood and adolescence. In addition to instruction in core areas of academics, these individuals were taught a number of skills that prepare them to succeed in a variety of environments, including requesting assistance, saying "please" and "thank you," controlling stereotypic movements, and utilizing tools facilitating independent task completion such as photographic or text-based activity schedules (McClanahan et al., 1999). Similar evidence-based educational programs for persons with ASD have also included instruction in skills that will eventually facilitate maintaining employment (e.g., effective social interaction, problem behavior reduction, independent completion of personal daily living skills; Handleman & Harris, 2006). Unfortunately, well designed and implemented science-based education is not yet a hallmark of public schooling despite the short- and long-term benefits of doing so (for reviews, see Eikeseth, 2009; Green, 2011). Thus, most individuals with ASD are reaching the transition stage without the benefit of such programming, complicating the task of utilizing multiple skill sets that many jobs require (e.g., job-specific skills, negotiating social and self-management requirements). This issue is likely the most significant regarding effective preparation for vocational and independent living opportunities.

An additional challenge in the preparation process is the difficulty that many students face in transition from special education to adult-based services. Many students do not experience a seamless transition from the entitlement-based special education system to the less-funded adult services world (Certo et al., 2003). Families are often unprepared to utilize a service system that typically yields fewer supports than they were accustomed to within special education. And although some individuals with ASD are able to successfully transition, most are faced with significant obstacles in multiple areas, even those individuals considered to be more skilled (Hendricks & Wehman, 2009). Obstacles include misperceptions about the nature and needs of persons with ASD and the need for intensive social skill and behavior management intervention. While attention to the transition process appears to be increasing, intervention and assessment methods facilitating effective transitioning have been slow to emerge, with research efforts focused primarily on younger ASD populations (Hendricks & Wehman, 2009). Empirically evaluated transition assessment tools offering a survey of employment-related skills, behavioral barriers, and interests are needed to facilitate effective transition processes.

Staffing Challenges

As outlined in the Current Service Models of this chapter, staff who effectively assist individuals with ASD directly are often crucial to meaningful employment experiences. However, there are a number of challenges to effectively staffing vocational programs for individuals who require it. These challenges are many, and mirror the difficulties encountered in service provision for adults with developmental disabilities. First, finding qualified staff has been a significant problem for a number of years (Hewitt & Larson, 2007; Larson, Hewitt, & Anderson, 1999). Direct support work is often viewed as an unskilled labor by educators and policy makers, contributing to few available career paths and related educational programs (Hewitt & Larson, 2007). Additionally, direct service positions are often low paying, to the degree of constituting poverty-level wages, in some cases (Hewitt & Larson, 2007). Training staff to implement appropriate supports in employment settings is another difficulty. While a number of studies have illustrated a range of effective staff training techniques (e.g., Reid, Parsons, Lattimore, Towery, & Reade, 2005), the implementation of such techniques is unusual as standard practice. Further, the position of direct staff is often multifaceted, encompassing responsibilities that extend far beyond the circumscribed duties of the job description (e.g., relationship building, communication, counseling; Hewitt & Larson, 2007). Thus, training individuals to handle all responsibilities that may come along with their position may be a challenge that is not adequately addressed. Given the many difficulties associated with direct support work, it is not surprising that staff turnover rates are high. This has long been an unfortunate hallmark of vocational and day services for adults with developmental disabilities. Estimates of turnover rates in employment settings have ranged from 33 to 86 % (Larson, Hewitt, & Knobloch, 2005); the Department of Health and Human Services (1994) estimated the rate at 46 % from 1998 to 2003.

These issues highlight the multifaceted nature of staffing-related challenges. Addressing this problem will therefore require multifaceted solutions. Hewitt and Larson (2007) review a number of them, including recognizing the profession of direct support as a primary labor market requiring skilled workers, creating programs to increase awareness of direct support career opportunities among educators, modification of employment selection strategies (e.g., utilization of realistic job previews), implementing effective programs to reduce employee stress and develop peer support, and implementation of competency-based training.

Societal Attitudes

Historically, persons with an ASD have been portrayed in media as presenting with a characteristic profile of challenges (e.g., Raymond Babbit in the movie *Rain Man*), with few strengths that might facilitate success in an employment setting. Much research has described the presence and negative impact of stigma—stereotypes, prejudice, and subsequent discrimination—on persons with mental and

developmental disabilities (for reviews, see Corrigan & O'Shaughnessy, 2007; Werner, Corrigan, Ditchman, & Sokol, 2012). Despite legislation preventing discrimination for persons with "mental disabilities," there is significant evidence that negative employer attitudes have served as a barrier for employment (Scheid, 2005), with assumptions primarily being that such persons would perform at an inferior level which would adversely affect business productivity. There have been reports of similar attitudes among employers for persons with developmental disabilities (Morgan & Alexander, 2005). Research on stigma for persons with ASD is relatively scant, though initial findings suggest that for one particular ASD—Asperger's Disorder—the label itself does not evoke reactions consistent with stigma, though contact with negative social behaviors does (Butler & Gillis, 2011). While further study related to stigma and employment barriers for persons with ASD is needed, it is likely that persons with an ASD have been negatively affected regarding employment opportunities, similar to other populations of individuals with disabilities.

Research on the reduction of stigma has highlighted the importance of interaction with disabled populations, such as persons with chronic mental illness (e.g., Corrigan, Edwards, Green, Diwan, & Penn, 2001). A number of employers have reported positive experiences in employing individuals with ASDs (Hagner & Cooney, 2005; Hillier et al., 2007). Specific benefits reported have included trustworthiness, high quality work performance, low absenteeism, and attention to job detail (Hagner & Cooney, 2005). There is also some evidence that for persons with developmental disabilities, employers may go well beyond ADA requirements in providing supports after receiving effective assistance from employment support professionals (Unger, 2002). Thus, it is likely that with application of supports and other programmatic elements found to lead to successful employment experiences, negative attitudes and stigma related to ASD will dissipate, facilitating increased employment opportunities.

Lack of Coordination with the Business Community

Despite legislation and policy initiatives supporting employment opportunities for persons with ASDs, there is often a "ground-level" lack of coordination between the general business community and those supporting individuals with ASD that may slow the employment process. Relations campaigns for persons with developmental disabilities have often utilized disability-centric terminology (e.g., "Hire the Handicapped") that appeals to advocacy agencies but may miss the mark with employers concerned primarily with operational or revenue objectives (Luecking, 2008). Luecking (2011) points out that traditional efforts to help obtain employment have overlooked such primary employer objectives, instead emphasizing employer awareness and recruitment initiatives regarding hiring persons with developmental disabilities. Not surprisingly, surveys of employers reflect that they perceive disability employment personnel as naïve about or unfamiliar with business practices (Luecking, 2008). Other contributors to a lack of effective coordination between disability employment service providers and employers include terminology

differences and different success metrics used by each group. These differences are not surprising given the differing missions, organizational structure, and financial priorities of these groups (Gerhardt & Holmes, 2005).

Measures can be taken to increase coordination and communication between the business and advocacy communities. For example, Gerhardt and Holmes describe the Business Advisory Council (BAC)—a group than can help ASD service providers better understand the needs, language, and culture of for-profit businesses. Specific functions include providing training on how to effectively interact with business community members, providing assistance in developing employer-friendly informational materials, and identifying areas of potential job development (Gerhardt & Holmes, 2005). The coordination process can also consist of helping employers recognize opportunities to meet their labor needs, to examine their work processes, and even to change the nature of their work environments through competitive employment (i.e., "Demand-Side" activities, Luecking, 2011). Luecking (2011) describes a case in which one potential employee's strengths and preferences were matched to unaddressed needs within a retail clothing store that were negatively affecting business (e.g., matching clothing sizes to size tabs on hangers, organizing the stock room), leading to the creation of a mutually beneficial position. Given the accumulating evidence that employers' experiences in hiring persons with an ASD are generally positive, better coordination and engagement with the business community could lead to significantly increased employment opportunities for this population.

Economic Challenges

Lastly, there are "macro" level difficulties impeding employment opportunities for persons with ASDs, factors that are unfortunately very difficult to address for those involved in the field of autism and developmental disabilities. In particular, recent economic difficulties have resulted in widespread challenges in employment, including the loss of jobs and cuts to a number of public funding agencies. Persons with disabilities have been differentially affected by the recent economic recession (Butterworth et al., 2011), and economic challenges appear to have contributed to recent declines in supported employment services (Rogan & Rinne, 2011). Under such circumstances, efforts to help employers create mutually beneficial employment positions through "demand side" activities may be particularly helpful, potentially allowing employers to address organizational needs that might increase revenue, as well as creating stable opportunities for persons with ASD.

Discussion

Despite the best efforts of parents, educators, and adult service providers the employment outcomes for adults on the autism spectrum continue to be, at best, disappointing. This despite that fact the studies, and day to day experience, have

repeatedly demonstrated the employability of these individuals when provided with proper training, support, and follow-up. So while, historically, much of our intervention effort has gone into changing the behavior of individuals with autism, perhaps it is time to alter that focus a bit and expand our sphere of intervention to include the behavior of families, professionals, and systems. In other words, if we are to more effectively and appropriately meet the needs of adults with ASD some significant changes to current systems of planning and intervention would appear to be necessary (e.g. Gerhardt & Lainer, 2011). While the federal and state authorization of additional funding for adult employment services is critical, this appears unlikely in the near term. This, however, does not mean we are without potential interventions, despite a challenging budgetary environment. Among the systemic interventions are:

- Proactive and effective coordination between the educational, vocational rehabilitation, adult developmental disabilities service systems along with the individual and their family needs to take place. In a desirable world this would take the form of a series of meetings dedicated to the programming needs of specific individuals throughout the transition process. However, given the current fiscal realities a system whereby a single, annual coordination meeting between all parties on a school wide basis would be desirable, affordable, and potentially help shift outcomes in a slightly more positive direction.
- Adult outcomes tend to indicate that transition plans developed under IDEA for individuals with ASD fail to comply with the transition requirements of IDEA (2004) such that individuals with autism are generally not provided with the skills necessary to successfully move from school to post-secondary education, *integrated employment* (including supported employment), adult services, *independent living*, or *community participation* (*emphasis added*). Not only does this need to change but the fiscal resources necessary to support such change are, potentially, available, under IDEA.
- Within the developmental disabilities adult system more effective strategies of staff recruitment, training, and retention (e.g. Reid, Parsons, & Green, 1989) need to be developed and implemented on a consistent basis to ensure both better trained staff and more consistent programs and supports for adults with ASD.
- While continuing the necessary focus on biomedical, genetic, and/or etiological research, an addition emphasis on research addressing "quality-of-life" and related intervention variables for adults with ASD needs to be actively implemented and the results disseminated in such a way to accessible to both families and professional staff.
- Efforts need to be undertaken to shift at least some of the focus of current public awareness efforts away from emphasizing the deficits and challenges associated with living with ASD to include attention to the strengths and competencies of individuals on the spectrum and the benefits of their active inclusion in adult life in the community (Gerhardt & Lainer, 2011).

Adults with ASD deserve the same opportunities and options that those of us not on the spectrum, more often than not, take for granted. This would include the

opportunity for a real job, a home in the community, people in their life for whom they care and who, in turn, care for them, to be free from abuse and neglect, to have access to healthcare, leisure and, if desired, a community of faith, and to be treated with dignity and respect. None of this should be considered beyond the scope of our current capabilities.

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Chapter 7
Innovative Programming to Support College Students with Autism Spectrum Disorders

Jane Thierfeld Brown, Lorraine E. Wolf, and Sarah Kroesser

Introduction

The percentage of students who have autism spectrum diagnoses who are attending college has dramatically increased in recent years. The Centers for Disease Control estimate that 1:88 people are on the autistic spectrum, and that this number will likely continue to increase (CDC, 2012). When the authors first began presenting to providers of disability services in 2001, Asperger's syndrome and other autism spectrum disorders (ASD) were not well-known diagnoses. Over the years, it has become clear that all colleges and universities now have seen a rise in the numbers of these students. One recent article estimated the prevalence of ASD in college students to be between 0.7 and 1.9 % (White, Ollendick, & Bray, 2011), which roughly parallels the incidence referenced above. Because of the increasing numbers of students diagnosed with ASD attending college, campuses are often unsure how to best serve this population (Wolf, Thierfeld Brown, & Bork, 2009).

Students with ASD often struggle in college (Cederlund, Hagberg, Billstedt, Gillberg, & Gillberg, 2010; Jobe & White, 2007, and many do not progress to gainful employment (Cimera & Cowan, 2009). There is little published data available, but anecdotal evidence supports that many struggle with social isolation, depression, and premature termination of their studies (Jobe & White, 2007; also see Wolf et al., 2009). The majority of students do not seek academic or disability support, perhaps because they do not perceive that they are eligible or perhaps because the supports offered have not been useful. This has been a focus of many disability services offices that seek to enhance the supports that can be utilized by students on their campus.

J.T. Brown, Ed.D.
University of Connecticut School of Law, Hartford, CT, USA

L.E. Wolf, Ph.D. (✉) • S. Kroesser, M.Ed.
Boston University, Boston, MA, USA
e-mail: lwolf@bu.edu

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The accommodations typically granted to level the playing field for students with learning disabilities (such as extra time for exams or audio books) or attention-deficit disorders (ADD coaching, training in how to use a planner) may not be helpful to the ASD population. Many students diagnosed with ASD have difficulty with executive functioning (Happe, Booth, Charlton, & Hughes, 2006; Hill, 2004; Russell, 1997), which refers to one's ability to set goals, initiate activity, organize information, and plan, monitor and regulate behavior over time (see Wolf & Kaplan, 2008).

Students may also struggle with emotional and social self-regulation, which impacts their ability to interact with others on campus. Areas of difficulty can include the ability to withstand and use feedback, understand and respect academic hierarchy, and relate to peers and classmates (to name but a few). These are critical skills in order for students to experience college success (Wolf, 2001; Wolf & Kaplan, 2008), and students with weaknesses in these areas will require accommodations and interventions specifically targeted to those deficits.

In the face of this increase in students and a gradual but steady development of understanding of student needs, many schools, nationally and abroad, have begun to develop expertise in programming to meet student needs while others still struggle to understand this population. In this chapter, we will review some of the core difficulties students with ASD bring to college. We will briefly discuss deficits in executive functioning, self-regulation, and social thinking. We will introduce the notion of the "dysregulated student" as it applies to students on the spectrum. We will also discuss some of the models currently in use across many campuses to meet the needs of students on the spectrum, including how to begin to match a student to a program. We refer interested readers to two in depth treatments of many of these issues (Thierfeld Brown, Wolf, King, & Bork, 2012; Wolf et al., 2009).

Executive Functions and ASD

Difficulties in executive functioning, involving both cognitive and behavioral deficits, are often seen in children, adolescents, and adults with ASD (Russell, 1997). Deficits have been noted in the areas of inhibition (Manoach, Lindgren, & Barton, 2004; McAlonan, Daly, Kumari et al., 2002), initiation of efficient strategies and cognitive switching (Kleinhans & Askshoomoff, 2005), impulse control, planning, shifting and attention control (Manoach et al., 2004; McAlonan et al., 2002), and using internal language to guide behavior when presented with a novel or complex task (Hill, 2004; Joseph, McGrath, & Tager-Flusberg, 2005; Joseph, Steele, Meyer, & Tager-Flusberg, 2005). Some authors have also extended the EF model to explain the well-documented deficit in "theory of mind" seen in ASD (Howlin, Baron-Cohen, & Hadwin, 1998; Joseph & Tager-Flusberg, 2004; Stuss & Anderson, 2004).

Taken across studies, it appears that a core deficit in ASD includes selective weaknesses in executive functioning. We can therefore extrapolate that students

with ASD in college may have difficulty with cognitive executive functioning (poor integration and synthesis, missing the big picture, planning deficits, inhibition, rigidity, shifting, and prioritizing) that necessarily will impact academic functioning in areas such as getting the big picture of an assignment integrating information across many sources or planning assignments over time (see Wolf et al. (2009) for a thorough discussion of the academic difficulties of students with ASD). Students will also struggle with social emotional self-regulation (perspective-taking, social perception, motivation, and initiation) (see Wolf & Kaplan, 2008), which can impact the non-academic, or co-curricular aspects of college life (housing, dealing with roommates, negotiating with faculty, joining activities, etc.) (Wolf et al., 2009). Thus, the difficulty students with ASD experience in college may be the result of an inability to self-regulate in the social domain tied to EFD (Joseph, McGrath, & Tager-Flusberg, 2005; Joseph, Steele et al., 2005).

Social Emotional Regulation

Social interaction is the embodiment of college life. The average college student is driven to be social and seldom has the need to think about his interactions. This innate ability to "know" how to read a social situation and interact properly has been called "intuitive social knowledge" (Tanguay, 2000). Garcia-Winner has described this as "social thinking" or a developmental progression of interest and the capacity to relate to others, and take their perspective, emotions, and beliefs into account (Garcia-Winner & Crooke, 2009). This skill is essential to a successful social life, on and off campus.

This drive towards engaging intensely with peers propels older adolescents into actively seeking out social situations. Indeed, most college students will state that their goals for their freshman year is to make life-long friends, meet potential mates, and spend weekends at parties with upperclassmen. However, a social life is not the only social activity required of a college student today. Students need to navigate across multiple settings on campus, interacting and negotiating with a wide variety of peers, staff, faculty and administrators (Wolf et al., 2009). This is not an easy task for many students with ASD, whose lack of intuitive social knowledge and inability to understand how to act across different settings can be truly disabling. However, other students report getting to college being "like heaven," where there were finally others with similar interests and a broader range of peers to choose from (Shore, presentation 2006).

Students who have pronounced difficulty understanding, initiating and regulating social interactions can be devastated by their disconnection, often leading to anxiety, depression and withdrawal. Therefore, the intensely social nature of higher education coupled with the core difficulty of understanding how to operate socially on campus can be devastating to students who are unprepared for college life (Wolf et al., 2009).

Critical Skills for College Success

We have outlined above two areas of deficit (EFD and social thinking) in many college students with ASD, which by their very nature can completely undermine high intelligence, the capacity to succeed academically, and the best of intentions. Students who struggle academically due to deficits in EFD and social emotional regulation may be described as "dysregulated" (see Wolf & Kaplan, 2008; Wolf, 2001 for a detailed discussion and review of the neurobiological underpinnings of academic dysregulation).

The dysregulated college student: The dysregulated college student finds it difficult to be an active participant in his or own learning. He or she is not in the driver's seat, but rather depends on external supports (such as parents or tutors). He or she is often described (but rarely by themselves) as disorganized. This student has a great deal of trouble following through with tasks on his/her own and often fails to sustain effort or energy. He or she is often inflexible or rigid, and has trouble accepting feedback, criticism or direction (and rarely changes per feedback). He or she may not have the ability to manage a schedule, take care of or organize personal belongings and materials, or maintain an effective workspace (Wolf, 2001). He or she sometimes has deficient academic skills, and does not use cognitive strategies or metacognitive awareness to guide learning (Trainin & Swanson, 2005), which makes it difficult to proceed with higher academics. This student often lacks the ability to self-reflect and counts on goals that are imposed by other people such as teachers or parents (Wolf & Kaplan, 2008). This student may have vague goals but does not plan ahead or understand how to break goals into steps that are achievable. It is well understood that internally generated and valued goals support academic motivation when the going gets tough (see Wolf & Kaplan, 2008). The lack of a life plan or even awareness of the value of long-term goals in the dysregulated student results in an individual who appears (and often is) unmotivated to be in school.

In summary, above we have characterized many college students with ASD as also struggling with deficits in some areas of executive functioning, self-regulation and social thinking which undermine their ability to succeed in college. Now that we better understand the social and cognitive weaknesses of these students, we will turn to service models, interventions, and programs that may best assist these academically capable students.

Specific ASD Programs

The past 5 years have seen an expansion of college programs specifically designed to support students with ASD. The number of campuses offering enhanced services and programs is currently increasing, and although we do not encourage families to make college decisions on this factor alone, it is something important to consider. It is also always important to base college decisions on factors such as where the

college is located, what special courses of study may be offered and what living situations are available. No matter how specially designed the program; this cannot take the place of motivation or happiness of the student. Programs, unfortunately, can also be inordinately expensive and have varying degrees of administrative support. Therefore, it is important to take into account above-mentioned factors in conjunction with the possibility of a special program. Some general service models of some of these programs are outlined below (we also refer interested readers to Thierfeld Brown et al. (2012) for a detailed discussion of the preparation, selection, admission process and transition goals for students on the spectrum).

As can be seen in the table below, different service models often reflect both the philosophy of the campus and program as well as the funds and support available.

Campuses that seek to understand ASD from a psychiatric perspective or those that desire to build training activities into their clinical degree programs (social work, psychology, counseling) may embrace programming with a clinical program. Other clinical programs have been developed to support students who are lower functioning and may require a higher degree of support to function independently. On the other hand, campuses that see difficulties in social activities and integration onto campus may support peer mentoring or social programming as the best model for their population. When students are seen as needing academic support or classroom management, a program may be developed which focuses on supporting the cognitive EFD discussed above. Research-based programs are usually grant-supported and guided by the overall scientific goals of the investigators. Finally, mixed models may embrace several of the above in an integrated or multi-disciplinary program.

Common service models

Types of ASD programs	Services that may be available	Providers
Clinical focus	Counseling, groups, supported living and transportation	Therapists, psychologists, or students. Some are off-campus residential programs with college as an add-on. Often expensive
Social skills focus	Peer or other mentors, social skills groups, social programming (activities)	Professors, graduate students, disability services
Academic skills	Academic coaching, special courses, tutors	Disability services offices, tutoring centers, outside agencies. Often fee-based
Research-based	Treatment, testing, support	Researchers and students
Mixed models	One or more of the above	Often fee-based, often external agencies to the college

Often, college students with ASD need additional services that are offered by these special programs and in some cases services are also offered by disability services or other student support organizations. Some programs are located within a larger campus, and others are separated from the campus, or are not tied to a specific campus at all, but offer students the ability to commute to several different

local colleges. The programs that are very expensive usually offer resources such as specialty housing, counseling or therapeutic environments, special advising, additional academic accommodations, and social skills training and tutoring.

Some are even more specialized and may offer supported living in a house or apartment, help with daily living tasks, and transportation to commuter schools in the area.

ASD Program Checklist for Parents

- The program is available in support of the course of study that my child is most interested in pursuing.
- The program includes the support my son/daughter's needs (i.e., specialty housing, academic advising, counseling or therapy, additional academic accommodations, tutoring and/or social skills training).
- The program is part of a larger campus supportive of my son/daughter's needs.
- The program has a track record of success with students with ASD and similar challenges.
- The staff member's qualifications and experience is available to me.
- The program clearly articulates what they can and cannot provide.
- The program can provide us with other families to talk to about their experiences.
- The program has options for levels of support should my student's needs change.

Not all students with ASD will benefit from specialty programs. Some students are not yet comfortable enough with their diagnosis to take advantage of such support. Because these programs are relatively new, it is important for families to keep in mind that there has not been extensive evaluation on the effectiveness of these types of programs. We believe it is important for families to examine these programs carefully, including the training and staffing of the institution.

Matching a Student to a Program

The beginning of the college discussion with any student should always be, "Do you want to go to college?" If the student does not have the motivation or desire to attend college, families should then begin to explore vocational training and job prospects. This article is focused on those who do want to attend college, which is not to say that going the vocational route should not be explored. For those who do want to attend, the process is similar to any other junior high school students beginning the search process. Do you want to live at home or on campus? Big or small school? Big city or rural? What are you interested in studying? It has been shown that 50 % of students change their major, so although one must take into account a student's

current interests, keep in mind that they may shift (Ronan, 2005). It is not rare that students, especially with ASD, run into problems with prerequisites or co-requirements and end up changing majors.

Is the Student Ready for College?

- Has the desire to go to college.
- Can independently meet with guidance counselor for info/advice on college search.
- Can independently research colleges.
- Can fill out applications independently.
- Can contact colleges with questions or to set up a tour and interview.
- Can organize their study time and study space.
- Can live independently (if living on campus).
- Can choose courses, request accommodations with disability services, and speak to professors about their accommodations.

If the Student Is Ready, What Type of Program Might They Need?

There are students on the autism spectrum who need little more than exam accommodations and a person to check in with at critical times of the semester (course registration, room selection, etc.). For this group of students, a typical college program with a solid disability support staff that has experience in working with ASD may be the perfect match. Disability services can assist with room selection, standard accommodations and even assist with finding tutors and mental health resources on campus as needed. However, other students will benefit from more structured support as described in the previous chart. Let us now turn to exploring some of the student issues that might make one sort of program a better match for a given student. We also add the caveat that not every program can deliver on its promises, and that success in college for students on the spectrum is far more than finding a support model which best fits their needs.

Clinical focus: Students who have struggled with the effects of co-morbid psychiatric conditions, who have been hospitalized or who have a history of decompensating under stress might require more clinical surveillance than students for whom mental health has not been an issue. Some programs function on campus within departments of counseling or psychology, and match students with graduate student therapists in training (supervised by trained clinicians) for daily or weekly sessions. Some clinical programs also offer social groups and social skills training. Others programs operate off campus, and also provide supported housing, transportation, and life skills. These programs may or may not be designed exclusively for ASD. Such programs might be best suited to a student who is lower functioning, or psychiatrically fragile or one who needs more support in developing independent living skills. Such programs may offer access to local colleges or may have developed a

relationship with one specific college. Some clinically focused programs aim to phase students out of an intense level of service, and families and clinicians should research carefully whether the student will be able to learn to function independently or not. Clinicians and families should also research the relationship between the program and the campus(s) they serve to determine who would provide accommodations, social programming, and academic service to enrolled students.

Social skills focus: Students who appear to be ready to live on campus but require assistance with learning how to negotiate with a roommate, talk to a professor, or find social outlets and activities on campus might be best suited for a program with a strong social focus. Many such programs offer peer or graduate student mentoring (not therapy) and will reach out to students to get them socially engaged. Some programs have special social activates for participants where they receive some social coaching and mentoring in vivo. Some programs embedded within campuses may offer formal social skills training; however these programs are in a minority. Social skills focused programs are most successful with students who are higher functioning on the spectrum and who can function fairly independently on campus and in the residence hall, as residence hall life is usually not part of the social programming.

Academic skills: Many students are able to navigate campus socially. They may have a special skill or niche that they can tap for social activities (a sport, music, political interest, etc.). Such students may only struggle with the cognitive EFD described above, and may benefit most from structured academic coaching. Time management, planning, understanding how to break assignments down, how to focus writing, active reading strategies, are but a few of the areas which might be addressed. Most campuses offer tutoring services to typical students in these areas, but students with ASD may require more or a higher intensity of such strategy learning. In addition, some students are difficult to engage in the process and will require a specially trained academic coach in order to be successful. Students who otherwise can function independently on campus and who can seek out help when needed would thrive with this level of support. If a student requires a very high degree of coaching, they may not be ready for this sort of program.

Research-based: Research-based programs often have specific criteria for inclusion. On-site assessment, treatment or follow-up is part of a protocol and usually cannot be altered too much. These programs can be a good venue for getting a comprehensive assessment, but families should carefully understand whether the research team is embedded within student services at the college or University or whether the student is simply being recruited as a subject.

Mixed models: Many models combine two or more of the above, most often social and academic coaching. In mixed model programs, approaches may be varied depending on the student need, the campus dynamics, and the mix of students enrolled.

Conclusions

Students on the autism spectrum have options for college which did not exist five years ago. The options are plentiful, but we need more programs at varied colleges and universities to meet the needs of this growing population. A well-trained staff and services that meet the needs of the individual are crucial to success. Students must be better prepared at the high school level in order to meet the demands of an intellectually challenging and socially rigorous college campus. In order to prepare students, families, teachers and clinicians must have goals in mind and a well-planned transition for the student. With this background and an appropriate college setting, students on the autism spectrum have increased opportunities for success in higher education and, hopefully, in the world of employment.

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Chapter 8
Adaptive Behavior, Life Skills, and Leisure Skills Training for Adolescents and Adults with Autism Spectrum Disorders

Nicole C. Turygin and Johnny L. Matson

Adaptive Behavior, Life Skills, and Leisure Skills Training

Life, leisure, and other adaptive behavior skills comprise the wide variety of abilities necessary for taking responsibility for and independently managing one's own life. Adaptive skills encompass the entire range of abilities necessary to complete virtually all activities that people engage in and comprise the broad set of skills necessary to live independently, (e.g., self-help, social, leisure skills) (Flynn and Healy, 2012). Maintaining health and hygiene, engaging in recreational activities, obtaining and maintaining one's job and place of residence, displaying the social and communication skills necessary for obtaining employment and maintaining relationships, managing money, and maintaining a household are all examples of the wide range of adaptive skills (Dawson, Matson, & Cherry, 1998).

The definition of adaptive behavior has changed little over time and has remained a broad construct. Adaptive behavior was first defined by the American Association on Mental Deficiency (1959) as "the effectiveness with which the individual copes with the natural and social demands of his environment." This definition included two major facets: (1) the degree to which the individual is able to function and maintain himself or herself independently, and (2) the degree to which (s)he satisfactorily meets the culturally-imposed demands of personal and social responsibility (Heber, 1959). The American Association on Intellectual and Developmental Disability (AAIDD) has recently defined adaptive behavior as "the collection of conceptual, social, and practical skills that have been learned and are performed by people in their everyday lives" (Schalock et al. 2010). The construct of adaptive behavior remains comprehensive yet broadly defined.

N.C. Turygin (✉) • J.L. Matson
Louisiana State University, Baton Rouge, LA 70809, USA
e-mail: nturyg1@lsu.edu; johnmatson@aol.com

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The difficulty in precisely defining adaptive behavior is due to the wide range of specific behaviors it comprises, because of the need for a definition that applies to people in all circumstances with varying levels of intellectual ability. Sometimes a discrepancy exists between what one is able to do and what one actually does, particularly among individuals with an intellectual disability (ID). In these cases, a caretaker may need to assist the individual in initiating a task. Conversely, the individual may refuse to engage in the task. Although the individual is able to complete the task, they do not, so the skill is not used adaptively due to lack of motivation.

Research on adaptive behavior has focused on these behaviors as a whole (i.e., global adaptive functioning) or has attempted to divide adaptive behavior into broad and more specific categories. For example, within the category of "self-care," more specific categories may include skills such as tying and lacing shoes (Nelson, Gergenti, & Hollander, 1980), exercise (Tomporowski & Ellis, 1984), and pedestrian skills (Matson, 1980). In some studies, researchers have defined adaptive skills according to adaptive behavior measures (Cone, 1987).

Adaptive Skills: A Particular Concern for People with ASD

The topic of adaptive skills and their acquisition and maintenance are of special concern for individuals with ASD (Matson, Mayville, Lott, Bielecki, & Logan, 2003). This fact is unsurprising, given that deficits in socialization and communication, which limit an individual's degree of independence, are core features of ASD. A persistent inability to socially engage and communicate can result in deficits in learning, and decreases opportunities for learning the skills needed to care for oneself. Given that the symptoms of ASD persist through the lifespan, there remains a need for effective treatment for deficits in adaptive behavior for adolescents and adults with the disorder. Also, as life circumstances change, the specific behaviors that one must conduct to adapt to one's environment also change, and corresponding therapies must be modified.

Research in adaptive behavior and its treatment has largely focused on populations of individuals with ID. Individuals with co-occurring autism spectrum disorders (ASD) have recently been included to a greater extent. Among individuals with ID, those with ASD are particularly likely to exhibit deficits in adaptive functioning. Individuals with ASD may be more likely than individuals with other intellectual, developmental, or psychiatric disabilities to exhibit deficits in adaptive behavior. Those with ASD are more likely than non-intellectually disabled individuals with psychotic disorder, and individuals with ID who exhibit challenging behavior (e.g., stereotypic behavior, self-injurious behavior, or aggressive/destructive behavior) to display deficits in adaptive behavior (Matson et al., 2003).

The purpose of this chapter is to describe the relationship between adaptive, life, and leisure skills: three interconnected concepts for the aforementioned handicapped groups. Previous research in training adaptive skills in adolescents and adults will be reviewed. In addition, particular challenges and needs in

training these skills in adolescents and adults with ASD will be discussed, along with commonly used empirically supported treatments and suggestions for their application.

Life Skills, Leisure Skills, and Other Adaptive Skills

Adaptive skills comprise the range of skills needed to accomplish daily activities and manage one's own life. These skills have been defined in a number of ways, and are generally considered to encompass communication, motor, daily living, vocational, leisure, and safety skills. Adaptive skills are thus defined as any skill necessary to independently conduct one's own life. However, these categories are not considered to be discrete, as any particular adaptive skill may apply to a number of these categories. For example, making a phone call requires skills in communication, daily living, motor functioning, and may also apply to the vocational, leisure, or safety skills categories, depending on the purpose of the behavior. In general, adaptive behaviors have been defined as externally observable behaviors, the presence of which result in increased independence, social acceptability and approval, quality of life, and self-sufficiency (Bellack, 1983; Matson, Carlisle, & Bamburg, 1998; Matson, Rivet, Fodstad, Dempsey, & Boisjoli, 2009; McFall, 1982).

Because the construct of adaptive behavior is so broad, there is no consensus among researchers on the precise definition of "adaptive behavior." As a result, adaptive behaviors are sometimes defined according to the method by which they are measured, and the purpose of the behavior. Because social, communication, and motor skills are addressed elsewhere, we will focus solely on research and treatment of life, leisure, and vocational skills; we will address related or prerequisite skills where applicable.

Life Skills Defined

Life skills encompass the abilities required for everyday independent living, and have been alternately referred to as "independent living skills" or "daily living skills" (Flynn & Healy, 2012). These skills include anything a person would do in the course of his/her life to maintain and utilize one's living area, and attend to his or her physical needs. This includes basic housekeeping skills (e.g., cleaning, and laundry), hygiene (e.g., bathing, toileting, eating, and dressing), safety (e.g., crossing the street, traveling independently), and community skills (e.g., paying bills, obtaining services). Life skills also encompass other skills needed to live independently, such as the ability to plan and provide for one's own physical needs. Life skills also encompass activities that occur outside the home, that are necessary to maintain one's life; such as planning, selecting, and purchasing items; time and money management; vocational skills; and safety skills. As a result, for an

individual to possess high levels of life skills, they must necessarily possess a degree of social and communication skills. As vocational skills have been more extensively studied than other types of life skills and require special considerations, they will be discussed separately.

Leisure Skills Defined

Leisure skills comprise the subset of abilities that are necessary for an individual to carry out activities other than those necessary to maintain one's living environment, vocation, or health, and include those activities that are conducted for recreation and relaxation. As such, leisure skills include the ability to identify, access, plan, and successfully participate in activities one finds pleasurable. For some, this may include being part of a club, service organization, or team. Leisure activities are often less structured than vocational or daily living activities. Leisure can involve a solitary hobby (such as maintaining collections or producing artwork), or more passive pleasurable activities such as visiting tourist destinations, shopping, or selecting and attending movies, plays, concerts, or exhibitions, alone or with others. Many of the skills needed in order to engage in leisure activities are the same skills needed for accomplishing the tasks required for daily living, and most leisure activities require some ability to communicate or socialize.

Adaptive behavior, life skills, and leisure skills comprise interdependent and overlapping skills. As a result, these three types of skills have proven difficult to define out of context of one another. Research in treatments targeting life and leisure skills in individuals with ASD has focused mainly on specific tasks, and has lagged behind research in social, communication, and academic skills. As research in communication and socialization will be reviewed elsewhere, this chapter will focus specifically on adaptive skills as they pertain to life, leisure, and vocation.

The Relationship between Adaptive, Life, and Leisure Skills and Quality of Life

Quality of life and the related construct of self-determination are topics at the forefront of consideration in intellectual and developmental disabilities. Quality of life refers to the degree that one possesses desirable levels of health, overall well-being, and life satisfaction resulting from self-determination (Goode, 1994). Self-determination is the ability of an individual to independently set goals, solve problems, make choices and decisions, regulate one's own life, and act as one's own advocate. A high quality of life presumes the person possesses developmentally appropriate levels of self-awareness and self-knowledge, and these may be increased

as the individual is exposed to the additional opportunities afforded by increased independence (Wehmeyer, 2010). Independence and self-determination are necessary components for high quality of life, which increases as an individual gains adaptive skills.

Adaptive behavior is important as it relates to one's ability to be self-sufficient and care for one's basic needs. However, the fulfillment of basic needs is not sufficient for quality of life. It is necessary for an individual to be involved in making choices about one's own life, participate in enriching activities that are pleasurable, and have an opportunity to be involved in social and community activities (Schalock & Parmenter, 2000). Ensuring that an individual with ASD achieves an acceptable quality of life poses particular challenges, as the core deficits of this disorder are direct obstacles to community inclusion and development of adaptive skills; namely deficits in communication, socialization, and repetitive interests, as well as a high prevalence of co-occurring intellectual disability (Matson & Nebel-Schwalm, 2007).

Importance of Life Skills

Deficits in life skills contribute to a number of negative outcomes, such as the development of mental illness and behavior problems (Borthwick-Duffy & Eyman, 1990; Matson & Sevin, 1994), and increased dependence on others (Soenen, Van Berckelaer-Onnes, & Scholte, 2009). Delays in independent living skills are often apparent at an early age and often remain without effective targeted intervention (Chadwick, Cuddy, Kusel, & Taylor, 2005; de Bidlt, Systema, Kraijer, Sparrow, & Minderaa, 2005; Kuhn & Matson, 2004; Rojahn, Matson, Naglieri, & Mayville, 2004). As what is considered to be developmentally appropriate, life skills change across the lifespan, cultures and situations, treatments for adaptive behavior must be adaptable to many different conditions.

Presently, research on treating deficits in independent living skills has focused mostly on children within educational or home settings. Little research on adaptive behavior has been conducted on adolescents and adults with ASD. This is surprising, given that most day and adult education programs strive to train vocational skills and increase independence so that individuals may be employed in affiliated sheltered or supported work programs, and live in less restrictive settings. Chadsey (2007) emphasizes that limiting adaptive behavior training to vocational skills is insufficient. A range of adaptive skills should also be taught, as overall functioning in the workplace depends on a range of adaptive skills. The inclusion of general adaptive skills training promotes healthy relationships between the individual and their coworkers, and overall job satisfaction. Thus, it is a priority to increase exposure to the full educational curriculum, and offer a variety of training options and alternate learning tracks. Therefore, an additional focus of research should be on the particular needs of adults and adolescents with ASD.

A major goal in vocational skills training programs for adolescents is to integrate individuals into the workforce and least restrictive residential settings once they no longer attend school. Therefore programs should ideally train a wide range of adaptive skills while offering long-term career development and planning programs. Success in the home and in the workplace depends on the ability of the individual to function independently in many contexts.

Special Considerations Related to Vocational Skills

Increases in vocational skills correspond with increased self-determination and independence in the workplace. However, vocational opportunities for individuals with ASD are scarce. Even among individuals with intellectual and developmental disabilities, individuals with ASDs appear to be at a particular disadvantage when it comes to occupational opportunities. Adults with ASDs represent the lowest employment rates among individuals with intellectual and developmental disabilities; a group already underrepresented in the workforce (Burke, Andersen, Bowen, Howard, & Allen, 2010.) Barnard, Harvey, Potter, and Prior (2001) found that 6 % of individuals with ASD were employed full-time and 4 % were part-time. In contrast, 70 % of adults without disabilities were employed (Bureau of Labor Statistics, 2010). Currently, those with adequate vocational skills experience challenges in obtaining employment.

Under-employment is common in those with "high functioning" as well as "low functioning" ASD. Engstrom, Ekstrom, and Emilsson (2003) found that only two percent of individuals with Asperger Disorder or high functioning ASD were employed. Similarly, in a longitudinal study, Bellstedt, Gillberg, and Gillberg (2005) found that among 120 participants with ASDs, 90 % were not only unemployed, but were also not living independently (in group homes, with family, or in residential treatment facilities). Those with sufficient vocational skills who seek employment face considerable obstacles. According to Howlin, Alcock, and Burkin (2005), only 68 % of adults with ASD who were candidates for vocational placement obtained employment. This finding may be due to reluctance of employers to hire individuals on the autism spectrum, as well as the reduced opportunities for those with ASD to obtain appropriate training.

Lack of adequate employment opportunities represents a significant roadblock to independence. Thus, it is important for therapists, families, and the individuals to consider the opportunities available when developing vocational treatment programs. Participation in the community is vital for an individual's well-being and quality of life. Researchers and service providers should also work to remedy this problem and find ways to ensure that individuals with ASD have opportunities for employment.

Choosing Appropriate Vocational Settings: There are two major types of employment settings for individuals with ASD who require employment supports: sheltered work centers and community-based supported employment. Sheltered work centers generally allow individuals the opportunity to engage in occupational tasks

in a group setting specifically for individuals with intellectual and developmental disabilities, including ASD. Many of these sheltered workshops offer only various types of piecework tasks. In contrast, those in community-based supported employment have job positions within the community, often janitorial, secretarial support, or food service. While community work is considered a less restrictive form of supported employment, sheltered work centers can provide additional structure, higher levels of support, and increased flexibility in work hours and conditions.

Those in supported community employment may have a job coach who may assist them in attending, completing, and maintaining their job. As a result, individuals with milder forms of intellectual and developmental disability who do not have behavior problems are most likely to secure these jobs. However, researchers have observed that community-based supported employment is associated with some negative outcomes; in one study, those in sheltered work environments experienced increases in autistic symptoms and decreases in overall functioning. No change in autistic symptomology was observed among those involved in supported employment in the community (Garcia-Villamisar, Douglas, & Paul, 2000). Although not all individuals are appropriate candidates for supported employment, it should be explored for those with adequate social and vocational skills.

Importance of Leisure Skills

Leisure activities are important in attaining a high quality of life for all individuals, including those with intellectual and developmental disabilities. These individuals may require assistance in selecting and exploring enriching activities. Leisure has been shown to decrease distress, increase positive affects, sustain efforts in coping, increase social involvement, improve access to social supports, and promote positive responses to difficult situations (Hutchinson, Yarnal, Staffordson, and Kerstetter, 2008). Leisure skills also provide some relief from life stressors for those with and without disabilities (Hutchinson et al., 2003; Hutchinson, Bland, and Kleiber, 2008). Meaning and pleasure is gained through participation in leisure activities. Among individuals with disabilities, participation in leisure enhances coping skills, has been associated with increased psychological well-being, and decreases in depressive symptoms (Dupuis & Smale, 1995).

Leisure activities promote social involvement and companionship, and moderate the relationship between stress and psychological well-being (Garcia-Villamisar & Dattilo, 2010). This finding may be partially due to the intrinsically reinforcing effect of leisure activities, as well as increased exposure to other forms of reinforcement that occur during one's chosen leisure activity. However, participation in active leisure activities can pose particular problems for individuals with ASD, as they are likely to exhibit deficits in postural stability, gait, balance, speed, and flexibility (Jansiewics et al., 2006; Lang et al., 2010; Minshew, Sung, Jones, & Furman, 2004; Mostoffsky, 2006; Page & Boucher, 1998). Motor deficits, including impairments in movement have been found in as high as 79 % of children with an ASD

and these deficits are believed to persist into adulthood. These deficits may be exacerbated by fewer opportunities to engage in physical leisure activities (Green et al., 2008; Lang et al., 2010). Motor difficulties may make certain leisure activities stressful or aversive.

There are other benefits that result from participation in active leisure activities. Exercise-based leisure activities in individuals with ASD have been shown to be beneficial. In addition to the usual benefits of exercise on physical fitness, studies involving physically intensive leisure activities have resulted in decreases in stereotyped behavior, and increases in on-task behaviors, correct responses to academic tasks, and improved motor control (Lang et al., 2009; Powers, Thibadeau, & Rose, 1992; Reid, Factor, Freeman, & Sherman, 1988; Rosenthal-Malek & Mitchell, 1997; Watters & Watters, 1980; Yilmaz, Yanardağ, Birkan, & Bumin, 2004). As a result, it may be desirable to include elements of physical activity in the leisure activities of individuals with ASDs.

Research on the acquisition of leisure skills in individuals with intellectual and developmental disabilities including ASDs is less common than research on other types of adaptive functioning (Burgess & Gutstein, 2007). Developing leisure skills programs for this population pose particular challenges. According to Pan, Tsai, Chu, and Hsieh (2011), individuals with ASD show less motivation and activity during physical education than typically developing peers. As a result, they may require additional assistance and prompting in order to actively engage. Researchers should continue to examine this area, as there may be alternative approaches that are more effective in teaching physical education in those with ASD. Ensuring that the chosen leisure activities are intrinsically reinforcing may increase the likelihood that these individuals participate in physical education and leisure activities. Preference assessments and behavioral observation can be used to help establish these preferences.

Garcia-Villamisar and Dattilo (2010) compared a group of 37 adults with an ASD who were actively engaged in a 12-month-long leisure program to a wait-list sample. A number of benefits to the treatment group were demonstrated, namely significant increases in overall quality of life, decreases in stress, increases in life satisfaction, competence, and productivity. Interestingly, no improvement was observed in the social integration and empowerment/independence domains (Garcia-Villamisar & Dattilo, 2010). Global adaptive functioning scores on the *VABS* were also significantly increased after participation in the program. Garcia-Villamisar and Dattilo (2010) emphasize that the positive effects of leisure are likely due to the necessity for an individual to utilize and practice other adaptive skills while engaging in leisure activities, and may be able to improve their ability to socialize and communicate.

Choosing Appropriate Leisure Activities

One criticism of commonly-targeted leisure activities in individuals with ASDs is that participation is generally passive, as they involve activities such as bird-watching, dancing, attending concerts, plays, and performances, and going to the

park. Currently, researchers have emphasized the need to include individuals with ASDs in those leisure activities in which they can take an active role or create a finished product, including art, collecting, recreational activities involving sports or games, or participation in a social club (Edrisinha, O'Reilly, Choi, Sigafoos, & Lancioni, 2011). It is preferable for individuals to engage in active leisure activities. Involvement in solely passive learning tasks has been associated with persistent delay in the development of independent living skills (Matson & Hammer, 1996).

Challenges and Considerations for Training Adaptive Behavior Skills

Training modalities for teaching skills to individuals with ASDs should take individual aptitudes and preferences into account. Because it is common for people with ASDs to exhibit heightened sensitivity to stimuli, a typical work, leisure, or home environment may be aversive due to environmental factors. Fans, bright lights, ticking clocks, loud or repetitive sounds, and brightly colored environments may be irritating or over-stimulating. When therapy must be conducted in such an environment, the therapist may want to consider attempting to habituate the person to relevant stimuli as an adjunct to the skills training. Therapists may also find it desirable to teach the skills both in and out of the environments where they will complete the target activity. Special attention should be ensured that skills learned in one environment generalize to others as needed.

The Effects of Cognitive Strengths and Weakness on Adaptive Skills Training

When developing a treatment, common cognitive strengths and weaknesses in individuals with ASD and the degree to which they apply to the individual should be considered. Approximately half of individuals with ASDs have an IQ at or below 70, ranging from mild to profound levels of intellectual disability (Charman et al., 2011). Visual tasks, including picture completion and arrangement tasks, represent strengths for many individuals with ASD (Charman et al., 2011). Some commonly measured tests of visual discrimination include; sorting, matching, image completion, and object and puzzle assembly (DeMyer, 1975). Therapists should consider including visual information in the training materials, and to modify treatment to the individual's particular cognitive strengths. Individuals with ASDs may be more likely to participate in leisure activities or jobs that utilize their strengths.

Researchers have suggested that individuals with high functioning ASD may also possess superior nonverbal intelligence compared to typically developing age-matched peers (Chen, Planche, & Lemonnier, 2010). As a result, it is important to consider potential strengths and weaknesses when designing treatment protocols. The use of visual schedules, modeling, and other methods of visual prompting may

be particularly useful and will be discussed in greater detail. Weaknesses include skills relevant to the diagnostic criteria for ASD (e.g., communication and social cognition). Individuals with ASD score lower on cognitive tests of vocabulary and comprehension (Charman et al., 2011). These deficits should be targeted within treatment. When designing treatment protocols, the therapist should ensure that the individual responds well to the types of instructions and reinforcers (e.g., praise, tangibles, attention) used.

Determining Target Behaviors

Targeted training goals should center on the needs of the individual, and should allow for access to natural reinforcers when possible (e.g., money, social reinforcement). The targeted skill should provide opportunities for additional generalization of behaviors, and probe for additional skills that may be taught later. For example, the ability to independently access preferred internet sites (the reinforcer) requires use of computer skills. Hobbies such as photography or art, can integrate the exploration of new environments and situations, result in a finished product, and can integrate adaptive behavior training in a variety of ways. Activities that are intrinsically reinforcing may also provide the trainer with insight as to future target behaviors, as well as preferred reinforcers.

When selecting targets for training, it is important to identify the component tasks behaviors that are necessary for carrying out the larger task. There are a number of factors to consider when selecting a target behavior for training. First, one must consider which skills are needed for the individual to carry out the task, and whether prerequisite skills must first be taught. For example, if one wishes to teach an individual to use the toilet appropriately, it may be necessary to first train prerequisite skills, such as dressing and undressing, or even simply following directions.

Second, it is important to consider which skills are the most relevant, important, and meaningful to the individual. If the individual's goal is to obtain a food service job, it may be preferable to teach relevant cooking skills prior to other vocational skills. Third, these preferences and goals of the individual should be considered within the context of his or her quality of life, and potential for increased independence as a result of the acquisition of the targeted skill.

Repetitive Interests Within the Context of Adaptive Behavior

Individuals with ASD often exhibit narrow interests and prefer to engage in activities directly related to them. These interests may provide a useful starting point for identifying which leisure and vocational skills to target in therapy. Moreover, the individual may be more motivated to communicate and engage socially with others if the client is able to share their preferred interest or activity. As leisure activities often involve the participation of others, social skills training can take place simultaneously. For those individuals whose interests are closely aligned with the chosen

leisure activity, the presence of other interested parties may help decrease some of the aversive aspects of social interaction. Tangible products of leisure activities, such as photographs or artwork can provide appropriate and relevant topics for the trainee to discuss during social interactions.

However, chosen recreational activities that are associated with a restricted interest may result in the individual becoming preoccupied with one certain activity, show, song, or scene. If passive activities (e.g., television shows, literature, or music) revolve around a restricted interest or become repetitive, the benefits of social interaction may be lost, and the behavior may become excessive or even maladaptive. These restricted interests may become so intense that the individual becomes upset when denied access to or discouraged from spending time engaging in the preferred activity, and may exacerbate challenging behaviors in some individuals.

A number of other considerations should be taken into account when choosing which adaptive behaviors should be targeted for treatment. Individual cognitive, social, and communicative weaknesses should be taken into account when determining targets for training. The behaviors which are most important for the individual and those that promote the highest levels of independence should be primarily targeted. These targets should ideally allow the individual to obtain reinforcers naturally as a result of the behavior. The individuals' particular interests, even if repetitive, may be included with caution.

Assessing Adaptive Behavior

Definitions of adaptive behavior vary according to the individual, and may differ between what one is able to do compared to what one does do. This poses challenges for measuring adaptive behavior. The categories within adaptive behavior are blurry, as the skills necessary to complete tasks within one category of adaptive behavior overlap with those skills to complete tasks in other categories. As a result, researchers and therapists must tailor the method of measurement to the purpose for which the information is used. Adaptive behavior can be measured in a number of ways, by using one of several norm-based adaptive behavior measures, or through ipsative methods.

Vineland Adaptive Behavior Scale, 2nd Edition (VABS-II; Sparrow, Cicchetti, & Balla, 2005)

Adaptive behavior is often defined by the instrument used to measure it. Perhaps the most commonly-used of these methods is the *VABS*. This instrument measures communication, daily living skills, socialization, and motor skills, and gives a composite score of overall adaptive functioning for individuals between 8–89 years of age. The communication subscale is divided into receptive, expressive, and written communication domains. The Daily Living Skills domain encompasses hygiene, self-care, household maintenance, and use of time, money, and some vocational skills. Leisure skills are defined even more precisely within the socialization domain,

which includes a subdomain for Play and Leisure skills, as well as for Interpersonal Relationship Skills, and Coping skills. There is also a Motor skills domain, which is comprised of both Gross and Fine Motor subdomains. Within the *VABS*, adaptive behavior encompasses all of the scores in the domains and subdomains. Subdomains relating to life skills are measured in the Daily Life Skills domain and leisure skills are measured only within a subdomain.

Adaptive Behavior Assessment System: 2nd Edition (ABAS-II; Harrison & Oakland, 2003)

Another commonly-used measure of adaptive functioning is the *ABAS-II*. This measure can be used from birth to age 89. Three domains are assessed; Conceptual Reasoning, Social Interactions, and Practical Functioning. The ABAS-II measures skills in the areas of communication, community use, functional activities, home living, health and safety, leisure, self-care, self-direction, social, work, and motor skills. A global measure of "life skills" would include home living, health and safety, self-care, and self-direction. Vocational skills are measured through the work and self-direction subdomains.

Scales of Independent Behavior, Revised (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1997)

The SIB-R is another norm-based assessment of adaptive behavior. The SIB-R has been normed for individuals from birth to age 80. This instrument measures adaptive behavior which is divided into the following categories: Broad Independence, Motor Skills, Social Interaction and Communication Skills, Personal Living Skills, and Community Living Skills. Vocational, life skills, and leisure skills are not defined as such and the skills that fall within these domains would be categorized by the SIB-R as either Broad Independence, Personal Living Skills, and Community Living Skills. Unlike the VABS-II and the ABAS-II, the SIB-R also measures maladaptive behavior and categorizes them by the following categories: General, Internalized, Asocial, and Externalized. This information is useful when planning treatment protocols for individuals, as this information can be used to help determine the appropriate training and setting for the individual.

The VABS-II, ABAS-II and SIB-R are useful for obtaining a global measure of an individual's adaptive behavior and can also be useful in determining specific skills deficits. This measure is useful for research or settings in which it may be necessary to compare individuals, as in group training settings. The specific subdomains can be targeted and trained. These measures can also be used to estimate an individual's developmental level.

Other Means of Measuring Adaptive Behavior

Adaptive behavior is also measured through other means, including task analysis and behavioral observations. In task analysis, an activity is analyzed and divided into its component skills, and the skill deficits in a task can be identified and measured. The presence of adaptive behavior skills can also be measured through direct observation, as well as by interviewing the individual and others who know him or her well. Ipsative methods are useful for determining which particular skills are needed to complete the individual's necessary or preferred tasks. These methods are particularly useful when one wishes to obtain information on adaptive functioning within a specific setting or for specific tasks.

Treatment Methods

There are a number of programs that exist to train social skills and communication to high functioning adolescents with ASD. Some of these programs focus on parent training, a cognitive-behavior therapy, or are specifically designed to generalize social skills to a variety of common situations. All of these methods are used to prepare the individual for more independent living (Cappadocia & Weiss, 2011; Rao, Beidel, & Murray, 2008). Fewer methods have been specifically used to train other kinds of adaptive skills. However, the most common and effective method of teaching all adaptive skills to those with ASD utilizes applied behavior analysis (ABA) (Callahan, Henson, & Cowan, 2008; Matson, Hattier, & Belva, 2012; Palmen, Didden, & Korzilius, 2010; Sheridan & Raffield, 2008; Simpson, 2005).

Applied Behavior Analysis

ABA is a subfield of psychology and education and as such will not be discussed in detail except within the context of the specific techniques that have been used to train behavior. An ABA program generally begins by measuring antecedents, operationally defining target behaviors, and determining the consequences of the behaviors. In a training session, the antecedent is the prompt, which is intended to result in the occurrence of the target behavior. Correct responses are followed by a consequence (generally the delivery of a reinforcer), which increases the likelihood of future correct responses.

Antecedents, behaviors, and consequences are recorded, and as the individual progresses through the training program and begins to master the target behavior, the target behavior becomes more challenging or complex. An ABA treatment can include functional analysis, task analysis, modeling, prompting, fading, shaping,

self-monitoring, punishment, role-play, and feedback, and may vary on the degree to which particular techniques are utilized in training. Some of the commonly-used techniques in training adaptive behavior will be discussed individually. The principles of ABA form the foundation of many specific methods used to train adaptive behavior and form the basis of many of the following techniques. Shaping, chaining, fading, modeling, and errorless learning are the methods that have most commonly been used to train adaptive behavior.

Choosing an Effective Reinforcer

Determining which reinforcers are most effective is important in the success of an ABA program. Most reinforcers utilized in ABA are positive reinforcers, in which the individual obtains or gains something from a correct response. Preference assessments can be utilized to determine the most effective positive reinforcer for the individual. There are a number of ways in which a preference assessment can be conducted. In the forced choice method, the therapist collects a number of the individual's preferred items; these may be edibles (e.g., candy, crackers, drinks), requests for activities (e.g., playing a favorite song), or tangible items (e.g., books, gadgets, art supplies), or social reinforcement (praise, social approval, or attention). These may include items that the individual is not familiar with but potentially reinforcing. The therapist then presents two reinforcers at a time, allowing the individual to choose the preferred reinforcer out of the two. Then, the most preferred reinforcers are paired with one another and the individual selects the preferred reinforcers out of those choices. In this way, the therapist develops a hierarchy of the items or activities that are most likely to effectively reinforce behavior during therapy.

Shaping

Shaping occurs when the trainer reinforces successive approximations to a target behavior. As training continues, the levels at which reinforcements are provided are defined according to predefined successive approximations. Thus, the individual's behavior is gradually refined into the target behavior. Criteria for reinforcement increase with increased skill proficiency.

Chaining

Chaining involves teaching the task step by step and is generally preceded by a task analysis. Three types of chaining have been developed: forward, backward, and total task. In forward chaining, the initial step of the target behavior is taught before the subsequent steps. The trainer may then use a prompt hierarchy to assist the individual in completing the remaining steps using increasing degrees of prompting, generally from verbal, to gestural, to physical (i.e., hand-over-hand assistance).

In backward chaining, the trainer will assist the individual in completing all steps ending with the last step of the task, which must be learned before the individual is taught the preceding step. Using total task chaining, the therapist uses the prompt hierarchy at each step of the task, allowing the person to complete the step with decreasing levels of assistance until the task is learned.

Fading and Errorless Learning

Shaping and chaining are often combined with fading, in which the prompts are gradually removed from the training situation. Ultimately, the individual completes the entire task without the need for prompts. These methods may be combined in a manner which minimizes client error, and is referred to as "errorless learning". In order for this to occur, shaping and chaining procedures must occur smoothly with only small differences between successive approximations of the behavior.

Modeling

Modeling occurs when the individual views the task being completed by another person. The individual should then imitate the actions of the therapist to complete the task independently. Modeling can be presented in a number of ways, and tasks can be presented as a whole, or in component parts as determined by a task analysis.

Task Analysis

Task analysis involves operationally defining a task and dividing the target task into smaller components. Then, the individual steps are defined and taught. This method can be conducted on its own, or can be combined with a prompt hierarchy in which the intensity of the prompts is decreased as the individual's skills improve.

Task analysis has formed the basis for many methods used to train adaptive skills. Garff and Storey (1998) trained workplace hygiene skills through teaching specific self-management strategies. Each of the three participants was chosen due to persistent hygiene issues that would result in undesirable social and occupational consequences. The target for the intervention was individualized according to the person's particular deficit. The treatment consisted of a prompt hierarchy including a task analysis checklist, initially developed to prompt the individual through the steps to rectify their hygiene issue. The trainer first modeled the steps. Correct imitation of the step was followed by a social reinforcer (praise), and corrective feedback as steps were completed. This study also trained individuals to self-reinforce in order to promote generalization and maintenance of the acquired behaviors. All participants successfully and significantly increased their level of appropriate hygiene.

Similarly, Edrisinha and colleagues (2011) taught four adults with mild or moderate intellectual disability photography. Participants learned to independently take pictures on a digital camera, transfer them to a computer, and print the photos. This training protocol included a video prompted task analysis. Notably, this study generalized learning to a naturalistic setting where the participants independently took pictures outside and then returned to independently transfer and print the images. This training method was also relatively efficient; all participants were able to respond independently 80 % of the time from between 1 and 8 training sessions. Two participants required a total of 14 training sessions to complete all steps independently (Edrisinha et al., 2011).

Prompt Fading

Prompt fading is an ABA method where prompts are gradually removed until individual no longer requires prompting to complete the targeted task. Two types of prompt fading are used: most to least, and least to most. In most to least prompt fading, the level of prompt begins at its highest level. The therapist immediately assists the individual through all steps of the task and then decreases prompt levels, (i.e., from physical to gestural assistance) as competence is achieved. Least to most prompt fading begins with the least amount of prompting, which increases as required by the individual. For example, the individual would be given the opportunity to independently tie his shoes before the therapist begins with the lowest level of prompt, (i.e., from verbal to gestural prompting).

Prompt fading has been used with moderate success in training vocational skills. Duran (1985), for example, trained three adolescents with ASD and mild intellectual disability (IQ 60–70) on an 18-step restroom-cleaning program using this technique. Training began with a task analysis followed by prompts that were administered decreased across three levels. The treatment was effective, with the participants achieving 70 % proficiency after prompts were withdrawn. Participants were able to generalize acquired cleaning skills to approximately 50 % of new restrooms.

Visual Cuing and Prompting

Cued prompts can be administered in a variety of ways, but generally involve some form of visual stimulus designed to guide the student through the task. As the student completes the task, (s)he follows each subsequent prompt. Prompts may be presented in many ways, such as written language, ideographs, photographs, or videos. A variety of novel methods are now being used to present visual prompts, particularly tablet computers and smart phones.

Frank, Wacker, Berg, and McMahon (1985) taught computer skills to people with ID. Picture prompts were used to guide participants through the steps of

opening, accessing, and closing computer programs. These participants quickly acquired skills and retained them after a 7-day period in which they did not have access to a computer.

Another effective job-skills intervention involved the use of antecedent prompting using audio or picture cues. This technique allowed the employee to independently initiate and self-monitor job tasks. Prompting in general has been successful in training relatively complicated task sequences as well as teaching individuals to manage their own time. In studies, these skills have readily generalized across situations and environments with little additional training (Bambara & Cole, 1997; Lancioni & O'Reilly, 2001).

Another study involved the use of teaching occupation-related sight word lists to employees who are unable to read, and trained work completion tasks on checklists. This technique has proven effective in one study. This study resulted in the successful self-initiation of job tasks, the ability to use job-related sight words, and enhanced greater satisfaction with the employee on job performance (Browder & Minarovic, 2000). An additional study by Minarovic and Bambara (2007) taught three adult janitorial employees with intellectual disability to use checklists through teaching word recognition, comprehension, and self-management instruction on effective use of a list. In this study the participants were able to not only utilize the original word list they had learned, but this ability generalized to other lists using the same words in a different order. Successful use of a checklist was maintained even after the withdrawal of verbal reinforcement. Generalization of learned sight wordlists is particularly applicable for use related to pedestrian and safety skills. The ability to identify and understand highly important words and follow a checklist can result in higher independence. This may result in a decreased need for assistance in the workplace, decreased stigma of the intellectual disability, and may allow for the individual to utilize the same checklists used by non-disabled coworkers (Minarovic & Bambara, 2007).

Video Modeling

In video modeling, a participant watches another person complete a task that the participant then imitates. Sometimes the whole task is shown at once, and other times the task is modeled step by step. The video is filmed so that the viewer watches the task from a third person perspective.

Video modeling has recently been explored as a method through which to provide cues, and has demonstrated some success. Rehfeldt, Dahman, Young, Cherry, and Davis (2003) taught individuals with moderate and severe intellectual disability to independently make a sandwich using video modeling. In this study three adults were able to make a peanut butter and jelly sandwich at 100 % accuracy after watching video modeling of the task. Verbal praise was used as the reinforcer. The skill was then successfully generalized to another kitchen at the individual's sheltered workshop, and successfully maintained the skill for a month after the termination of training.

Goodson, Sigafoos, O'Reilly, Cannella, and Lancioni (2007) taught developmentally disabled adults to independently set a table using antecedent prompts presented in the form of step-by step computer-administered video clips. Of the four participants, three had an additional diagnosis of ASD. One of the four participants learned to set a table solely as a result of viewing the video prompt. However, when an error-correction protocol was implemented; the appropriate step in the video clip was replayed when an error was made. Using this technique all four participants were able to learn to set the table independently and without error.

Video Prompting

In this method, prompts used to guide participants through a task are administered by video. In contrast to video modeling, video prompts are filmed from the perspective of the participant. The video pauses after each step of the task to allow the person to complete that step before watching the subsequent step.

Video prompting has been shown to be effective for administering prompts. Sigafoos et al. (2005) successfully used this method to teach individuals with an intellectual disability to use a microwave oven. Additionally, Cannella-Malone et al. (2006) compared video prompting to video modeling in individuals with ASD. Video prompting was more effective than video modeling in six adults. In this study, video modeling was found to be ineffective. However, these results seem to be related to experimental conditions. In the modeling protocol, the participants watched the task in its entirety prior to starting, instead of watching and completing each step individually.

ABA-Based Therapies and Techniques

When designing a therapy, ABA methods may be combined in the way that is most appropriate to the target task. Specific methods are rarely used in isolation. ABA-based therapy can be administered to the individual in a number of innovative ways, which allow for the use of additional materials, technology, and provide a high degree of flexibility to the setting without compromising the integrity of the method.

In one such study, Jerome, Frantino, and Sturmey (2007) combined errorless learning and backward chaining to successfully teach three people with ASD and mild intellectual disability to use a computer to access-preferred websites. Two participants required a single 40-min teaching session to learn to complete the task, while the third was able to independently complete all steps of the task after five training sessions. In this case, the reinforcer (the preferred website) was intrinsic to the task, and the access to preferred website also functioned as the goal of the treatment. This treatment developed skills that will result in self-reinforcement of leisure behavior. These skills can then be generalized to other computer tasks where the individual can either obtain reinforcers independently, or produce something (such as a document) that may lead to social reinforcers.

ABA encompasses a variety of techniques that may be combined when designing a treatment. However, there are numerous ways to administer the antecedent, delivery of reinforcer, and structure a treatment. A major strength ABA is that it is highly adaptable and can be used to train a wide variety of life, leisure, and vocational skills.

Individualized Scripts

Scripting of self-care, vocational, and leisure scenarios may be used to increase adaptive behavior. In this method, scripts are written in the first person and designed to guide the individual through the target activity. This technique has not been widely researched for use in conducting vocational or leisure tasks, and is most commonly used in training social communication. One system for scripting social situations is Social Stories™.

Individualized scripts are designed to guide the person through the various steps of a social situation. Scripts can be used alongside ABA. Task analysis, visual aids and symbols, priming, and cueing can be used to inform the development of such a script. Scripts generally involve descriptions of relevant social, environmental, and behavioral cues present in the situation, directive statements and instructions on how to respond to cues, statements illustrating thought sand feelings of others, and qualities and expected or typical behaviors that occur within the setting.

The principles of individualized scripting can be adapted for occupational and recreational situations. For example, a script to teach an individual to play tennis might first describe the preparations one would undertake prior to playing tennis. Relevant information about social expectations would be reviewed (e.g., dressing appropriately, wearing tennis shoes, and using a water bottle). Training could include a variety of details about the situation according to the needs of the individual. For example, it could describe the court and the meanings behind the different lines on the court (in- vs. out-of-bounds) and may illustrate rules (different lines used for doubles vs. singles matches), and the object of the game. It could then describe the individual's expected behavior while playing tennis ("I stand behind the base line as I serve the ball, taking care not to cross the line before the ball is struck"), typical game play, and responses to common occurrences. The story could include descriptions of alternate ways the game could end. The narrative could also describe how the individual can keep score, and what interactions are likely to occur after a game ("When the game has ended, we approach the net, shake hands, and say 'good game' to one another"). Scripts can and should be constructed based on a task analysis of the situation, taking into account social, leisure, and situation-relevant information.

An advantage in using social scripts is that it is a highly face valid method of teaching skills, and may function as a prompt. However, research on this method of treatment is lacking, and many of the studies used very small samples, which may have suffered from selection bias, and results have been mixed. However, there is some support that scripting effectively increases participation in leisure activities

(Barry & Burlew, 2004). Based on a meta-analysis of scripting studies based on Social Stories™, this method is considered to be only mildly effective. However, results may be obscured due to vast differences between methods, lack of participant information, lack of a diagnosis, and issues with procedural reliability. According to Reynhout and Carter (2011) scripting appears to be only mildly effective overall, but may be highly effective in certain cases. Further research into this topic may help to elucidate those cases in which scripting is most effective.

Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH; Mesibov, Shea, & Schopler, 2004)

Vocational and life skills training are a major focus of a TEACCH program. TEACCH is a program for training and educating children with ASD and differs from ABA in a number of ways. TEACCH focuses on training both the children and their families to cope with the condition of ASD, and does not aim to cure ASD, but rather assist these in adapting to their environment. This training program engages parents as co-therapists for their children, and provides structured teaching, supported living, and occupational opportunities for the individual. It is based on the developers' findings that social interactions are the result of perceptual particularities, and that inappropriate maternal behavior results from these particularities. According to TEACCH, these issues can be remedied through education, and the program was designed to reverse this effect and provide targeted training for individuals with ASD, which was a particularly underserved population at the time of its development (Mesibov, Shea, and Schopler, 2004).

Few studies have been conducted to examine the effect of a TEACCH curriculum on global or specific adaptive skills. However, the TEACCH program does specifically address the vocational skills needs of its students (Keel, Mesibov, & Woods, 1997). There are three types of employment placement offered by TEACCH: individual placement, dispersed enclave, and mobile crew models. For students in any of the placements, emphasis is placed on identifying the individual's strengths and interests, and ensuring that jobs meet their goals. The individual placement model is similar to typical community placement arrangements, where a job coach assists with an individual's job placement in the community. In the TEACCH framework, this job coach eventually fades out of the setting. In dispersed enclave model, a job coach is assigned to several individuals with ASD who work in the same setting. However, in this model the individuals with ASD work independently and may not have the same job. These individuals receive daily assistance from their coach. The mobile crew consists of 2–3 individuals with ASD who provide mobile community services, such as housecleaning. This arrangement is for those who are less independent and receive constant supervision from their job coach.

Two fundamental elements of the TEACHH curriculum are "work systems" and "task organizations". Work systems are sets of visual information that instruct a student on what to do at their work and recreational stations, including

what to do, how much to do, and how they will know when they are finished. Task organizations provide visual information about the learning task, and may include a "blueprint" of the layout of items needed for the task, with more detailed explanations. These visual cues provided in the work systems and task analysis aim to foster independent functioning and decrease error and need for correction. The four basic components of the TEACHH program include the physical structure of the classroom, visual schedules, work systems, and task organization (Mesibov et al., 2004).

A study by Hume and Odom (2007) utilized "work systems" according to the TEACCH framework. This study included three students, ages 6, 7, and 20 with ASD, who were identified by teachers as having particular difficulty initiating and completing tasks independently, and who were familiar with the use of visual schedules, but no experience with work systems. The study utilized an ABAB withdrawal treatment design alternating the baseline, during which no treatment was given, with the administration of the work system. This program resulted in increased on-task work and play behavior and decreased the need for teacher prompts, and these differences were maintained for at least one month post training.

A quasi-experimental study compared levels of adaptive behavior among children in Italy who received a TEACCH curriculum compared to children who lived at home and received a standard Italian special education curriculum, and children receiving a standard Italian educational curriculum with TEACCH-trained teachers and parents (Panerai, Ferrante, and Zingale, 2002). Those in the TEACCH groups exhibited better developmental progress and fewer challenging behaviors than those in the standard curriculum. While a TEACCH-based curriculum seems promising and integrates some of the components of ABA-based programs, additional experimental research is needed to investigate its efficacy compared to standard school and ABA-based methods, and to determine to what extent it is effective in teaching other types of adaptive behavior.

Types of Treatment Settings

It is important to consider the role of setting when designing and planning a treatment. Skills may be trained in a variety of places. In particular, it is important to determine whether the training will take place in vivo (i.e., where the behavior would naturally occur), a simulated setting, or general setting. In vivo settings may be within environments in the community, or take place within settings specifically for individuals with intellectual disability or ASD (e.g., sheltered work settings, day programs, recreational areas, community employment setting, or schools). While in vivo training is generally preferred because it provides the natural setting and avoids the need to generalize training from an artificial setting, there are some drawbacks. For example, therapy in a simulated or general setting may be preferable for those who display problem behaviors in the natural setting, for situations in which the natural setting is not readily accessible, or situations in which the natural setting may distract from the therapy.

The question of setting is of a greater consideration for some tasks compared to others. For example, therapy for many basic hygiene tasks (e.g., toileting, brushing teeth) should take place solely where these tasks will be performed. Other, more advanced skills (e.g., using a telephone, safety and pedestrian skills) should generalize to all settings to be considered adaptive and should thus be trained in various settings. This should be taken into account during training. However, as vocational and recreational skills are ideally performed in community settings, treatment setting is an important consideration.

In-Vivo Training: In this type of treatment, participants immediately engage in the targeted activity, and are trained at their place of work or leisure. A variety of methods can be used to model the target behaviors. An advantage to training in vivo is that individuals can immediately participate in the target activity in the work environment, which minimizes the need to generalize the behavior to the work setting at a later time.

Placement of individuals with ASD in work settings has been shown to result in decreases in the core symptoms of ASD and problem behaviors. A benefit of in-vivo training over treatments that take place outside the workplace is that the individual is placed immediately in the work environment, which results in increases in cognitive functioning. Garcia-Villamisar and Hughes (2007) compared the cognitive functioning of 44 adults with ASD placed in competitive employment to those with no employment while members of each group received vocational training at home or in the workplace. Only those in competitive employment settings experienced significant increases in cognitive functioning over the 30-month course of the study. This illustrates a potential benefit of integration into a workplace or community setting.

It is therefore preferable to place eligible individuals in in-vivo work training settings instead of simulated or general training settings, when possible. Similar studies have corroborated the benefit of on the job training in contrast to purely developmental center-based training (Olney & Kennedy, 2001; Rusch & Hughes, 1989). This finding may be in part due to a wider variety of tasks available to those in supported employment, which is also likely to expose individuals to a variety of adaptive skills and allow greater independence. In addition, those in the community are able to interact with others, obtain social reinforcers, and develop relationships outside their home or training setting.

Simulated Work Environments: Simulated work environments can also be used to train skills, particularly when training in vivo is not practical or feasible. In this method, the training is conducted in a setting that resembles the actual work or leisure environment. Care is taken to obtain the same materials that would be used in the actual environment, and the work environment is simulated as closely as possible.

Lattimore, Parsons, and Reid (2006) utilized a simulated occupational setting to train adults with ASD to work at a publishing company and an adult education center. In this setting, the study compared job site training involving decreasing levels of prompt to job-site training with supplemental simulation, and found that

conditions with supplemental simulation improved learning. Participants included four men ages 29–49 with severe to profound intellectual disability. Participants were matched against a control with a similar functional level who worked the same amount of time. One pair was trained to prepare envelopes for mailing books and to empty garbage cans, and the other was trained to prepare envelopes and make packing paper. Criteria were met when the worker was able to prepare all steps of the task independently (with no prompting).

Those in the simulation condition were also trained at an in-vivo work site at the developmental center where they lived. Items they were trained on were similar to what the workers used on the job. Those who received simulation in addition to on the job training learned more quickly. However, all participants were able to maintain acquired job performance skills. This study demonstrated the efficacy of the training protocol, but it was not clear as to whether the simulated work environment or the additional training sessions accounted for improvement learning.

Another study successfully trained a group of four 12- and 13-year-old boys to successfully request vocational assistance for both trained and unexpected problems in a simulated job setting (Dotto-Fojut, Reeve, Townsend, & Rogar, 2011). This study utilized ABA methods of prompt hierarchy, scripts, and fading within the setting. All boys successfully learned to ask for help, but generalization to an actual work setting was not attempted.

General Settings: Skills may also be effectively taught within a general setting. That is, a setting that does not attempt to provide a naturalistic setting for the target behavior (e.g., a school or training center). Therapy in a general setting is preferred for those skills that should be practiced frequently, for building prerequisite skills, and for when in vivo or simulated settings are not necessary, convenient, or feasible. Most ABA training takes place in academic or home settings and remains an effective method in which to teach skills. Care must be taken, however, to ensure that target skills generalize to the environments where they will be performed, in order for the developed skills to be truly adaptive.

Additional Innovations in Treatment Techniques

Because ABA consists of principles and specific components that are necessary for effective treatment of adaptive behavior, specifics of the treatment are flexible. Training materials can be adapted or presented in a number of ways, and recently devices such as smart phones and tablet computers have been used as unobtrusive cueing devices in training scenarios. Eyetracking devices allow for new ways of interfacing with a computer and provide a promising method in which antecedents and reinforcers can be administered with great precision and customizability to individuals of all intellectual levels, but as of yet, the potential of this technology to teach adaptive behavior has not been explored. Video games are becoming increasingly realistic and have the potential to provide more sophisticated simulation with potential for widespread applications in therapeutic contexts.

Such technology is becoming less costly and more widely available and has resulted in simpler and more portable means of prompting and modeling. The possibilities for the ways these devices may be used are just beginning to be explored. These technologies have potential to be used as adaptive devices that can allow an individual to carry a large number of personalized prompts, video models, scripts, and other training and adaptive materials. Because smart phones and tablet computers are now ubiquitous, they are not likely to be perceived by others as training or adaptive devices, which reduces stigma and increases privacy for users.

Clever uses of these devices have been shown to be effective. In one study, six adolescents with ASD were trained to teach fire safety drills while dressed in an inflatable mascot costume. The company's behavioral training did not prove effective for these individuals; only one met criteria and was able to complete the task after standard training. However, the inflatable costume allowed participants to utilize a cuing device (Iphone™) unbeknownst to observers. Those who used the performance cueing device while inside the costume were able to learn the routine to criterion more quickly and maintained criterion levels of performance compared to controls. Participants also increased their levels of social responding while in the inflatable mascot costume compared to when they were engaged in face-to-face interactions (Burke, Andersen, Bowen, Howard, & Allen, 2010). Continued studies of potential uses for ubiquitous new technologies such as smart phones and tablet computers may result in effective assistive technologies for individuals with ASD.

Researchers have begun to explore potential uses for consumer-level technologies. Though these technologies have potential to be used in training adaptive behaviors, these trainings have presently focused on training communication skills in an ASD population. Recently, Shane, Laubscher, Schlosser, Flynn, Sorce, and Abramson (2012) described various ways in which these technologies are currently being used as augmentative and alternative communication devices, and offer suggestions as to how they may be used in the future.

Conclusions

Adaptive behavior comprises all of the skills needed to perform the activities necessary for independently managing one's life, and participating in enriching activities. Compared to individuals with developmental disabilities and mental illness, those with ASD are more likely to exhibit deficits in adaptive behavior. Deficits in adaptive behavior are closely linked to the core deficits of ASD, which impede learning. Adaptive behavior is a broad category encompassing life skills, which comprise all of those skills needed to manage one's own life, and conduct leisure and occupational/vocational activities. Currently, the most effective treatments for improving adaptive behavior skills in individuals with ASD utilize an ABA framework.

Vocational, leisure, and other adaptive skills are necessary for individuals with ASD to successfully integrate into the community and attain high quality of life. The development of adaptive skills can help to provide increased access to social opportunities. Participation in leisure and vocational activities provides individuals

naturalistic environments to engage in communication and social behavior. High levels of adaptive, vocational, and leisure skills are associated with a number of positive outcomes, including increased independence and quality of life.

As deficits in adaptive, vocational, and leisure activities persist throughout the lifespan, adolescents and adults with ASD should receive continued, effective training to increase their skills and promote independence. The most effective treatments are based on ABA: a scientific, evidence-based framework which is centered on the measurement and observation of antecedents, behavior, and consequences. The specific treatment can be presented in a variety of ways, some of which were discussed. Treatments based on ABA have repeatedly proven successful in the acquisition and maintenance of adaptive skills.

ABA allows for a great deal of innovation and flexibility in the administration of treatment, and is highly specific to the individual. The administration of prompts, models, and scripts can be carried out in innovative ways. As sophisticated devices such as such as smart phones, tablet computers, video/still cameras, and eye trackers continue to become more affordable and accessible, they can be widely used to train skills and can provide the user a customized, personal, on-demand training and assistive experience. Researchers should continue to explore effective uses of new technology in training adaptive behaviors.

In conclusion, life, leisure, and other adaptive skills encompass the myriad of abilities and activities needed to function independently. Thus, adaptive behavior is not only a broad construct but also one that is of the utmost importance when considering treatment for individuals with ASD. A variety of techniques have been developed that have been shown to be of use, or appear promising in aiding acquisition of adaptive behavior skills. ABA has been found to be the most effective method of teaching a wide range of adaptive behaviors, and has become the standard framework for treating ASD. As training one skill can be done in a variety of ways using ABA, the specific manner in which the principles are applied allows for a great deal of innovation. Researchers should continue to investigate effective treatments for increasing all types of adaptive behavior skills, given the universal need for such training for persons with developmental delays.

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Chapter 9
Pharmacotherapy of Behavioral Symptoms and Psychiatric Comorbidities in Adolescents and Adults with Autism Spectrum Disorders

Carolyn A. Doyle, Christopher J. McDougle, and Kimberly A. Stigler

This chapter will focus on the pharmacologic treatment of adolescents (12–18 years) and adults with autism spectrum disorders (ASDs). Research on the pharmacotherapy of associated symptoms of autism, such as interfering repetitive behaviors, irritability (tantrums, aggression, self-injury), and hyperactivity will be reviewed. In addition, the available literature on drug treatment of psychiatric comorbidities in ASDs will be covered, including mood and anxiety disorders, among others. This chapter will cover the available literature in adolescents and adults with ASDs. Because research to date in ASDs has largely focused on the treatment of children, key double-blind, placebo-controlled studies in this population will be summarized where applicable. Further, many studies of pharmacotherapy include children as well as adolescents and/or adults, making it difficult to generalize the results to any population.

C.A. Doyle, M.D. • K.A. Stigler, M.D.
Department of Psychiatry, Indiana University School of Medicine, Indianapolis, IN, USA

Christian Sarkine Autism Treatment Center, Riley Hospital for Children,
Indianapolis, IN, USA
e-mail: cardoyle@iupui.edu; kstigler@iupui.edu

C.J. McDougle, M.D. (✉)
Department of Psychiatry, Harvard Medical School, Boston, MA, USA

Massachusetts General Hospital, Lurie Center for Autism,
1 Maguire Road, Lexington, MA, USA
e-mail: cmcdougle@partners.org

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Developmental Perspectives on Psychopharmacological Treatment

It is important to emphasize that evidence supporting the efficacy and tolerability of medications in children and adolescents with ASDs may not necessarily be applicable to adults with ASDs, so practitioners should exercise scrutiny when applying such findings to adults and vice versa. Differences have been observed between children and adults with ASDs with regard to psychotropic medication response and tolerability. These differences are likely attributable to central nervous system neurotransmitter changes, most notably serotonergic, that occur across the lifespan (Vitiello & Jensen, 1995). Understanding changes within the serotonin system and potential correlations with symptom manifestation may help guide practitioners in choosing appropriate pharmacotherapeutic interventions.

Serotonin

Serotonin [5-hydroxytryptamine (5-HT)], was one of the first neurotransmitters to garner attention in the pathophysiology of autism. The 5-HT system is one of the first neuronal systems to develop in the human brain, with 5-HT guiding brain proliferation and maturation (Whitaker-Azmitia, 1993).

In 1961, Schain and Freedman noted hyperserotonemia among a cohort of children with autism, and hypothesized that 5-HT dysregulation may contribute to the neurobiology of the disorder. Children and adolescents with autism have been found to have elevated whole blood serotonin (WBS) levels compared to non-autistic children with mental retardation (MR) (Schain & Freedman, 1961) as well as typical controls (Anderson et al., 1987; Leboyer et al., 1999; Ritvo et al., 1970). Leboyer et al., (1999) observed that although WBS concentrations decreased with age in typical controls, WBS levels were independent of age in subjects with autism. Clinical variation in response to selective serotonin reuptake inhibitors (SSRIs) has been shown in individuals with autism compared to non-autistic patients. These studies underscore significant differences in the concentration and function of 5-HT in individuals with autism across the lifespan.

Pharmacotherapy of Symptoms Associated with ASDs

Interfering Repetitive Behaviors

Medications with serotonin reuptake blocking properties have been widely studied in the treatment of interfering repetitive behaviors in ASDs. As described above, dysfunction of the 5-HT system has been implicated in the pathophysiology of autism, rendering the possibility that medications affecting this system may be helpful.

Secondly, the efficacy of many SSRIs [as well as the tricyclic antidepressant (TCA) clomipramine] in the treatment of obsessive-compulsive disorder (OCD) has led researchers to study their effects on the interfering repetitive behaviors seen in ASDs. Studies involving interfering repetitive behaviors that do not involve comorbid OCD will be reviewed in this section.

Tricyclic Antidepressants

Clomipramine

In adults with autism, an early case series and an open-label trial of clomipramine demonstrated effectiveness in the treatment of interfering repetitive thoughts and behaviors (Brodkin, McDougle, Naylor, Cohen, & Price, 1997; McDougle et al., 1992). Differences in global clinical improvement with clomipramine treatment were observed by diagnosis, with response noted in 63 % of those with autism, 33 % of those with Asperger's disorder, and 55 % of those with pervasive developmental disorder not otherwise specified (PDD-NOS) (Brodkin et al., 1997).

There are two double-blind, placebo-controlled crossover trials of clomipramine that include combined cohorts of children, adolescents, and young adults (Gordon, State, Nelson, Hamburger, & Rapoport, 1993; Remington, Sloman, Konstantareas, Parker, & Gow, 2001). Mean ages were 16.3 and 10.4 years, respectively, so results may be more applicable to younger populations.

The Gordon et al. (1993) study compared treatment with clomipramine to desipramine, another TCA with more prominent noradrenergic activity, in 12 subjects, aged 6–23 years (mean age, 10.4 years). Clomipramine (mean dose, 152 mg/day) was found to be more effective than placebo and desipramine (mean dose, 127 mg/day) at decreasing stereotypies, anger, and compulsive, ritualized behavior. Both TCAs were superior to placebo at ameliorating hyperactivity. Adverse effects as a whole were minor, with no statistically significant differences between the drugs and placebo. However, clomipramine was associated with prolonged QTc interval in one subject and tachycardia in another. Dose reduction resolved these issues. Another subject experienced a grand mal seizure and was dropped from the study.

The Remington et al. (2001) study compared clomipramine to haloperidol, a typical antipsychotic, in the treatment of stereotypy in 36 subjects aged 10–36 years (mean age, 16.3 years). Clomipramine doses ranged from 100 to 150 mg/day (mean dose, 128.4 mg/day). Due to poor tolerance, only 37.5 % of the participants randomized to the clomipramine group were able to complete the trial, compared to 69.7 % in the haloperidol group and 65.5 % in the placebo group. Among those who completed trials of both drugs, clomipramine was comparable to haloperidol in terms of improvement from baseline. Clomipramine was effective on a measure of stereotypy, but it was not more effective than haloperidol. Identified adverse effects that limited trial completion in 12 (37.5 %) of the 32 clomipramine-treated subjects included fatigue or lethargy, tachycardia, insomnia, diaphoresis, nausea or vomiting, decreased appetite, and behavioral problems.

Selective Serotonin Reuptake Inhibitors

Fluvoxamine

A case report of a 20-year-old female with autism showed that fluvoxamine (100 mg/day) led to improvements in repetitive behaviors, as measured by the Yale-Brown Obsessive Compulsive Scale (Y-BOCS) (Harvey & Cooray, 1995).

A 12-week, randomized, double-blind study examined fluvoxamine (276.7 mg/day) in 30 adults with autism, aged 18–53 years (mean age, 30 years), and found the drug superior to placebo for repetitive thoughts and behavior, maladaptive behavior, and aggression (McDougle et al., 1996). Eight (53 %) of 15 patients who received fluvoxamine were considered responders, compared to none in the placebo group. Language usage also improved as the result of decreased repetitive questioning. Fluvoxamine was well-tolerated with few adverse effects. Nausea and mild sedation occurred in a few patients.

In contrast to these studies of adults, controlled studies of fluvoxamine in children with autism have revealed poor efficacy and tolerability (McDougle, Kresch, & Posey, 2000; Sugie et al., 2005).

Fluoxetine

Case reports in adolescents and adults have shown both favorable and unfavorable responses to fluoxetine in the management of interfering repetitive behaviors.

One double-blind, placebo-controlled study of fluoxetine in adults with autism has been conducted to date. This 12-week trial of 37 subjects, aged 18–60 years (mean age, 34 years), revealed moderate efficacy of fluoxetine (mean dose, 64.8 mg/day) in the treatment of repetitive behaviors (Hollander et al., 2012). There was a 50 % response rate in the fluoxetine-treated group compared to 8 % in the placebo group. Adverse effects were mild to moderate and included bad or vivid dreams, insomnia, dry mouth, and headaches.

The results in adults are in contrast to a large, multi-site, randomized study of fluoxetine in children, where the drug was not effective in the management of repetitive behaviors (Autism Clinical Trials Network, Autism Speaks press release, 2009).

Sertraline

One open-label study of sertraline in 42 adults with ASDs, aged 18–39 years (mean age, 26 years) demonstrated moderate effectiveness and good tolerability in the treatment of repetitive behaviors (McDougle, Brodkin, et al., 1998). Notably, better treatment responses were observed in adults with autistic disorder and PDD-NOS compared to Asperger's disorder.

Citalopram

There are currently no published double-blind, placebo-controlled studies of citalopram in the treatment of repetitive behaviors in adults with ASDs. In children and adolescents, King et al. (2009) conducted a large, multi-site, double-blind, placebo-controlled trial that found no significant difference between citalopram and placebo in the treatment of repetitive behaviors. There also was an increased likelihood of adverse events. This study demonstrates poor response and tolerability of the drug in children. Studies in adults are needed to better understand the efficacy and tolerability of citalopram in this population.

Antipsychotics

Haloperidol

The only study of haloperidol that included adolescents and adults with autism was in the aforementioned study by Remington et al. (2001). Haloperidol was dosed from 1 to 1.5 mg/day (mean dose, 1.3 mg/day). In the treatment of stereotypy, haloperidol and clomipramine were comparable in terms of improvement from baseline. Adverse effects, such as fatigue or lethargy, dystonia, depression, and behavioral problems, led to discontinuation in 7 of 33 (21 %) subjects.

Risperidone

A 12-week, randomized, placebo-controlled trial that examined 31 adults with autism and PDD-NOS, aged 18–44 years (mean age, 28 years), found risperidone (mean dose, 2.9 mg/day) significantly more effective than placebo in reducing interfering repetitive behavior, as measured by the compulsion subscale of the Y-BOCS (McDougle, Holmes, et al., 1998). Aggression towards self and others was also significantly reduced. Risperidone was well-tolerated. Adverse effects included mild, transient sedation.

Olanzapine

One small open-label study of olanzapine (mean dose, 7.8 mg/day) in 12 adults with ASDs, aged 5–42 years (mean age, 20.9 years), showed no statistically significant change in repetitive behaviors as measured by the Y-BOCS compulsion subscale (Potenza, Holmes, Kanes, & McDougle, 1999).

Quetiapine

Quetiapine treatment (mean dose, 250 mg/day) of two adolescents with autism, aged 13 and 15 years, revealed no statistically significant improvements in repetitive behaviors based on the Aberrant Behavior Checklist (ABC) Stereotypy subscale and the Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS) compulsion subscale (Martin, Koenig, Scahill, & Bregman, 1999).

Ziprasidone

One open-label trial of ziprasidone (mean dose, 98.3 mg/day) in 12 adolescents with autism, aged 12–18 years (mean age, 14.5 years), did not reveal statistically significant decreases in repetitive behavior as measured by the ABC Stereotypy subscale (Malone, Delaney, Hyman, & Cater, 2007).

Other Medications

Riluzole

A case series examined this glutamate antagonist in the treatment of three individuals with autism and MR, aged 15–20 years (Wink, Erickson, Stigler, & McDougle, 2011). Dosages ranged from 100 to 200 mg/day. There were reductions in interfering repetitive behaviors in all three subjects. Adverse effects included mild anemia in one individual.

Conclusions

Controlled studies have found that clomipramine has poor tolerability that significantly limits its use, although it has demonstrated some effectiveness in managing interfering repetitive thoughts and behaviors in adolescents and young adults with ASDs. Fluvoxamine and fluoxetine are moderately efficacious and well-tolerated in adults with ASDs, while open-label sertraline showed promising results in the treatment of interfering repetitive thoughts and behaviors. In contrast, controlled studies of SSRIs in children with ASDs have demonstrated poor efficacy and tolerability, suggesting a possible age-effect with regard to this drug class. Additional double-blind, placebo-controlled studies are needed to determine the efficacy and tolerability of SSRIs in adolescents and adults with ASDs.

Haloperidol is comparable to clomipramine in the management of stereotypy in adolescents and adults with ASDs, while risperidone is significantly more effective than placebo at reducing interfering repetitive behaviors in adults with ASDs. Further double-blind, placebo-controlled trials are needed with other antipsychotics to establish efficacy and tolerability in the treatment of interfering repetitive behaviors.

Irritability (Aggression, Self-Injurious Behavior, and Severe Tantrums)

Antipsychotics

Antipsychotic medications are the most efficacious medication class for the treatment of irritability in individuals with ASDs. To date, risperidone and aripiprazole are the only medications that are FDA-approved for the treatment of irritability in children and adolescents with autism. Typical vs. atypical antipsychotics are purported to have a higher risk of extrapyramidal symptoms (EPS) and tardive dyskinesia (TD). Atypical antipsychotics are often associated with increased appetite, weight gain, and metabolic changes.

Haloperidol

The only study of haloperidol that included adolescents and adults with autism was in the aforementioned study by Remington et al. (2001). Haloperidol (mean dose, 1.3 mg/day) was favored over clomipramine in the management of irritability, hyperactivity, and global symptom severity using the Childhood Autism Rating Scale (CARS) and the ABC as outcome measures. Adverse effects, such as fatigue or lethargy, dystonia, depression, and behavioral problems, led to discontinuation in 7 of 33 (21 %) subjects.

Clozapine

Clozapine is an atypical antipsychotic that is limited in use due to an increased risk of agranulocytosis and potential to lower the seizure threshold. A case series in three individuals with autism, aged 15-, 17-, and 27-years-old, highlighted successful treatment with clozapine for the management of recurrent aggression toward self and others (Chen, Bedair, McKay, Bowers, & Mazure, 2001; Gobbi & Pulvirenti, 2001; Lambrey et al., 2010). In all cases, prior antipsychotic medications were not efficacious or had caused EPS. Clozapine (275–400 mg/day), with treatment duration ranging from 15 days to 5 years, was well-tolerated and led to marked behavioral improvement and decreased aggression in all individuals. The Lambrey et al. (2010) report observed a 1-kg weight gain in one individual. Favorable results were also observed in a retrospective analysis of six adolescents and adults with ASDs, aged 14–34 years (mean age, 23 years), who were treated with clozapine (from 10 months to 7 years) for severe aggression, property destruction, and self-injurious behavior (SIB) (Beherec et al., 2011). Weight gain (mean 14.3 kg) was the only significant adverse event.

Risperidone

Risperidone is an atypical antipsychotic that is FDA-approved for the treatment of irritability associated with autism in children and adolescents aged 5–16 years. As such, multiple controlled studies have been conducted of risperidone in youth, supporting its efficacy for this target symptom domain in autism (Desousa, 2010; McCracken et al., 2002; McDougle et al., 2005; Shea et al., 2004).

A 4-week, open-label study of risperidone (modal dose, 0.5 mg twice/day) in 11 individuals with autism, aged 6–34 years (mean age, 18 years), showed improvement in explosive aggression, SIB, and poor sleep hygiene (Horrigan & Barnhill, 1997).

Risperidone was efficacious in a 12-week, double-blind, placebo-controlled trial that examined 31 adults with ASDs, aged 18–44 years (mean age, 28 years) (McDougle, Holmes, et al., 1998). Risperidone was dosed between 1 and 10 mg/day (mean dose, 2.9 mg/day). Eight (57 %) of 14 risperidone-treated participants were deemed responders compared with none in the placebo group. Risperidone was superior to placebo in reducing aggression, irritability, and the overall behavioral symptoms of autism, as well as repetitive behavior, anxiety or nervousness, and depression. Of the 15 patients in the placebo group who received open-label risperidone following the double-blind phase, nine (60 %) were judged to be responders after 12 weeks. Risperidone was well-tolerated. Adverse effects were mild and included mild, transient sedation, and there was no evidence of EPS, cardiac events, or seizures.

The adverse effect of weight gain has also been assessed in adolescents and adults with ASDs, with significant weight gain observed over 1 year of treatment. A double-blind, placebo-controlled crossover study of risperidone in 19 children, adolescents, and adults with autism and MR, aged 6–65 years (mean age, 21 years), for the management of aggression and SIB was conducted (Hellings, Zarcone, Crandall, Wallace, & Schroeder, 2001). Adolescents aged 13–16 years ($n=6$) gained a mean of 8.4 kg (range 3.6–15.5 kg), and adults aged 21–51 ($n=8$) gained a mean of 5.4 kg (range 0–9.5 kg). Tapering and discontinuation of the drug resulted in diminished weight gain.

Long-term risperidone treatment has also been assessed in adolescents and adults with ASDs. A double-blind, placebo-controlled crossover study examined 40 children, adolescents, and adults with MR, 36 of whom had ASDs, aged 8–56 years (mean age, 22 years) (Hellings et al., 2006). Twenty-four (57.5 %) of 40 subjects were considered responders according to a 50 % decrease in the Aberrant Behavior Checklist-Irritability (ABC-I) subscale score, while 35 of 40 (87.5 %) subjects showed a 25 % decrease. Gender, autism diagnosis, mood disorder diagnosis, or concomitant seizure medications did not affect the response. Dosages ranged from 1.2 to 2.9 mg/day for children and adolescents and 2.4–5.2 mg/day for adults. Common adverse effects included increased appetite and weight gain, with mean weight gain equalling 8.3 kg for adolescents and 6.0 kg for adults.

Olanzapine

A 12-week, open-label study of olanzapine (mean 7.8 mg/day) in eight individuals with ASDs, aged 5–42 years (mean age, 21 years), found significant improvements in irritability (and other symptoms) among 75 % of participants (Potenza et al., 1999). Olanzapine was well-tolerated but adverse effects included increased appetite, weight gain, and sedation. Neither EPS nor changes in liver function tests were observed.

Quetiapine

Two open-label studies (12- and 8-weeks, respectively) that have examined quetiapine for adolescents with ASDs (mean ages, 14 years) revealed minimal global treatment response despite significant improvements in irritability (Findling et al., 2004; Golubchik, Sever, & Weizman, 2011). Mean doses were 291.7 and 122.7 mg/day, respectively.

Ziprasidone

A case report described a 15-year-old male with autism and moderate MR who had poor responses to previous psychotropic medications but responded well to ziprasidone dosed 60 mg, twice daily, combined with methylphenidate (MPH) dosed 60 mg/day in divided doses (Duggal, 2007). He demonstrated improved maladaptive behaviors, attention to tasks, hyperactivity, impulsivity, and listening.

A retrospective chart review examined ten adults with autism (mean age, 43 years) who were switched to ziprasidone (mean dose, 128 mg/day) from another atypical antipsychotic to target maladaptive behaviors (Cohen, Fitzgerald, Khan, & Khan, 2004). Sixty percent showed improved behavior, while 10 % had no change and 30 % showed decompensated behavior.

A 6-week, open-label study of adolescents (mean age, 14.5 years) treated with ziprasidone (mean dose, 98.3 mg/day) found 75 % to be treatment responders (Malone et al., 2007). Cardiac QTc interval increased by a mean of 14.7 ms, which was a statistically, but not clinically, significant increase.

A case series that examined children, adolescents, and young adults treated with ziprasidone (mean dose, 59.23 mg/day) for at least 6 weeks found 50 % to be responders (McDougle, Kem, & Posey, 2002). No cardiovascular side effects were reported.

Aripiprazole

Aripiprazole is an atypical antipsychotic that is FDA-approved for the treatment of irritability associated with autism in children and adolescents aged 6–17 years. Thus, several controlled studies have demonstrated its efficacy for irritability in youth with ASDs (Marcus et al., 2009, 2011; Owen et al., 2009; Stigler et al., 2009).

In adults, a case report of a 38-year-old Afro-Caribbean man with autism and MR found that aripiprazole treatment resulted in decreased aggression, weight loss, and improved mobility and alertness (Shastri, Alla, & Sabaratnam, 2006).

Two multicenter, 8-week, double-blind, placebo-controlled studies demonstrated the efficacy, safety, and tolerability of aripiprazole in children and adolescents with autism, aged 6–17 years (mean ages, 9.7 and 9.3 years, respectively), in the treatment of irritability (Marcus et al., 2009; Owen et al., 2009). Dosages were fixed at 5, 10, and 15 mg/day, and all treatment arms produced significantly greater improvement from baseline than placebo in the Marcus et al. (2009) study. The Owen et al. (2009) study utilized a flexible dose design.

Paliperidone

Case reports of a 16-year-old female and 20-year-old male with autism and comorbid MR found significant improvements in irritability after treatment with paliperidone (Stigler, Erickson, Mullett, Posey, & McDougle, 2010).

An 8-week, open-label study of paliperidone (mean dose, 7.1 mg/day) in adolescents and young adults with autism, aged 12–21 years (mean age, 15.3 years), showed significant improvement in the treatment of irritability, as evidenced by an 84 % response rate (Stigler, Mullett, Erickson, Posey, & McDougle, 2012).

Tricyclic Antidepressants

Clomipramine

A case series that examined five individuals with autism, aged 13–33 years, revealed reduced aggressive and impulsive behavior in three of the subjects after treatment with clomipramine (McDougle et al., 1992). An open-label trial of clomipramine (mean dose, 139 mg/day) in 35 adults with ASDs, aged 18–44 years (mean age, 30 years) showed improvement in aggression, among other symptoms (Brodkin et al., 1997).

In the aforementioned study by Remington et al. (2001), which compared clomipramine (mean dose, 128.4 mg/day) to haloperidol in 36 subjects with ASD, aged 10–36 years (mean age, 16.3 years), the two drugs were found to be equally effective for the treatment of irritability, although clomipramine was significantly limited in use due to adverse effects (Remington et al., 2001).

Selective Serotonin Reuptake Inhibitors

Fluvoxamine

A case report of a 30-year-old male with autism and comorbid OCD exhibited decreased temper tantrums with fluvoxamine 150 mg/day (McDougle, Price, & Goodman, 1990).

A double-blind, placebo-controlled study in 30 adults with autism, aged 18–53 years (mean age, 30 years), found fluvoxamine (mean dose, 276.7 mg/day) superior to placebo for reducing maladaptive behavior and aggression, in addition to repetitive thoughts and behavior (McDougle et al., 1996).

Fluoxetine

A 26-year-old female demonstrated reduced temper outbursts at home and at school when treated with fluoxetine 20 mg/day, in addition to improved repetitive, stereotypical behavior (Mehlinger, Scheftner, & Poznanski, 1990). A case series that examined patients with autism between 13 and 21 years of age found improvements in irritability during treatment with fluoxetine (20 mg/day for at least 6 weeks), although this symptom was often thought to be part of the patients' depressive illnesses (Ghaziuddin, Tsai, & Ghaziuddin, 1991). A retrospective chart review of seven subjects with autism, aged 9–20 years (mean age, 16 years), treated with fluoxetine (mean dose, 37.14 mg/day) for 1.3–32 months found improvement in the ABC-I subscale by 21 %, as well as other domains (Fatemi, Realmuto, Khan, & Thuras, 1998).

Sertraline

An open-label study of nine adults with MR, five of whom had autism, aged 20–47 years (mean age, 31 years), found that sertraline (mean duration, 110 days) resulted in improved self-injury and/or aggression in 89 % of participants (Hellings, Kelley, Gabrielli, Kilgore, & Shah, 1996). A 12-week, open-label study in 42 adults with ASDs, aged 18–39 years (mean age, 26 years), found a 57 % response rate to sertraline (mean dose, 122 mg/day), mostly in the areas of aggressive and repetitive symptoms (McDougle, Brodkin, et al., 1998). An enhanced clinical response was observed in individuals with autism and PDD-NOS as opposed to Asperger's disorder.

Other Medications

Clonidine

One case study highlighted successful treatment of violent aggression with transdermal clonidine in a 26-year-old female with autism and intermittent explosive disorder (Koshes & Rock, 1994). The subject's regimen of thioridazine, carbamazepine, and clonazepam was augmented with two 0.3-mg transdermal clonidine patches per week (total 0.6 mg/day), with significant improvement in behavior.

Naltrexone

Double-blind, placebo-controlled trials of naltrexone in adults with autism have generally demonstrated poor efficacy in managing SIB (Willemsen-Swinkels, Buitelaar, Nijhof, & van England, 1995; Zingarelli et al., 1992). In one study, only

one subject in eight (age range, 19–39 years; mean age, 29 years) showed a partial decrease in maladaptive behaviors (Zingarelli et al., 1992). No adverse effects were observed. Another study found naltrexone to have no therapeutic effect on the management of self-injury among 33 adults with MR, 16 of whom had autism (age range, 18–46 years; mean age, 29 years), and it was poorly tolerated (Willemsen-Swinkels et al., 1995).

Buspirone

Buspirone has shown favorable results in case reports of adults with ASDs treated for severe aggression and self-injury. One case of a 41-year-old male with autism and mild MR showed decreased frequency and severity of aggression over 2 years after buspirone (80 mg/day) was added to a regimen of phenytoin, haloperidol, phenobarbital, and imipramine (for enuresis) (Hillbrand & Scott, 1995). Another case of a 33-year-old female with autism and profound MR showed positive response to buspirone (90 mg/day) in the management of self-injury, property destruction, and physical aggression over 1.5 years (Brahm, Fast, & Brown, 2008). Buspirone was well-tolerated with no adverse effects observed in these patients.

Divalproex Sodium (Valproate)

A retrospective pilot study that examined 14 individuals with ASDs, aged 5–40 years (mean age, 18 years), found improved aggression, irritability, and affective instability in 71 % of subjects treated with divalproex sodium (mean dose, 768 mg/day), although many had comorbid Axis I psychiatric diagnoses (Hollander, Dolgoff-Kaspar, Cartwright, Rawitt, & Novotny, 2001). Subjects were treated for 0.5–43 months (mean duration, 10.7 months). Adverse effects were mild to moderate and included fatigue/sedation, behavioral activation, digestive disturbance, and weight gain, among others.

Double-blind, placebo-controlled studies in children and adolescents have revealed mixed results. One study (mean age, 11 years) found no differences between valproate and placebo groups in the management of severe aggression (Hellings et al., 2005), although the other (mean age, 9.5 years) found statistically significant improvement in irritability compared to placebo (Hollander et al., 2010).

Lamotrigine

There are no published reports of lamotrigine treatment for irritability in adolescents or adults with ASDs. A 12-week, double-blind, placebo-controlled study in

children with ASDs (aged 3–11 years) revealed unfavorable results, finding no differences between drug and placebo for the treatment of irritability, hyperactivity, stereotypies, lethargy, and emotional reciprocity (Belsito, Law, Kirk, Landa, & Zimmerman, 2001). Parent rating scales showed marked improvement, which was thought to be due to expectations of benefits.

Levetiracetam

There are no published reports of levetiracetam treatment for irritability in adolescents or adults with ASDs. A 10-week, double-blind, placebo-controlled study of levetiracetam (mean dose, 862.50 mg/day) in children and adolescents with ASDs (mean age, 8.72 years) revealed no significant difference between drug and placebo for the management of aggression and affective instability (Wasserman et al., 2006).

Topiramate

There are no published studies of topiramate for irritability in adults with ASDs. However, an open-label retrospective study of topiramate (mean dose, 235 mg/day) in adolescents with ASDs (mean age, 14.7 years) found 53 % to be clinical responders with improvement in conduct, hyperactivity, and inattention (Hardan, Jou, & Handen, 2004).

In children with autism, a double-blind, placebo-controlled study of topiramate combined with risperidone found that, compared to risperidone monotherapy, combination treatment led to a greater reduction in hyperactivity/noncompliance, irritability, and stereotypic behavior (Rezaei et al., 2010).

Conclusions

For the treatment of irritability controlled studies have found the typical antipsychotic haloperidol to be effective in adults and the atypical antipsychotic risperidone to be effective in adolescents and adults with ASDs. In addition, controlled research supports the use of aripiprazole in adolescents with ASDs for this purpose. Preliminary research of other atypical antipsychotics has shown promising results. Adverse effects from atypical antipsychotics that are of concern in the adult population include increased appetite, weight gain, and transient sedation. Double-blind, placebo-controlled studies are needed in other drug classes, including the SSRIs and alpha-2 agonists, among others, to determine the efficacy and tolerability of these drugs in adolescents and adults with ASDs and irritability.

Hyperactivity and Inattention

Medications Traditionally Used to Treat the Symptoms of Attention-Deficit/Hyperactivity Disorder

Methylphenidate

A case report describes treatment with MPH (dosed 40 mg/day in divided doses) in a 26-year-old male with Asperger's disorder (Roy, Dillo, Bessling, Emrich, & Ohlmeier, 2009). MPH resulted in improved attention, aggression, impatience, and social behavior.

The remaining available research has been focused on children with ASDs (Birmaher, Quintana, & Greenhill, 1988; Di Martino, Melis, Cianchetti, & Zuddas, 2004; Ghuman et al., 2009; Handen, Johnson, & Lubetsky, 2000; Jahromi et al., 2009; Nickels et al., 2008; Posey et al., 2007; Quintana et al., 1995; RUPP, 2005; Santosh, Baird, Pityaratstian, Tavare, & Gringras, 2006; Schmidt, 1982; Strayhorn, Rapp, Donina, & Strain, 1988). Controlled research, such as the large, multi-site study conducted by the Research Units on Pediatric Psychopharmacology Autism Network (2005), suggests that children with ASDs are less likely to respond to psychostimulants and more likely to experience adverse effects compared to typically-developing children with attention-deficit/hyperactivity disorder (ADHD).

Atomoxetine

A case report of atomoxetine (ATX) in a 22-year-old adult with autism found improvement in hyperactivity on the ABC Hyperactivity subscale (Niederhofer, Damodharan, Joji, & Corfield, 2006). Other symptoms such as irritability, inadequate eye contact, and inappropriate speech were also noted to decrease. However, clinician ratings did not show any improvement. Adverse effects included increased drowsiness.

ATX appears safe and effective for treating hyperactivity in some children with ASDs, with fewer intolerable adverse effects than MPH (Arnold et al., 2006). An open-label study of ATX (mean dose 1.2 mg/kg/day) in children and adolescents with ASDs aged 6–14 years (mean age, 7.7 years) found a 75 % response rate with significant improvement in ADHD symptoms (Posey et al., 2006). Other improvements were noted in irritability, social withdrawal, stereotypy, and repetitive speech. The drug was overall well-tolerated.

Clonidine

There is one double-blind, placebo-controlled, crossover study of clonidine involving adolescents and adults in the treatment of "hyperarousal behaviors" associated with autism (Fankhauser, Karumanchi, German, Yates, & Karumanchi, 1992).

These behaviors were defined in terms of affectual and sensory responses, and did not refer specifically to the symptoms of ADHD. This study examined nine males with autism, aged 5–33 years (mean age, 13 years), who were treated with transdermal clonidine patches dosed 0.005 mg/kg/day (mean dose, 0.16 mg/day). Transdermal clonidine resulted in significant clinical improvement on the Clinical Global Impression-Improvement (CGI-I) scale.

In some children with ASDs, clonidine has been moderately effective in the treatment of hyperactivity and irritability (Jaselskis, Cook, Fletcher, & Leventhal, 1992).

Guanfacine

There are no published studies of guanfacine in adults with ASDs. In children (aged 5–9 years), a double-blind, placebo-controlled study of guanfacine (dosed between 1 and 3 mg/day) revealed significant benefits in the ABC Hyperactivity subscale (Handen, Sahl, & Hardan, 2008). Adverse effects of drowsiness and irritability were observed.

Other Medications

Buspirone

There are no published studies of buspirone for ADHD symptoms in adolescents or adults with ASDs. In children, a case report (using a double-blind, placebo-controlled approach) found buspirone to be efficacious in decreasing hyperactivity (McCormick, 1997).

Hypersexual Behaviors

Mirtazapine

Mirtazapine was found to successfully treat two adolescent males with ASDs, aged 13 years, with hypersexual behaviors (Coskun & Mukaddes, 2008; Nguyen & Murphy, 2001). In one individual, mirtazapine dosed 30 mg/day in divided doses over many weeks resulted in decreased self-stimulatory activity from 2 to 3 h/day to 2–3 times/week (Nguyen & Murphy, 2001). In the other individual, mirtazapine dosed 15 mg/day over 10 weeks resulted in decreased fetishistic and self-stimulatory behavior from 5 to 8 times/day to complete cessation of hypersexual behaviors (Coskun & Mukaddes, 2008). Symptoms reemerged after discontinuation of the drug, but again disappeared after drug re-initiation. In both cases, the drug was well-tolerated.

Pharmacological Treatment of Comorbid Psychiatric Disorders

Anxiety Disorders

Prevalence

Anxiety poses a significant problem for adolescents and adults with ASDs. A study of 122 adults with ASDs and normal intelligence, aged 16–60 years, found that comorbid anxiety and mood disorders were common (Hofvander et al., 2009). Gillott and Standen (2007) found that adults with autism were three times more anxious than a comparison group of age-, gender-, and IQ-matched adults with intellectual disabilities, and scored higher on anxiety subscales of panic and agoraphobia, separation anxiety, OCD, and generalized anxiety disorder. The more anxious the adults with autism, the less likely they were able to cope with change, anticipation, sensory stimuli, and unpleasant events. Studies specific to Asperger's disorder have also found high occurrences of anxiety disorders (Lugnegard, Hallerback, & Gillberg, 2011; Tantum, 1991; Wing, 1981).

Pharmacological Treatments for Anxiety Associated with ASDs

Mirtazapine

An open-label study of mirtazapine (mean dose, 30.3 mg/day) for at least 4 weeks in 26 subjects with ASDs, aged 3–23 years (mean age, 10.1 years), found nine (35 %) to be clinical responders based on improvement in anxiety, hyperactivity, aggression, self-injury, irritability, depression, and insomnia (Posey, Guenin, Kohn, Swiezy, & McDougle, 2001).

Obsessive-Compulsive Disorder

Differences Between OCD and Repetitive Thoughts and Behaviors Associated with ASDs

Diagnosing OCD in individuals with ASDs can be challenging given limitations in language ability and intellectual level. McDougle et al. (1995) found that the repetitive thoughts and behaviors characteristic of autism differ significantly from symptoms displayed in OCD. Compared to individuals with OCD, adults with autism were more likely to experience repetitive ordering; hoarding; telling or asking; touching, tapping, or rubbing; and self-damaging or self-mutilating behavior. They were also less likely to experience thoughts with aggressive, contamination, sexual,

religious, symmetry, and somatic content, as well as behaviors like cleaning, checking, and counting.

Fluvoxamine

A case report highlighted the treatment of OCD symptoms with fluvoxamine in a 30-year-old male with autism and comorbid OCD, with significant reduction in OCD symptoms after 8 weeks of treatment as measured by the Y-BOCS and CGI scales (McDougle et al., 1990). The subject's OCD symptoms included hoarding sticks, ritual lining up of objects, contamination fears, and ritualized hand-washing, showering, and grooming. Fluvoxamine doses higher than the therapeutic 150 mg/day resulted in racing thoughts, irritability, and insomnia. Therapeutic effect was sustained 8 months later without adverse effects. Secondary benefits included increased interest in social relationships, improved social interaction, decreased temper tantrums, and less withdrawal from human contact.

Another case report of a 20-year-old female with autism revealed improvement of interfering repetitive behaviors when treated with fluvoxamine dosed 100 mg/day (Harvey & Cooray, 1995).

Fluoxetine

A report of two adults with autism described reduction in obsessive-compulsive symptoms and overlying depression with fluoxetine (Koshes, 1997). One subject was a 26-year-old male with autism, mild MR, and symptoms suggestive of OCD. He exhibited anxiety about his mother and her health, and had daily rituals with bathing, eating, and preparing for his day's program. These symptoms increased in severity and frequency when the subject became anxious. Fluoxetine 20 mg/day for 4 months led to a cessation of rituals with dramatic improvement in anxiety, eye contact, and social exchange. The second subject was a 42-year-old woman with autism and moderate MR who exhibited preoccupation with order and cleanliness. A concern for depression led to initiation of fluoxetine 20 mg/day, with overall clinical improvement after 1 month.

Mood Disorders

Depression

Prevalence

Depression is one of the most common psychiatric disorders in individuals with ASDs (Ghaziuddin, Ghaziuddin, & Greden, 2002; Ghaziuddin & Greden, 1998; Wing, 1981). Lugnegard et al. (2011) found that among 54 adults with Asperger's

disorder, mean age 27 years, 70 % had experienced one major depressive episode and 50 % had suffered from recurrent depressive episodes. Munesue et al. (2008) found a 25 % prevalence rate of depression among a cohort of 16 adolescents and adults with Asperger's disorder or PDD-NOS.

Individuals with autism and depression present symptoms ranging from irritability and sadness to aggressive outbursts and suicidal behavior (Ghaziuddin et al., 2002). In individuals with ASDs, symptom improvement may manifest as increased communication or decreased irritability as opposed to symptoms seen in non-autistic individuals, such as improved appetite, emotional reciprocity, or psychomotor retardation (Perry, Marston, Hinder, Munden, & Roy, 2001).

Fluoxetine

A case series described three adolescents and one young adult with autism, aged 13–21 years, who were treated with fluoxetine for symptoms of depression (Ghaziuddin et al., 1991). Depressive symptoms varied for each individual and may have included social withdrawal, crying spells, poverty of speech, anhedonia, increased irritability, changes in sleep and appetite, and psychosomatic symptoms like fatigue and facial pain. Therapeutic doses of fluoxetine ranged from 20 to 40 mg/day, with some individuals experiencing increased agitation at higher doses. Despite decreased irritability with fluoxetine, the youngest patient experienced increased compulsive behaviors, agitation, and aggression, so fluoxetine was replaced with clomipramine. Notably, no patients experienced a reduction in stereotypies or ritualistic, compulsive behaviors with fluoxetine treatment.

Electroconvulsive Therapy

One case study described a 25-year-old male with Asperger's disorder, OCD, major depression, and 45,X/46,XY mosaicism whose depression was treated successfully with electroconvulsive therapy (ECT) (Fontenelle, Mendlowicz, Bezerra de Menezes, dos Santos Martins, & Versiani, 2004). Prior treatment for depression included sertraline, which was discontinued due to adverse effects, and imipramine, which was ineffective. ECT was initiated after the patient attempted suicide, and depressive symptoms improved significantly after six sessions of ECT.

Another case report described a 19-year-old male with autism and mild MR whose severe depression, catatonia, and life-threatening SIB remitted after receiving bilateral ECT (Wachtel, Griffin, & Reti, 2010). Prior to ECT, the patient had exhibited poor responses to numerous psychotropic and behavioral interventions.

Mood Disorders

Bipolar Disorder

Prevalence

Munesue et al. (2008) found that among 44 adolescents and adults with Asperger's disorder or PDD-NOS, aged 12–39 years, 12 (27 %) had some form of bipolar disorder. Of the 44 study subjects, two (5 %) had bipolar I disorder, six (14 %) had bipolar II disorder, and four (9 %) had bipolar disorder not otherwise specified (NOS). Lugnegard et al. (2011) found that among 54 adults with Asperger's disorder, mean age 27 years, 9 % met criteria for bipolar II disorder, although none met criteria for bipolar I disorder. In a cohort of adult patients with ASDs, aged 19–60 years, 7 % had bipolar disorder with psychotic features (Stahlberg, Soderstrom, Rastam, & Gillberg, 2004).

Lithium

A case report described a 33-year-old female with autism, profound MR, and a 15q12 chromosomal deletion who was diagnosed with bipolar disorder NOS after she presented with cyclical episodes of explosive behavior, mood elevation with giggling and laughter, pressured speech, and insomnia (Kerbeshian, Burd, Randall, Martsolf, & Jalal, 1990). These episodes continued despite continuation of phenobarbital and phenytoin for epilepsy. Lithium carbonate was titrated to a plasma level of 1.2 mEq/L, and the patient experienced diminished aggression with improvements in mood, pressured speech, and insomnia.

Another report described a 20-year-old male with autism and MR who developed cyclical, manic-like episodes that occurred each fall and spring, lasted several months, and remitted spontaneously (Steingard & Biederman, 1987). Symptoms included insomnia, restlessness, and increased aggression and self-injury, and upon evaluation he exhibited expansive affect and unusual and excessive smiling. Prior treatment with chlorpromazine was minimally effective. Lithium carbonate was titrated to a plasma level between 1 and 1.2 mEq/L and his clinical picture stabilized within 3 weeks. Subsequent behavioral cycles were prevented and the subject slept through the night for the first time in 20 years.

Quetiapine

A case report describes an adolescent with autism and bipolar I disorder who responded to quetiapine dosed 25 mg twice daily after exhibiting resistance to

multiple other treatments (Howell, Larson, & Coffey, 2011). The subject was a 15-year-old male with autism who exhibited yearly mood disturbances during the previous 4 years. These episodes included decreased need for sleep, increased energy, inappropriate masturbation, mood lability, provocative and attention-seeking behaviors, and aggression. At presentation, the subject was experiencing an episode of depression with bouts of elevated mood and hypersexuality. Trials of multiple psychotropic medications, including antidepressants, mood stabilizers, neuroleptics, benzodiazepines, and medications used to treat symptoms of ADHD, resulted in adverse effects. Adverse effects from quetiapine included sedation and dysarthric speech.

Clozapine

A case report described a 25-year-old male with Asperger's disorder who was diagnosed with bipolar I disorder with psychotic features after exhibiting a period of hyperactive, irritable, and assaultive behavior, reduced need for sleep, and grandiose, persecutory delusions (Arora, Praharaj, Sarkhel, & Sinha, 2011). Symptoms of mania improved on a combination of clozapine 200 mg/day and haloperidol 20 mg/ day.

Another case report examined treatment with clozapine in a 16-year-old female with Asperger's disorder and mania (Atlas & Gerbino-Rosen, 1995). The subject's symptoms included manic mood, flight of ideas, gaze aversion, and interpersonal intrusiveness. Her prior medication regimen, which included divalproex sodium, thorazine, MPH, clonazepam, and lithium, was discontinued and replaced with clozapine 350 mg/day in divided doses. The patient experienced modulation of mood and improved thought process. The only adverse effect was nocturnal salivation.

Psychotic Disorders

Prevalence and Important Considerations

Psychosis has been observed in adults and adolescents with ASDs. Stahlberg et al. (2004) found that among 241 adult patients with ASDs and/or ADHD, 7.8 % had schizophrenia or another psychotic disorder. Lugnegard et al. (2011) found that among 54 adults with Asperger's disorder (mean age, 27 years), one had a brief psychotic episode and one had psychotic disorder NOS. Seven (13 %) had experienced recurrent (primarily auditory) hallucinations without other signs of psychosis. No subjects met criteria for schizophrenia, schizoaffective disorder, or substance-induced psychotic disorder.

Psychotic episodes in adults with Asperger's disorder are an important cause of referral to mental health services, and individuals with Asperger's disorder have demonstrated higher levels of psychosis, violent behavior, and mood disorders

compared to autistic disorder (Szatmari, Archer, Fisman, Streiner, & Wilson, 1995; Volkmar, Klin, Schultz, Rubin, & Bronen, 2000). Abell and Hare (2005) reported higher levels of delusional beliefs in Asperger's disorder, mostly of the grandiose or paranoid type, compared to the general population. However, Dossetor (2007) suggested that symptoms indicative of psychosis in individuals with ASDs may be pseudo-psychotic phenomenon secondary to the ASD diagnosis. These symptoms should be carefully considered in the context of diagnosis, developmental level, and intellectual delay.

Schizophrenia

Clarke, LittleJohns, Corbett, and Joseph (1989) described a 20-year-old male with PDD-NOS and schizophrenia who responded favorably to 15 months of treatment with antipsychotics and lithium. Schizophrenia had been diagnosed at age 15 years, and he exhibited symptoms such as bizarre behaviors, belief in special powers, hallucinations, and paranoia.

Psychosis Not Otherwise Specified and Other Episodes of Psychosis

Haloperidol

Arora et al. (2011) described a 27-year-old male with Asperger's disorder who was diagnosed with psychosis NOS after he began wandering away from home and was found hitting others, muttering and smiling to himself, exhibiting poor self-care, and making delusional misinterpretations. Risperidone and fluoxetine were ineffective, although haloperidol dosed 20 mg/day successfully decreased his aggression and wandering behaviors after 2 months of treatment. Effects were maintained at a 6-month follow-up.

Quetiapine

Arora et al. (2011) described an 18-year-old male with Asperger's disorder who was diagnosed with psychosis NOS after exhibiting irritable behavior and hearing commanding auditory hallucinations for 2 months. Previous trials of haloperidol, aripiprazole, and olanzapine were not effective, but quetiapine dosed 500 mg/day was effective at improving his hallucinations.

Trifluoperazine with Propranolol

Clarke et al. (1989) described an 18-year-old male with PDD-NOS who was diagnosed with psychosis NOS after developing persecutory delusions. These delusions included the belief that his father would be jailed for nonpayment of an electricity

bill, his homosexuality was broadcast on television, and that he was suffering from AIDS. Treatment with trifluoperazine and propranolol resolved these delusions with no return of symptoms 18 months later.

Trihexyphenydil with Bromperidol

Kurita (1999) described an 18-year-old male with high-functioning PDD-NOS who was diagnosed with psychosis NOS after exhibiting persecutory delusions that started at age 17. He was unable to leave his home due to beliefs that strangers, children, and television announcers talked negatively about him and thought that cats and dogs bore ill feelings toward him. For treatment, he took trihexyphenydil dosed 6 mg/day and bromperidol dosed 5 mg/day with abatement of the delusions after 3 months. Bromperidol was tapered down to 2 mg/day with successful treatment of the delusional thinking at a 3-year follow-up.

Electroconvulsive Therapy and Lithium

Clarke et al. (1989) described a 44-year-old male with PDD-NOS and history of depression who was diagnosed with psychosis NOS that was successfully treated with ECT and lithium (Clarke et al., 1989). The subject's symptoms consisted of 4–6-week cycles of overactivity, overeating, stealing other patients' property and smearing feces, which alternated with 2–3-week periods of withdrawal, mutism, and catatonia. Due to an absence of prominent mood abnormalities, psychosis NOS was diagnosed versus bipolar disorder. Treatment with haloperidol and amitriptyline was ineffective, but the subject's symptoms responded well to ECT and lithium.

Eating Disorders

Prevalence

The prevalence of eating disorders in individuals with ASDs has not been well studied. Lugnegard et al. (2011) found that among 54 adults with Asperger's disorder (mean age, 27 years), two subjects had bulimia nervosa and none had anorexia.

Anorexia Nervosa

Fisman, Steele, Short, Byrne, and Lavallee (1996) described a 13-year-old female with autism and anorexia nervosa who was successfully treated with a combination of risperidone and structured behavioral therapy. Prior to treatment, symptoms of

anorexia included food restriction, a preoccupation with weight, displeasure with physical appearance, increased exercise, attempted self-emesis, and the use of laxatives. The subject became suspicious of her parents, believing that they were trying to make her fat, and hid food to deceive them into thinking she had eaten. She also had a history of obsessive-compulsive symptoms that included checking behaviors, washing rituals, repeated showering, and straightening of furniture. Clomipramine was ineffective and resulted in increased agitation. Risperidone 0.5 mg twice daily combined with a structured behavioral approach led to decreased agitation and aggression, loss of paranoid ideation, and improved attention. The subject's eating habits changed, her range of affect improved, and she showed less rigidity. She maintained her ideal body weight 12 months post-discharge.

Coprophagia

This variant of pica was described in a 29-year-old male with autism who was successfully treated with aripiprazole (Pardini, Guida, & Gialloreti, 2010). The subject had developed coprophagia and increased aberrant motor behaviors while treated with risperidone. Risperidone was replaced with aripiprazole dosed 15 mg/day, resulting in marked reduction in coprophagic behaviors after 4 weeks of treatment. Aripiprazole was well-tolerated with no reported adverse effects. The effect was sustained at an 8-week follow-up.

Tic Disorders

Prevalence

Tic disorders are rarer in adults compared to children and adolescents, with no published studies of prevalence in adults with ASDs. Baron-Cohen, Scahill, Izaguirre, Hornsey, and Robertson (1999) reported an 8.1 % prevalence rate of Tourette's disorder in a cohort of children and adolescents with autism, aged 10–19 years (mean age, 14 years). The following are case reports describing adults with ASDs who have been treated for tics.

Haloperidol

A case report described a 13-year-old male with autism and Tourette's disorder whose tics improved with haloperidol treatment (Realmuto & Main, 1982). The subject's motor and phonic tics had been worsened using MPH, and phenobarbital was ineffective. Haloperidol dosed 5 mg/day resulted in near complete remission of the tics.

Electroconvulsive Therapy and Clonidine

Dhossche, Reti, Shettar, and Wachtel (2010) described a 19-year-old male with high-functioning autism who was treated with ECT for a depressive disorder with catatonia, and whose tic disorder improved with ECT. The subject's tic symptoms included repetitive grunting, barking, and chirping. The subject underwent 18 sessions of bilateral ECT, which yielded a reduction in tics and overall positive clinical response. Pharmacotherapy for residual symptoms initially included pimozide, although this was discontinued due to adverse effects of agitation, SIB, worsening tics, and hypertension. A moderate reduction in symptoms was observed with risperidone dosed 0.5 mg/day to target psychosis, sertraline 100 mg/day for depression, clonidine 0.15 mg three times daily for residual vocal and motor tics, and maintenance ECT every 2–3 weeks.

Conclusions

The majority of published research on the pharmacological treatment of comorbid psychiatric disorders is limited to case reports and a few open-label studies. Prevalence rates of comorbid Axis I disorders are also limited, with many studies limited to subjects with Asperger's disorder. This is likely due to preserved language function in individuals with Asperger's disorder and an improved ability to communicate interfering symptoms. More studies are needed that identify the prevalence of psychiatric comorbidities in ASDs so that these disorders are treated effectively in clinical practice. Although case reports have found some pharmacologic treatment beneficial for psychiatric comorbidities in individuals with ASDs, double-blind, placebo-controlled studies are needed to demonstrate further efficacy and tolerability in this population.

Future Directions

Although significant progress has been made in identifying drugs for the treatment of behavioral symptoms associated with ASDs, additional research continues to be needed in adolescents and adults. Effective treatment for repetitive behaviors in this population is necessary. SSRIs appear to be of greater benefit to adolescents and adults with ASDs for this symptom domain compared to children with ASDs, although additional, larger randomized, controlled trials are needed. Regarding the treatment of irritability, drugs with an improved safety profile are needed. Continued research into antipsychotics, such as ziprasidone and paliperidone, may be beneficial, particularly given the decreased risk of weight gain with ziprasidone, and the encouraging preliminary data with paliperidone for irritability in adolescents and young adults with autism, including those that didn't respond to or tolerate a prior

trial of risperidone. Other antipsychotics that may hold potential for future study include asenapine and iloperidone. Double-blind, placebo-controlled studies of ATX, a non-stimulant treatment for ADHD, as well as the alpha-2 agonists clonidine and guanfacine, are needed for the treatment of hyperactivity in adolescents and adults with ASDs.

As noted above, double-blind, placebo-controlled trials for the treatment of psychiatric comorbidities in individuals with ASDs warrant further study. Today, there are no published randomized, controlled trials of any drug for the primary treatment of mood or anxiety disorders in individuals with ASDs of any age. Studies of SSRIs and other first-line agents are needed for the treatment of comorbid depression, as well as of lithium and valproic acid for the treatment of mood stabilization in bipolar illness. Buspirone and mirtazapine may be beneficial for the treatment of anxiety but randomized, controlled studies are needed. Additional study of antipsychotics for those individuals with ASD and comorbid psychosis is also necessary. Lastly, the safety and efficacy of ECT needs to be established in individuals with ASDs.

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Chapter 10
Residential Options and Treatment for Individuals on the Autism Spectrum

Paul K. Cavanagh and Ernst O. VanBergeijk

Just more than a generation ago, there were few "options" for living situations for an adolescent or adult with an intellectual disability. Prior to the 1970s an adolescent or adult with a developmental disability either lived with or near their family, where they could receive financial and physical support, or they lived in one of a variety of institutionalized settings. There were a handful of community residences (read, group homes), but they were not well funded and were few and far between (see Bruininks & Lakin, 1985; Scheerenberger, 1983, 1987) that has changed, and is continuing to change even as this chapter is being written. As the result of more than a century of intergenerational advocacy for individuals with developmental disabilities, there are more living options for adults with intellectual disabilities (IDs) now than at any time in history. Nevertheless, there continues to be more demand for quality living situations than supply, and much more is needed in integrating adults with developmental disabilities into society.

Simultaneously during the 1960s and 1970s, the deinstitutionalization movement led to the uncovering of the horrors of large-scale congregate care. These individuals were segregated from the greater community. Individuals with mental illness and developmental disabilities were warehoused together in large state run institutions with little treatment. In fact, the patients were often neglected and abused by the very staff members who were hired to take care of them. The most famous case of institutionalized abuse was the uncovering of the deplorable conditions of the Willowbrook facility in Staten Island, NY (See Rothman and Rothman, 1984).

Modern special education began with the passage of PL 94-142, the Education of All Handicapped Children Act of 1975 (later renewed as the Individuals with Disabilities Education Act, or IDEA). PL 94-142 was grounded in the concept of

P.K. Cavanagh, Ph.D., M.S.W. (✉) • E.O. VanBergeijk, Ph.D., M.S.W.
Vocational Independence Program, New York Institute of Technology,
300 Carleton Avenue, Central Islip, NY 11722, USA
e-mail: pcavanag@nyit.edu; evanberg@nyit.edu

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least restrictive environment. The US Supreme Court's Olmstead Decision in 1999 legitimized the residential equivalent of a least restrictive environment. This decision, grounded in the American's with Disabilities Act, stated that "unjustifiable institutionalization of a person with a disability who, with proper support, can live in the community is discrimination" (U.S. Department of Health & Human Services, 2000). Consequently, the long-term residential care and treatment of individuals with autism spectrum conditions (ASCs), and other developmental disabilities, have moved away from large-scale congregate care to smaller scale living arrangements with varying degrees of supervision. This chapter will review the different models of residential care and treatment as well as the scope of the situation. The ultimate goal for an individual on the autism spectrum should be to live in the least restrictive environment possible where he or she may enjoy the benefits of being a member of the community and enjoying a high quality of life. The level of supervision and restrictiveness will vary across individuals. The key determining factor for the level of supervision should be safety. Is the residential placement one in which the individual on the spectrum can live integrated in the community and still maintain his or her personal safety?

Scope of the Problem

The prevailing wisdom is that 1 out of approximately every 110 children in the United States (see Center for Disease Control and Prevention, n.d.) has an ASC. According to the US Census, there are approximately 82,600,460 under the age of 20 years (U.S. Census Bureau, 2011). Therefore, roughly 750,913 individuals under the age of 20 have an ASC. There is no definitive estimate of the number of adults with autism. However, a recent report by England's NHS Information Center (Brugha et al., 2009) found a prevalence rate for autism in the adult population in England of 1.0 %, essentially the same as the prevalence rate for children. Not every person with an ASC will require residential care and treatment. However, of those Americans with the diagnostic label of Autistic Disorder as defined in the Diagnostic and Statistical Manual of Mental Disorders IV-TR, approximately 55–75 % of these individuals will also have a cognitive disability with full scale IQ scores falling below 70. Fombonne's (2005) review of epidemiological studies with autistic samples found that 29.6 % of those sampled had a cognitive impairment (as cited in VanBergeijk, Klin, & Volkmar, 2008). Individuals with this profile will need higher levels of supervision and more intensive treatment than individuals who are higher functioning on the autism spectrum and with all other factors being equal. However, both and Fombonne (2003) determined that between 70 and 80 % of children diagnosed with an ASC continued to have significant social impairments into adolescence and young adulthood (as cited in VanBergeijk et al., 2008).

Individuals with Asperger syndrome (AS) and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) may have average to even above average IQ scores. The general perception is that as a group they are higher

functioning and consequently, require less supervision and treatment. However, as many as 65 % of individuals with AS have comorbid conditions such as Attention Deficit Disorder both with and without Hyperactivity (ADD & ADHD), Depression, Generalized Anxiety Disorder (GAD), Tourette's syndrome (TS), Obsessive Compulsive Disorder (OCD), and Seizure Disorder (SD) (VanBergeijk et al., 2008). These comorbid conditions can affect even an individual with high IQ's ability to live independently. Depending upon the severity of these comorbid conditions, individuals with AS and PDD-NOS may require a more restrictive environment with higher levels of supervision and structure. Each individual with an ASC should be evaluated for their ability to live independently with the person's safety being paramount.

A recent study released by the National Center for Education Statistics (NCES) found that only 7 % of individuals with the educational label of autism had lived independently within the last 8 years (NCES, 2011). Even, the NCES perceives this number to be very low and perhaps not entirely reliable. Individuals with an educational label of autism are more likely to have an autistic disorder diagnosis where a cognitive impairment is also present. Individuals with Childhood Disintegrative Disorder (CDD) may also earn an educational label of autism. Individuals with CDD have significant cognitive impairment and would be less likely to live independently. School districts may be less inclined to label a student with Asperger syndrome or Pervasive Developmental Disorder-Not Otherwise Specified as having autism. Individuals with AS and PDD-NOS are more likely to be able to live independently and require less supervision and structure. Regardless of how accurate these numbers are, it suggests that a major educational objective for students on the autism spectrum is independent living.

What is Independent Living?

Independent living is the ability to support and integrate oneself in his or her local community. This is an incredibility complex task. Both neurotypical individuals and individuals with an ASC have varying levels of ability to support and integrate themselves in their local community.

Gerhardt (2009) created a conceptual model of level of community integration by employment setting that is useful when thinking about level of community integration by residential model. We have adapted Gerhardt's conceptual model and applied it to residential settings. At the apex of the pyramid is an individual who is completely integrated into the community. He or she lives in his or her own apartment or house. The person may or may not be married, have a life partner, or have children. This person is employed, pays taxes, and supports him or herself financially. He or she may also belong to a religious community or belong to some other social group or club. This person is able to get along reasonably well with his or her neighbors and maintain his or her property. He or she is able to use and develop natural social networks for support and does not rely upon formal organizations or

programs for support. The person at the apex also is able to organize his or her own recreational and social lives.

The next level of independent living is where the individual with an ASC lives in his or her own apartment or house with formal organizations providing support as needed. The individual again may have a roommate, spouse or partner, but needs support from formal organizations and cannot rely upon friends and family alone for support. This support may come in the form of financial assistance from government agencies (e.g., Social Security Disability Insurance, Food Stamps, Medicaid). For individuals who are otherwise eligible for Medicaid, a variety of supported living and group home models may be supported by the Home and Community Based Services waiver program (see, Research & Training Center on Community Living, 2011, and Smith, O'Keefe, Carpenter, Doty, & Kennedy, 2000). In addition, the State may offer employment assistance, training, and job placement through a state office of Vocational and Rehabilitative Services. State operated or subcontracted social service agencies may provide in home support for a variety of instrumental tasks. A state office of persons with developmental disabilities or private social service agency may provide assistance with bill paying and home budgeting skills, food shopping and meal planning, laundry, home maintenance, and other services such as the teaching of home safety skills, first aid, and emergency management. Other agencies may teach the individual to use mass transit to go to work and perform routine errands. If mass transit is not available, and the individual qualifies for services, then he or she may be eligible for para-transit services. Para-transit services pick up and drop off individuals to work, shopping, or recreational activities that are scheduled in advance. Individuals living in this situation are well integrated into the community. They are not segregated and physically isolated from the general community.

Supervised apartment living situations are the next level down in the pyramid in terms of independent living. Supervised apartment living situations share many of the same features as the previous level. However, the difference is that the social service agency provides staff that lives in the same apartment complex as the individuals with ASCs. The staff is on call 24 h a day, 7 days a week, and 365 days a year to contend with emergencies that arise. The staff of the social service agency will teach independent living skills such as cooking, laundry, and bill paying in the home of an individual with an ASC. This is a good way to teach skills to an individual with an ASC who has difficulty generalizing skills across different environments. The apartment complex is generally not dedicated solely to individuals with developmental disabilities. This means residents share common spaces such as laundry rooms, pools, and lounges with individuals both on and off the spectrum.

Individuals who live in one of the three previous models of residential living are high functioning. They are able to take care of their basic needs including feeding themselves, taking medication as needed, paying bills, and keeping their residences clean. They are able to navigate around their surroundings without getting lost. They are able to meet their transportation needs, either by driving a car, using public transportation, or a para-transit system. These individuals are also able to insure their own personal safety in terms of medical care, pedestrian skills, fire, theft, and assault prevention. This is not to say, these individuals may not need assistance from

time to time, or will not need safety reminders. However, for the most part, people who are responsible for the individual's residential placement and not overly concerned with the individual's personal safety.

Independent living has a distinctly different meaning for individuals who live in group home settings. Here, independent living means not living in the home of one's parents or other immediate family. Candidates for a group home experience are those that are unable to maintain themselves in an apartment or house with only intermittent supervision and support. Safety of the individual on the spectrum is a primary concern. A group home is usually a house where six or less individuals with a developmental disability live together under one roof. The agency that provides the group home has staff present in the dwelling 24 h a day, 7 days a week, and 365 days a year. Social workers, nurses, therapists, and care workers are regularly available to the residents for supervision and support. The staff helps the residents with activities of daily living (ADLs) such as reminders to bathe, take medication, and eat healthy meals. They also help organize and escort the residents on social outings.

Living with one's parents is included in this conceptual model because it is a reality for many families that have an adult child on the autism spectrum. In fact, according to Hartley and Mailick Seltzer (2011), somewhere between 1/4 and 1/3 of 30 year olds with an ASC continue to live with their parents. Often it is the "higher functioning" individuals who continue to live with their parents well into adulthood. For individuals with significant autism symptoms and severe cognitive deficits, funding, residential placements, and support services are more readily available than for an adult with Asperger syndrome and no cognitive impairment, (i.e., Full scale IQ 70 or greater). These individuals are often unemployed, and socially isolated. A crisis occurs when the parents become too infirmed to continue to care for their son or daughter or die. Unless the family is receiving services from a formal agency, and participating in day habilitation, vocational training, or employed in a supported or competitive worksite, individuals living at home with their parents are more likely to be not well integrated into the community and socially isolated.

The final level of the conceptual model, and the environment that has the least amount of community integration, is the residential care model. The residential care and treatment model involves the care of individuals on the autism spectrum in larger concentrations than group homes and consist of 16 or more residents (Hartley & Mailick Seltzer, 2011). They may take the form of public or private psychiatric hospitals or mental health facilities, specialized programs that are designed to care for lower functioning individuals on the autism spectrum, therapeutic boarding schools, or nursing home type facilities. Individuals on the autism spectrum who are lower functioning may access the residential care facilities while still in the public school domain. The Individualized Education Plan (IEP) committee at the local school district may determine that the student's IEP goals cannot be reached within programs provided by the school district. Therefore, the school district under the IDEA may use funds to secure a private placement in a residential facility.

Students who are placed in residential facilities while still of school age are generally the lowest functioning students on the autism spectrum. Their autistic symptoms are quite pronounced. They are more likely to have full scale IQ scores below 70 and are more likely to be nonverbal. Aggressive, self-injurious, and other

maladaptive behaviors are often a concern and placement in a more restrictive environment is often done to protect the individual and the family as well as provide respite for the family. Some lower functioning students on the autism spectrum may also require very little sleep and be at risk of wandering away from their homes. The placement in the more restrictive environment is also a safety precaution when there is a risk that the student will wander off in the middle of the night.

The residential care facility is the most formal organizational structure that is used to provide routinized care for individuals on the autism spectrum. It is also the least integrated into the community. All of the medical, educational, prevocational, recreational, independent living and mental health services are provided within the confines of the facility with occasional outings into the community for recreational activities and stimulation. Medical and mental health professionals are available 7/24 for the residents. This model provides the maximum amount of structure and is the most restrictive environment. Residents are carefully monitored in terms of their health, food in-take, exercise, and medication. Other professionals who help provide structure and support in residential care settings include social workers, psychologists, psychiatrists, nurses, nutritionists, occupational therapists (O.T.s), physical therapists, speech therapists, recreational therapists, and Applied Behavior Analysis specialists. Consequently, this model is the most expensive approach in providing residential care to individuals with ASCs.

Predictors of Independent Living and Success in Adulthood

There are limited studies that examine adult outcomes of children who were diagnosed with autism. Howlin, Goode, Hutton, and Rutter (2004) studied 68 adults with performance IQs > 50 who met the diagnostic criteria for autism as children. As a group these adults were still quite dependent upon their families or formal support systems. Only about 22 % of the sample had very good to good outcomes. Another 19 % were rated as having fair outcomes. This meant that few of the participants lived independently and had friends. Unemployment was a persistent issue for this group. Many stereotyped behaviors and persistent interests continued into adulthood. Individuals who scored above 70 on the performance IQ portion of IQ tests generally had better outcomes than individuals who had lower scores. However, it should be noted that within the normal intelligence range neither verbal nor performance IQ consistently predicted a positive outcome in this sample.

McMahon and Farley (2011) reviewed seven studies which examined outcomes of adults who were diagnosed as having an ASC during childhood. Their conclusion was that only about "…15 % of those diagnosed achieve a fully independent or even mostly independent lifestyle…" (p. 84). Furthermore, they found that 15–48 % of adults with ASC achieve relatively good outcomes which they defined as involving employment, independent or mostly independent living, and having one or more reciprocal relationships (meaning that they had a friend, partner or spouse). McMahon and Farley (2011) concur with Howlin et al. (2004) that individuals who achieve adult independence had IQ scores in the normal range (i.e., >70) as children

and "…used meaningful phrase speech by age six" (p. 84). They admonish readers, however, that even individuals with average childhood IQs and early phrase usage can still have limited outcomes as adults.

Some of the limited outcomes can be attributed to comorbid conditions and maladaptive behaviors. Howlin (2011) noted that the greater the severity of autistic symptoms during childhood, the poorer the adult outcomes. Additional medical problems such as epilepsy further compounded the problem. Howlin found that despite high IQ, comorbid mental health problems (which occur in at least 30 % of adults with ASC according to the author) negatively affect independent functioning as do high levels of stereotyped and ritualistic behaviors and anxiety (p. 88).

Howlin (2011) reviewed Farley et al.'s (2009) follow-up study of 41 adults with ASC ages 22–46 years old. Here the results were more encouraging and point to the importance of environmental factors. The outcomes regarding employment, independent living, and friendships were all significantly greater than those of previous studies. "Compared with previous follow-up studies of individuals of similar age and IQ, rates of tertiary education were higher (39 %), as were rates of full-time employment (27 %), friendships (52 %), close sexual relationships (20 %; 12 % were or had been married and 7 % had children of their own), and independent or semi-independent living (27 %)" (p. 88). Howlin attributed some of the significant improvements in this group to the fact that all but three study participants were part of a religious community that is known for providing high levels of support to its church members. This fact is worthy of future research. Membership in a religious community may provide not only additional support necessary for independence but also a social network that provides a protective function.

A final comment needs to be made regarding "successful adult outcomes" for people with ASC. The prevailing notion is that we have "failed to launch" an individual with an ASC if they are still living with their family of origin in their mid- to late-20s or early 30s. Perhaps, individuals with ASCs have a trajectory that is more gradual than neurotypical young adults. It may take some individuals until their mid-30s or even early 40s before they acquire all the necessary skills to live independently or even semi-independently. More research needs to be conducted regarding not only the predictors of successful outcomes for adults on the spectrum but also empirically based interventions that promote independent living. With empirically based increases to our knowledge base, we should expect more individuals to live independently or semi-independently. We already know this is a possibility because of the fact that far fewer individuals with ASCs are requiring large-scale institutional care than a generation ago (Lakin, Larson, Salmi, & Webster, 2010).

On-going Assessment is the Key

VanBergeijk and Shtayermman (2005) have promoted the notion that the assessment of an individual who may be on the autism spectrum should be conducted by an interdisciplinary team of professionals who are trained in the diagnosis, assessment, and treatment of ASCs. Some of the assessments can be done by

professionals who work in the child's local school district free of charge under the IDEA. Intelligence tests such as the WISC-R or the WAIS and achievement tests such as the WRAIT can easily be administered by school personnel in order to determine an individual's intelligence quotient or IQ, and their grade equivalent reading, writing, and arithmetic scores. Under IDEA, the assessments should be conducted on a triennial basis. Individuals with an ASC should have performance IQ scores that remain fairly constant or stable. Verbal IQ scores, however, are more amenable to change if the child receives proper treatment to address expressive and receptive language deficits. One would also expect some change in the grade equivalent academic achievement scores, depending upon the nature of the individual's expression of autistic symptoms.

More specific tests such as the ADOS and ADI will need to be conducted in a clinical setting outside of the school district. It is unlikely that school personnel will be trained in conducting such specific tests. Parents should identify a nearby hospital or clinic that specializes in autism and ask if they have personnel trained to administer these tests. Neuropsychologists and clinical psychologists are the professionals most frequently trained in these assessment techniques. Other members of the assessment team should include a speech pathologist or speech therapist. These professionals will assess the child's expressive and receptive language skills, not just the child's ability to articulate or pronounce words or sounds. It is critical that a speech professional be specifically trained in ASCs because higher functioning individuals who have a considerable vocabulary may still have a disability. Individuals with Asperger syndrome for example have an impressive vocabulary even at a young age, but they have impairments in the semantics and pragmatics of speech. They may also have issues with prosody that need to be assessed and addressed. Finally, a speech pathologist will be able to identify any mechanical issues with the child's ability to form words, chew, and swallow. Most often issues with the mechanical or motor abilities to swallow arise around the child's eating habits. Many children and adults on the spectrum have very limited food choices (Cermak, Curtin, & Bandini, 2010). This is perhaps due to motor difficulties swallowing or sensory integration issues where the individual does not like the texture or smell of the food.

Other members of the clinical assessment team should include a physical therapist and an occupational therapist. The physical therapist will assess the child's gross motor skills. Some individuals with ASCs are described as clumsy and have problems with proprioception and balance. Some of these children stand too close to people and invade their personal space or frequently bump into others. Other children on the spectrum, possess a gait that is awkward and walk on their tip toes rather than the balls of their feet. Some children will also have difficulty with bilateral integration of movement, i.e., they have difficulty with movements across their meridian line of their bodies. A qualified physical therapist will be able to assess these issues and design appropriate therapies to treat them. Occupational therapists (O.T.s), on the other hand, deal with fine motor and sensory integration issues. O.T.s will assess the child's ability to conduct ADLs such as putting on one's clothing, buttoning a shirt, zipping a zipper and tying shoes. These ADLs are crucial to

independent living. The O.T. will also be able to assess sensory issues that might interfere with the child's ability to conduct ADLs and design therapies to address them as well.

Whether the child who is suspected as being on the autism spectrum is "high" or "low" functioning, it is important to ascertain a sense of their global functioning particularly in the area of ADLs. Many professionals erroneously assume a "high-functioning" individual with perhaps, Asperger syndrome functions in the community at an age appropriate level. Professionals are often beguiled by "Aspies" vocabularies and intelligence. They may think it is unnecessary to conduct an assessment of the person's adaptive functioning because his or her IQ is in the normal to superior range. However, because of impairments in social communication, executive functioning, and the ability to read facial expressions and non-literal communication, individuals with Asperger syndrome can have extreme difficulty functioning on a daily basis. An assessment must be done of their adaptive behavior. The current goal standard assessment tool is the Vineland Adaptive Behavior Scales (VABS). The Vineland Adaptive Behavior Scales provide a global assessment of the individual's functioning in five different domains including communication, self-care, fine and gross motor skills, and communal living (VanBergeijk, Klin, & Volkmar, 2011). It also includes a subscale of maladaptive behaviors that may be useful deciding whether or not to place an individual in residential care. Furthermore, although a person with an ASC may have an IQ in the "normal" intelligence range and therefore be ineligible for state level disability services, developmentally delayed scores on the VABS even for a person with IQ in the "normal" range can help the person qualify for state-funded services.

Social workers are useful members of the assessment team in that they will conduct a psychosocial history of the child, noting when certain developmental milestones were reached or not (e.g., sitting up, crawling, walking, talking), physical and mental health history, educational history, therapeutic interventions, family crises and losses (death, divorce, domestic violence, etc.), medications, involvement of outside agencies, economic stability/job history of the family and individual, and other relevant information. Part of the psychosocial history/assessment should be an evaluation of the individual's safety including ability to ask for help in an emergency, pedestrian skills, and ability to use mass transit. These three areas are critical in determining the level of supervision required of a residential placement of an individual on the spectrum. Accidents are the most frequent cause of death among individuals on the spectrum. Individuals with lower IQs are 3.1 times more likely to die than a person from the general population (Mouridsen, 2011). Even a person with an ASC without a cognitive impairment is 2.4 times more likely to die than a non-impaired peer (Mouridsen, 2011). Suffocation, often in the form of drowning, followed by car accidents is the most common cause of death (Mouridsen, 2011). A large number of the car accidents involve individuals with ASCs as pedestrians.

Independent travel skills on mass transit are essential for independence. Not only should the person's pedestrian skills be assessed but also his or her ability to use the bus, subway, or train systems for work, personal errands, and recreational activities.

Many individuals with an ASC will not learn to drive a car. Therefore, in order to maximize independence and have them live in the least restrictive environment, they will need to rely upon public transportation. A lack of reliable transportation is a significant barrier to employment for individuals with a variety of disabilities (Lemaire & Mallik, 2008). The assessment should include the person's ability to read maps and schedules, behave appropriately in public, ability to use money when purchasing tickets, ask appropriate people for help, and deal with unexpected contingencies. Only after a complete assessment is completed, with an emphasis on independent living skills, can one then consider the level of residential treatment and community integration appropriate for a particular individual on the autism spectrum.

Working Backwards, but Looking Forward

Once a comprehensive assessment has been completed with a child and his or her family on the autism spectrum, it is possible to begin some preliminary planning for the child's residential placement and treatment. If maladaptive behaviors are overwhelming and cannot be addressed in the least restrictive environment of a public school system setting and the child's home, then a private placement must be arranged in a therapeutic boarding school or larger institutional setting such as a public or private state hospital that deals with aggressive or self-injurious behaviors of people with ASCs. The overriding concern should be for the child and the family's safety.

If this is not an overriding concern of the child and his or her family, then the family along with the educators and other professionals must begin planning for the child's future and transition into the greater community. With a global assessment of the child's IQ and adaptive functioning, parents and professionals can set a goal of the least restrictive environment that the child hopes to live in once he or she has completed his or her public education. The team of parents and professionals must envision the child in that environment? What does his or her level of integration and independence look like? What behaviors must the child be able to demonstrate in order to maintain that level of community integration and independence?

With this image in mind the team needs to create a checklist of all the behaviors necessary for that level of independence. Chances are the behaviors are quite complex (e.g., money management skills) and need to be broken down into its most basic parts and taught in a sequential manner. In other words, the team needs to visualize the end goal and its supporting behaviors and work backwards from that point. An elementary school child will not know how to use and balance a budget. However, elementary school level skills can be taught and should be a part of the child's IEP that support money management skills. An elementary school child will first need to learn how to count and recognize numbers. He or she will also need to learn denominations of coins and dollar bills, followed by their relative values. Next the child will need to learn arithmetic functions such as adding, subtracting, multiplying, and dividing. He or she may need to learn to use a calculator during the interim as well.

In middle school the child may be able to run errands for parents to the corner store to foster independence and to see if he or she is able to use money independently and receive the correct change. Learning how to count change back is an independent living skill that could be written into a middle school aged child's IEP. In high school, he or she will need to learn how to write checks, use a check register, use a debit card, and pay bills electronically. In a transition program or a post-secondary program the young adult on the spectrum should be given his or her own bank account and practice creating and maintaining a weekly budget in vivo-paying for his or her recreational activities and sundry needs out of this account as practical training and practice for eventually living independently or semi-independently.

The concept of working backwards, but looking forward, needs to be applied to all dimensions of the child's ADLs. If the team's vision is that the student will earn a college degree and live independently after high school, then the team not only needs to develop an IEP that will foster his or her academic success but also his or her social, vocational, and independent living skills success. Once the basic building blocks of the complex behavior are mastered, the student then needs to have additional elements of the behavior added on sequentially in a logical manner. The team needs to build a scaffolding of supports and teach parts of complex behaviors in an integrated manner that will help the individual reach the goal of independence in the future of the child with an ASC.

The Fluidity of Residential Placement and Treatment

Most teenagers/young adults in the United States live with their family of origin until they have completed secondary education. It is only when the young person is considering either post-secondary education or vocational training does the young person have the opportunity to live independently from his or her family of origin. Many neurotypical students, with intact social skills and no disabilities, have difficulty with this transition. Balancing the demands of school, a social life, and taking care of daily living needs is the first task for a freshman to figure out. Some college students determine living away from home and attending school is not for them. They move back home and attend a local college or vocational program.

For the student on the autism spectrum any transition is difficult, but the transition to vocational training, college, and/or independent living is exceptionally difficult. The choices facing the student regarding training, treatment, and independent living are: (1) to continue living at home and continue to matriculate in the school district's curricula until his or her 21st birthday; (2) to continue living at home and begin to participate in treatment/training in day habilitation programs; (3) to continue living at home and participate in a vocational training program; (4) to accept an out of family placement and an out of district placement in a residential treatment program; and (5) applying directly to college along with his or her neurotypical classmates (Cavanagh & VanBergeijk, 2012).

A new model for residential treatment and training are the Comprehensive Transition and Post-secondary programs (CTPs). CTPs are not specifically designed for students with ASCs. Rather, they are designed to provide a broad range of supportive services to students with Intellectual Disabilities (IDs). This term is also broadly defined. An eligible student with an intellectual disability as defined in section 760 of the Higher Education Opportunities Act (with slight modifications) is a student: with mental retardation or significant cognitive impairment AND who is/was eligible for FAPE under IDEA. This can include private and/or home-schooled students. The institution determines if student meets the definition (Bergeron, Murray, Shanley, & Dailey, 2010). The institution can define an ASC as an eligible cognitive impairment. It is incumbent upon each institution of higher education to design its CTP to support its students with ID as it sees fit. CTPs are to augment the support given by college offices of students with disabilities. The offices of services to students with disabilities are adept at creating reasonable accommodations under the Americans with Disabilities Act for students with learning disabilities and physical impairments such as hearing or vision loss. They are less comfortable with providing the type of support necessary for a student with a social disability. CTPs are to help these students transition from high school to the college environment. The support may not only include academic and organizational support, mentoring, and modifications to assignments but also help negotiating roommate conflicts, learning how to do laundry, personal budgeting & banking, and practicing social skills in the residence hall cafeteria. If the student's IEP team deems it appropriate, funds under the Individuals with Disabilities Education Improvement Act of 2004 (IDEIA; P.L. 108-446) can be used to pay for a Comprehensive Transition and Post-secondary Program (CTP) (34 CFR Parts 300 and 301 Assistance to States for the Education of Children With Disabilities and Preschool Grants for Children With Disabilities; Final Rule; Final Rule (p. 130)). This can be written into the student's transition plan as a part of the IEP.

The federal government is promoting this model of residential treatment through recent changes in legislation. Prior to 2008, students had to be enrolled full time in degree bearing program at an accredited institution of higher education in order to be eligible for federal student aid. The student and his or her family simply had to complete the Free Application for Federal Student Aid (FAFSA). Depending upon the Expected Family Contribution (EFC) the student could be eligible for a Federal Pell Grant, a Federal Supplemental Education Opportunity Grant, and Federal Work-Study programs funds, and federally subsidized and unsubsidized loans. Although many higher functioning individuals with ASCs could handle the academic demands of individual courses, the full-time course load requirement was a barrier to receiving financial aid for many students on the spectrum. The Higher Education Opportunities Act of 2008 (P.L. 110-315), the Act that governs Title IV, which regulates Federal Student Aid, was amended to allow students with ID to apply for federal financial aid in the form of Federal Pell Grants, Federal Supplemental Education Opportunity Grants, and Federal Work-Study programs funds. However, students with ID will NOT be eligible for federally subsidized or unsubsidized loans. The student with ID, in order to be eligible to complete the FAFSA, must be enrolled in a U.S. Department of Education

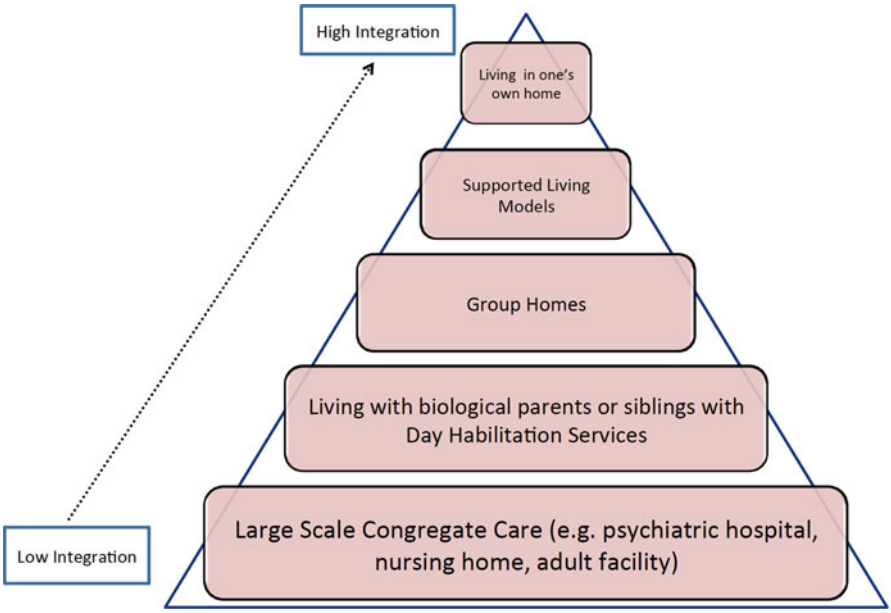

Fig. 10.1 Degree of expected community integration as a function of residential living model. Adapted from Gerhardt, P. F. (2009). *The current state of services for adults with autism*. Organization for Autism Research. Presented at the advancing futures for adults with autism: think tank. New York, NY

approved CTP (Finkel, Anderson, & Shanley, 2010). The federal government is invested in this model and is currently soliciting the participation of CTPs in research.

Enrollment in a CTP is the residential placement most similar the neurotypical population. It represents a high degree of community of integration. In fact, students enrolled in a CTP must spend over 50 % of their time in the program among the general population. This model embodies the concept of Least Restrictive Environment.

Irrespective of the residential placement and level of community integration of the person with an ASC, professionals working with the person should strive to help the individual reach the next highest level of independence and community integration possible. Looking at Fig. 10.1, this would mean moving toward the apex of the pyramid. For the majority of the individual's life this should be the goal of treatment and residential care.

However, professionals working with adults on the spectrum need to adopt a life course perspective (Gitterman & Germain, 2008). Under the life course perspective, individuals move in and out of periods of autonomy and independence. The perspective holds that this is a universal event that is affected by a person's age and health. The population of the United States has grown healthier and older when compared to previous centuries of Americans. The age at which older Americans need more supports and are less able to live independently has risen.

Likewise, it is generally accepted that the average age of death of individuals with disabilities has risen over this time period due to better living conditions and increased quality of care. Our understanding of the medical issues facing this population and the barriers to treatment have increased so that we are better able to provide preventative and primary medical care to this population. For example, our increased understanding of sensory integration dysfunction and the advent of desensitization clinics has allowed medical practitioners to provide preventative dental and gynecological care to lower functioning individuals on the autism spectrum. Consequently, the ASC population is living longer and is now facing some of the same issues of aging as the neurotypical population. Planning must be done to allow the individual who has reached his or her maximum level of independence and community integration to be allowed to return to a lower level of independence and community integration with more structure and support to help them with the issues of aging they might face. An individual who lived completely independently in the community with the informal support of friends, family, and a religious community many need formal supports such as visiting nurse services to provide care or homemaker services to help maintain their independence in the least restrictive environment. A person with an ASC who lived semi-independently in a supervised apartment setting may need to return to a group home setting as he or she ages.

The crisis points or triggering events should be anticipated by the professionals working with the person. These triggering points are often the decline of the person with an ASC's own health or the decline or death of parents, siblings, or other people in his or her own informal support network. Given that individuals with ASCs often have difficulty with change and sudden transitions, professionals and family members should discuss this inevitability with the person on the spectrum ahead of time at a level that he or she can understand and that causes the least amount of distress. This discussion may need to be repeated a number of times of the course of the individual's life.

What Are Effective Treatments for Young Adults with ASCs?

There are very few studies on effective treatments for young adults with ASCs. Much of the interventions with young adults are extrapolations of research findings with children. The National Research Council (2001) examined effective interventions or treatment for children with ASCs in the following variety of domains that define the disability. These domains were in the development of communication, social skills, cognitive skills, adaptive behavior, sensory and motor development, and the treatment of maladaptive behaviors. Treatment of young adults will need to continue addressing these domains as the focus of intervention. The report from the National Research Council (2001) highlighted the need for educators to use empirically validated techniques. Treatment for young adults with ASCs, whether it is educational or medical in nature, should be based upon techniques with scientific support.

The treatment of young adults with ASCs (as is also the case with children) is educational/behavioral or biological in nature. According to Froelich and Lotspeich

(2011), the treatments for autism can be divided into these two broad categories: "(1) Educational and behavioral treatments, such as educational interventions, developmental and behavioral therapies, communication interventions, social skills interventions, sensory-motor interventions, psychological therapies, and physical therapies; and (2)biologic treatments, including prescription medication, over the counter medications, nutritional supplements, and diet changes" (p. 158). The authors admonish readers from utilizing treatment techniques that have no scientific support. In their review of effective treatments, Froelich and Lotspeich (2011) cite the National Autism Center's, 2009 National Standards Report. This report identified 11 established treatments, i.e., 11 treatments that were supported by research to be effective in treating aspects of ASCs. Incidentally, all 11 established treatments were based upon behavioral psychology (e.g., Applied Behavioral Analysis).

The National Standards Report went on to identify 22 "emerging" treatments: "treatments that have some evidence of effectiveness, but not enough for us to be confident that they are truly effective" (National Autism Center, 2009). Among the promising treatment techniques were: Augmentative and Alternative Communication Devices, Cognitive Behavioral Intervention Packages, Developmental Relationship-based Treatments, Exercise, Picture Exchange Communication Systems, Scripting, Social Skills Package, Structured Teaching, Technology-based Treatments, and Theory of Mind Training. More evaluative research will need to be conducted before some of the 22 emerging treatments will be placed among the list of established treatments.

Five treatments were deemed to be "Unestablished" treatments: "treatments for which there is no sound evidence of effectiveness. There is no way to rule out the possibility these treatments are ineffective or harmful" (National Autism Center, 2009). Three treatments, Academic Interventions, Auditory Integration Training, and Facilitated Communication, were identified as falling into the "unestablished" level of evidence category (p. 22). Gluten- and Casein-Free Diet interventions initially showed some promising results. However, the report cited better controlled studies indicating no educational or behavioral benefits and referred readers to studies that had mentioned "medically harmful effects" (p. 23). Sensory Integrative Packages were the final treatment techniques listed as unestablished. However, the report went on to indicate that there were probably many more treatment techniques (e.g., hyperbaric oxygen) that belonged in the "unestablished" category, but the methodology used by the creators of the report only reviewed treatment techniques that were published as research studies in peer-reviewed journals. Treatment providers should view any techniques published in non-peer-reviewed publications as "unestablished".

Conclusions and Future Directions

A significant limitation in detailing the state of services for a population such as adolescents and adults with a diagnosis of autism is that you are trying to take a static picture of a moving target. The modern history of services for all individuals

with a developmental disability has been more than a century of parents, siblings, and self-advocates demanding, and fighting for, an increasing degree of quality and community integration in all aspects of life for the person with the disability. This has continued, and if anything expanded, with the families of individuals with a diagnosis of an autism spectrum disorder. As stated above, the current state of residential services for individuals with a developmental disability ranges along a continuum of both the degree of community integration as well as the degree of paid professional support. This continuum ranges from a person living completely independently in the community, to a person living independently but with a combination of paid and unpaid (family and friends) support, to a person living in the community but in a staffed facility, and finally to a person living in a larger congregate care facility.

The population of individuals with a diagnosis of an autism spectrum disorder is expanding, and it is also aging. Every year adolescents are becoming young adults, and eventually, adults. As families of individuals with a diagnosis of autism have experienced throughout the lives of these individuals, the demand for services increases more quickly than the availability of the services. A group of individuals with a diagnosis of autism is coming of age for which their families have been fierce advocates for better quality and more innovative services. For a significant number of these families, it has become routine for them to develop their own team of both professional and volunteer (family and friends) service providers. There is every reason to expect that these families will continue to take a natural and intentional community approach to developing increased residential opportunities for individuals with a diagnosis of autism. The person-centered planning and inclusive community approaches advocated by such advocates as Burton Blatt and Wolf Wolfensburger (see O'Brien & Lyle O'Brien, 2000, as well as the Center on Human Policy, Law and Disability Studies of Syracuse University, http://disabilitystudies.syr.edu) call for more creative and innovative hybrid residential models. Inclusive models draw on both professional services providers and also natural community supports such as faith communities. The international L'Arche movement founded by Jean Vanier (see L'Arche USA at www.larcheusa.org) is one example of nontraditional approaches to providing natural living opportunities for individuals with a developmental disability.

Assuming no major changes to federal programs such as Medicaid, there is every reason to expect that the basic residential living models for adolescents and adults with a diagnosis of autism will continue long into the future. However, it is likely that more hybrid and combinations of models will develop as the demand increases and the movement towards more community integration continues. Families of individuals with developmental disabilities have never been a retiring lot. As the population of individuals with a diagnosis of autism grows into adulthood, self-advocates and families will continue to demand that society finds a natural place for them in the community.

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Chapter 11
Range of Outcomes and Challenges in Middle and Later Life

Megan Farley and Bill McMahon

Introduction

As will already be clear at this point in this volume, the focus in research and treatment of autism spectrum disorders (ASDs) since its first description in 1943 has been on children. While some attention was given to the adult outcomes of people with ASD as early as the 1960s (Kanner, 1971; Lotter, 1974; Rutter, Greenfeld, & Lockyer, 1967), the proportion of resources and research focused on adults with ASD has historically been minute compared to that given to children. Large-scale efforts are now underway by community support groups, provider groups, governments, and research organizations to understand the natural progression of ASD across the lifespan and to support adults with autism and their families to achieve the best possible outcomes.

Autism was first formally described by Kanner (1943) in a paper characterizing the presentations of 11 children. Psychiatry was mired in controversy over the causes of autism and its relation to other conditions for the next three decades, and it was not until 1980 that "Infantile Autism" was officially recognized as a distinct diagnostic concept in the DSM-III (APA, 1980). A handful of research reports describing late adolescent outcomes for individuals with so-called childhood schizophrenia (Lotter, 1978) or infantile psychosis (Rutter et al., 1967) were produced in the intervening years. The body of published research on ASD exploded in the late 1980s following its formalization as a diagnostic entity, with a modest increase in published information concerning adults. Since 2000, a number of

M. Farley (✉)
Waisman Center, University of Wisconsin, Madison, Madison, WI, USA
e-mail: farley3@waisman.wisc.edu

B. McMahon
University of Utah School of Medicine, Salt Lake City, UT, USA
e-mail: william.mcmahon@hsc.utah.edu

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important studies have characterized outcomes for adults with ASD and begun to define common aspects of development and current status for adults.

This chapter concerns the outcomes of adults with ASD into middle and later life, a period that remains poorly understood for a number of reasons. First, the bulk of adult studies published to date focuses on middle life (i.e., 18–40). Survivors from early studies of children with ASD, typified by small numbers of participants, are only now in the late period of life (over 40 years of age). Many studies published since the late 1990s included larger sample sizes or offer other uniquely beneficial perspectives. Yet these studies vary in numerous ways, including subject characteristics (e.g., IQ ranges, gender composition, age cohort of participants), recruitment sources (e.g., community-based, clinical, or population-based), methods (e.g., retrospective, cross-sectional, longitudinal), and measures used. These differences present challenges to efforts to draw conclusions from the body of literature available, but a few robust findings have emerged.

As they are currently understood, ASDs are a spectrum of conditions, and individuals with ASD may possess any constellation of the full range of symptoms and functional abilities. This heterogeneity adds another layer of complexity to understanding development and outcomes in ASD. In addition, the diagnostic definitions of ASDs have shifted since 1980, resulting in a larger number of individuals in the ASD population with normal-range intellectual and functional abilities as well as less severe symptom presentations. Thus, the population of individuals with ASD diagnosed using DSM-III criteria is different in important ways from those diagnosed after the 1994 DSM-IV diagnostic revisions. Generalizations about adult outcomes for individuals diagnosed in the 1980s are likely to be only partially applicable to later cohorts.

Seltzer, Shattuck, Abbeduto, and Greenberg (2004) highlighted the importance of cohort effects in terms of diagnostic criteria and practices across time. Additional variation in outcomes for cohorts results from changes in social, educational, and therapeutic practices over time. For example, roughly half of the participants in early studies of outcome were institutionalized (Lotter, 1978; Rutter et al., 1967). Prior to 1975, schools in the US could defensibly deny a place in public education programs for children with the complex and sometimes difficult presentations exhibited by youth with ASD. With the passage of the Education for All Handicapped Children Act (PL 94-142) in 1975, students with ASD were guaranteed an education. Thus, significant changes in the environmental situation and supports for children with ASD were mandated, with corresponding changes in adult outcomes for these individuals.

Sampling a population of adults with ASD using current diagnostic criteria would be a useful way to further understanding of the life course of ASDs. Such an enterprise would be highly challenging, however. As we will describe in more detail, a number of studies demonstrate that individuals with ASDs show marked decreases in symptom numbers and severity from childhood through adulthood (Piven, Harper, Palmer, & Arndt, 1996; Seltzer et al., 2003; Shattuck et al., 2007). Symptoms are, therefore, most readily identified in children. While the gold-standard instruments used to systematically diagnose individuals with ASDs have

been used widely in research and clinical settings with adults, they were designed for use with children and are most useful in detecting ASD in elementary-aged children with mild to moderate intellectual disability (Gotham, Bishop, & Lord, 2011). Efforts are underway to establish revised or complementary tools to support diagnosis in adults (Ritvo et al., 2008; Woodbury-Smith, Robinson, Wheelwright, & Baron-Cohen, 2005), but diagnosis of adults is frequently a complicated process. Information from early childhood development is very useful in diagnosing ASDs, and parents of adults who are aging, themselves, often have difficulty recalling details of their adult son or daughter's early childhood behavior that are helpful in making a diagnosis. Unlike schools, where aspects of children's developmental progress are systematically monitored and evaluated, there are no uniform institutions that systematically collect behavioral and performance data on adult populations. This limits the utility of records-based surveillance for adult populations.

We define middle and later life as ages 18–40 and greater than 40 years for the purposes of this chapter; however, many studies of adults with ASD include people from adolescence through adulthood. We have attempted to address outcomes for adults across the spectrum and the full range of intellectual and functional abilities. An important note when considering the results of many studies described in this chapter is that characterizing outcomes for people with ASD is not the same as describing quality of life in this group. Outcome characterization is an objective measure based on employment situation, residential status, and social relationships. Categories reflect broad values in adulthood typically held by developed, Western cultural groups. Quality of life is a subjective concept that can only be rated by the individual. Someone may have a "poor" outcome according to the objective metrics used to characterize outcomes and still subjectively experience a much better quality of life. The concept of quality of life is just beginning to be characterized in adults with ASD.

Adult Prevalence Studies

The current US prevalence figure for all ASDs is estimated to be 1 in 88 (Centers for Disease Control and Prevention [CDC], 2012). In spite of the challenges previously noted related to surveillance of adult populations, two investigative teams have estimated prevalence of adult ASD. The first was an Icelandic group (Saemundsen et al., 2010) that evaluated a small number of adults with severe intellectual disabilities living in Reykjavik. They calculated a prevalence rate of 21 % in their sample of adults with severe intellectual disabilities. Only 11 of the 25 cases identified from the 119 adults participating had previously been diagnosed with an ASD. Another team investigated the rate of ASDs across a community population in England (Brugha et al., 2011). One of the questions the team sought to answer was whether they would detect an increase in ASD prevalence that is commonly reported based on surveillance studies of childhood populations. If true, the prevalence figures would be lower for older groups of people. The study team collected diagnostic

information in three phases. In the first phase, 7,461 adults completed a screening instrument for ASDs in adults. The second phase involved direct observation of 618 adults who endorsed ASD symptoms in the first phase. In the final phase, informants provided detailed information concerning early childhood development and current behaviors for 54 individuals who crossed the diagnostic threshold in the second phase. The estimated prevalence for the population studied was 9.8 per 1,000, similar to current estimates for childhood populations. There was no difference detected in prevalence rates for older versus younger adults, arguing against the notion that there is a true increase in ASD prevalence and demonstrating that some adults in the community have ASDs that have gone undetected. The results suggest that there are more than two million adults with ASD currently living in the USA.

Prognostic Variables

Understanding which variables predict adult outcomes in ASD is a crucial goal for the field, but we know little about what variables predict different outcomes. Child characteristics that suggest specific outcomes are useful in informing parents who want to know what to expect in terms of their child's potential and needs for long-term support. This information is also useful from a societal perspective so that government agencies can anticipate the future needs of the populace. Information about childhood characteristics and behaviors that are associated with specific outcomes can guide development of intervention strategies for children and adults.

Longitudinal studies of ASD from childhood to adulthood have consistently yielded only two useful prognostic factors for adult outcome in ASD. A childhood IQ score in the near-average or average ranges (i.e., $\geq$70) and communicative phrase speech before 6 appear necessary but insufficient for a person to access a moderate level of independence in adulthood (Billstedt, Gillberg, & Gillberg, 2005; Farley et al., 2009; Howlin, Goode, Hutton, & Rutter, 2004; Kobayashi, Murata, & Yoshinaga, 1992). Individuals having these childhood characteristics have widely varying adult outcomes, so exhibiting these characteristics in childhood is no guarantee that a person will achieve adult independence.

The predictive utility of other childhood variables has been examined. Findings regarding severity ratings of childhood ASD symptoms have been mixed (Rutter et al., 1967; Szatmari, Bartolucci, Brenner, Bomd, & Rich, 1989). Early studies indicated that the amount of schooling a child received was an important factor in outcome (Kanner, 1971; Lotter, 1974; Rutter et al., 1967), but these studies took place before developed countries began mandating public education for all children, and the results from those studies may no longer have much practical meaning for children with ASD raised in developed countries today.

In Gillespie-Lynch et al.'s (2012) recent study of childhood variables associated with adult outcome, participants' response to joint attention in early childhood, together with early childhood language ability, predicted composite measures of adult outcome.

This important finding was possible because of detailed, systematic assessment of salient nonverbal social communication behaviors in early childhood. We can anticipate further testing of this result, and perhaps other important early developmental behaviors, in coming studies of adult outcome from childhood samples from whom this type of rigorous data collection on "red flag" behaviors was obtained.

Developmental Course

Almost all studies that have examined developmental trajectories for individuals with ASDs show that these individuals exhibit reductions in autistic symptoms over time (Billstedt et al., 2005; Cederlund, Hagberg, Billstedt, Gillberg, & Gillberg, 2008; Farley et al., 2009; Piven, Harper, Palmer, & Arndt, 1996; Rumsey, Rapoport, & Sceery, 1985; Seltzer et al., 2003; Shattuck et al., 2007). Symptoms of ASD tend to diminish both in severity and number. The most improvement has usually been recorded for participants with IQ scores in the normal range and the least severe symptom presentations at their initial evaluation (Gonzales, Murray, Shay, Campbell, & Small, 1993; McGovern & Sigman, 2005).

Published reports also indicate that there are subgroups of individuals with ASD who experience marked change in the course of their development at some point, either as deterioration or dramatic improvement. Billstedt et al. (2005) examined outcome information from 120 Swedish adults identified through three population-based studies of ASD. Participants in this study experienced particularly limited outcomes in terms of adult achievement and independence compared to other adult samples. Seventeen percent of this sample was described as having "a clear set-back in puberty," and half of that subgroup never recovered from the downturn. This phenomenon was also noted in a Japanese sample of 201 young adults, although marked improvement was also described (Kobayashi et al., 1992). Roughly one-third of this sample experienced a marked deterioration in behavior, most often occurring after age 10. The change occurred after age 20 in six cases. Declines were characterized by specific skill regressions or by increases in hyperactivity, aggression, destructiveness, obsessive behavior, or stereotyped behaviors. Notable improvements in the developmental course occurred in 43 % of the sample and were remarkable for dramatic improvements in symptoms alongside decreased reliance on others. Improvements occurred between the ages of 10 and 15 years for most participants. No predictable antecedents to changes in the developmental course have been noted in previous studies. Rutter et al. (1967) suggested that decreases in language functioning by late adolescence in three members of their sample may have been related to adolescent onset of seizures; however, other members of their sample experienced similar regressions without co-occurring seizure disorders. Eaves and Ho (2008) also recorded changes in developmental trajectory for members of their sample of 48 adults, with a clear improvement occurring in 21 % and deterioration during adolescence for roughly one-third of the sample.

"Recovery" from ASD

Several researchers have identified a small proportion of affected individuals who eventually acquire sufficient skills so that they no longer meet diagnostic criteria. In Rutter et al.'s (1967) study, nine individuals were described as no longer being "autistic." It is unlikely that these individuals no longer exhibited any symptoms of ASD, but rather more likely that they did not meet full diagnostic criteria any longer. Szatmari et al. (1989) reported that 4 of the 16 adults in one sample he studied "had very good outcomes and might be considered 'recovered.'" Nine of 140 men studied by Cederlund et al. (2008) did not meet criteria for a clinical diagnosis on the autism spectrum in adulthood. While six adults in our study of 41 (Farley et al., 2009) did not reach the ASD cut-off on the ADOS, only one was clearly without any ongoing symptoms that might interfere with his own potential to achieve his goals. It is critical to recognize that most individuals who no longer meet criteria retain subtle impairments that interfere with fully independent functioning. Experts have emphasized the idea that ASDs are *lifetime disorders* in spite of some limitations in current diagnostic procedures to detect subtle but important ASD symptoms (Farley et al., 2009; Piven et al., 1996; Seltzer et al., 2004). While individuals may no longer meet full diagnostic criteria for ASDs, they may still require some forms of social support.

While the question of whether people with ASDs ever "recover" is a popular one, the concept of "recovery" must be considered in terms of its cultural implications. There is a strong and growing social movement within the larger ASD community to recognize that it is not necessarily a misfortune to have an ASD, and that along with the differences in social and communicative behavior come many strengths that enable some individuals with ASD to do things like solve problems in novel ways, work diligently, and behave in a forthright manner. Conventional research and medical approaches to developmental conditions focus on deficits, often out of a sense of urgency and in response to limited resources. Historically, many community groups within the larger ASD community sought "cures" or measures to ameliorate perceived or experienced stress and suffering of individuals with ASD and their families. The perspective and teaching activities of emerging ASD cultural groups, that coalesce under names like the "Neurodiversity Movement," "Aspies," or "Aspergians" (Broderick & Ne'eman, 2008), have considerable force in shaping the future of ASD research and policy toward an inclusive society that supports its members regardless of the nature of their learning style.

Mortality

As a group, people with ASDs appear to experience mortality earlier than the general population. Five studies have specifically addressed mortality and causes of death in samples of individuals with ASD (Isager, Mouridsen, & Rich, 1999; Pickett,

Shavelle, & Strauss, 2006; Shavelle & Strauss, 1998; Shavelle, Strauss, & Pickett, 2001). Isager et al. (1999) studied a clinical sample of 341 Danish children with pervasive developmental disabilities seen as inpatients between 1960 and 1984 and then followed over an average of 24 years. The standardized mortality ratio (SMR; the ratio of observed deaths in a specific sample to expected mortality in the general population matched on variables such as age, gender, and length of follow-up period) for the sample was 1.9, almost twice the expected rate for the general population. Causes of death included physical diseases such as epilepsy and unnatural causes such as accidents, suicide, and drug overdose. A relatively high risk of mortality was found for subjects with severe intellectual disability and for subjects with normal intelligence.

In another mortality study, Shavelle and Strauss (1998) examined 11,347 subjects with autism for the years 1980 through 1996 using the California Department of Developmental Services' database. They found a statistically significant gender difference for mortality rates across age groups, with females at higher risk for mortality. Shavelle et al. (2001) explored other variables related to mortality (e.g., intellectual ability and cause of death) in those with autism. This time, 13,111 individuals diagnosed with autism who were receiving services from the California Department of Developmental Services were followed over a period of 14 years. The sample's SMR was 2.4, more than twice the rate expected from the general population at the same time period. There was a large discrepancy in mortality by gender, with males having an SMR of 1.7 and females having an SMR of 5.5; yet age and cause of death patterns were comparable between males and females. Children aged 5–10 years had the highest mortality rates. Those with moderate to severe intellectual disability also had a higher risk of death compared to those with mild intellectual disability or of normal intelligence. Premature death resulted from seizure disorders in many cases. Other causes of death included nervous system dysfunction, drowning and suffocation (more frequent among the average and mildly intellectually impaired groups), respiratory disease (more frequent in those with severe intellectual disability), physical disease, and other external causes. The same research team published a report updating their findings for the years 1998–2002, demonstrating an increased SMR of 2.6 for the entire sample (Pickett et al., 2006).

Recently, Gillberg, Billstedt, Sundg, and Gillberg (2010) reported on their study of mortality in a sample of adults derived from three previous population-based studies of ASD. These individuals were 23–46 years old at the time of the study. Nine had deceased, indicating a mortality rate for this group that was over five times greater than expected in the general population. As in the studies by Shavelle and colleagues, most of the deaths occurred in early childhood, in females, and among those with significant intellectual disability. Five of the six females who died had epilepsy, and death was associated with this condition in four of these women. Other causes of death were related to other medical conditions, and, in one case, an accident.

Together, these studies indicate that there is an increased risk of early death for individuals with ASD that is two to five times greater than expected for the general population. However, the subgroups at greatest risk for early death consistently

appear to be individuals with severe intellectual disabilities and females. Premature death has occurred most frequently in childhood and is most often associated with related medical conditions such as seizure disorders and cardiac conditions. These results suggest a need for careful monitoring by medical professionals especially for those individuals with the high-risk characteristics identified in these studies.

Outcome Studies

Rutter and Lockyer (1967) developed a system for categorizing adult outcome in terms of broad social and educational or occupational criteria, and several investigators have since refined and expanded the system (Howlin et al., 2004; Marriage, Wolverton, & Marriage, 2009). Outcome classifications usually include five nodes ranging from Very Poor (i.e., the person cannot function independently in any way) to Very Good (i.e., achieving great independence; having friends and a job). There is considerable variation in outcomes for samples studied, but in general outcome for approximately 60 % of individuals with ASD is considered Fair, Poor, or Very Poor (Billstedt et al., 2005; Eaves & Ho, 2008; Farley et al., 2009; Howlin et al., 2004). Table 11.1 provides information from selected outcome studies.

In one of the earliest studies of post-childhood outcome for adults with ASD (termed "infantile psychosis" in the original publication), Rutter et al. (1967) examined adolescent outcomes for 63 children who had been identified between 1950 and 1958 through clinical and educational programs at the Maudsley Hospital Children's Department. About one-fifth of the sample experienced a developmental regression in early childhood. The sample included children at all levels of intellectual ability, with 43 % having severe intellectual disability, and 29 % having IQs in the near-normal or normal ranges. Like other studies from this period, half of the participants were institutionalized at the time of the outcome assessments. The investigators noted prognosis for these individuals was poor as only 17 % could be "said to be well adjusted." One person was described as having "normal" adult functioning, and eight more were doing relatively well in regard to achieving some independence in adulthood. Outcomes were Poor or Very Poor for 61 % of the sample. Unlike children today whose access to public education is protected by legislation, 21 of the individuals in this sample never attended any school at all, and less than half of the children had as much as 2 years of formal schooling.

Lotter (1974) followed 32 individuals who were identified through an epidemiologic survey in Middlesex, England when they were 8–10 years old. The mean IQ for these individuals in childhood was 71, with a range of 55–90. Eight years later, one person had passed away, and two were lost to follow-up. Sixty-two percent of those remaining were described as requiring "extensive care and supervision." Outcomes were rated as Good for 14 % and Poor or Very Poor for 60 %. Half were institutionalized. Five of the individuals in the Very Poor outcome category had been excluded from any educational services as they grew up, and Lotter reported

Table 11.1 Outcomes reported in studies of adults with ASD

Study	Country	Sample type	*N*	Diagnosis	Mean age	IQ	Social functioning composite		
							Very/good	Fair	Very/poor
Rutter and Lockyer (1967)	UK	Clinical	63	Infantile psychosis	15; 7	Child: 64.5	14	25	61
Lotter (1974)	UK	Epidemiologic	32	Autism	16–18	Child: 71 (range = 55–90)	14	24	62
Gillberg and Steffenburg (1987)	Sweden	Epidemiologic	24	Infantile autism	20	Child: 74 % <50	48	48	4
Kobayashi et al. (1992)	Japan	Clinical	201	Autism (DSM-III)	21.8 (3.6 SD)	Child: 75 % ID	27	27	46
Howlin et al. (2000)	UK	Clinical	19	Autism	23.9 (1.8 SD)	Child: NVIQ 92–93	16	11	74
Engstrom et al. (2003)	Sweden	Cross-sectional	16	Asperger, high-functioning autism	30.8 (8.3 SD)	Adult: >70	12	75	12
Howlin et al. (2004)	UK	Clinical	68	Autism	29.33 (8.0 SD)	Child: NVIQ 80.2 (19 SD)	23	19	58
Billstedt et al. (2005) and Cederlund et al. (2008)	Sweden	Epidemiologic	114	Autism, atypical autism	25.5 (range 17–40)	Adult: 71 % with severe ID	0	21	78
Eaves and Ho (2008)	Canada	Clinical	48	ASD	24 (range 19–31)	Child: 83 % VIQ <70, 49 % NVIQ < 50	21	32	47
Farley et al. (2009)	USA	Epidemiologic	41	Autism	32.5 (5.7 SD)	Adult: 88.93 (25.7 SD)	48	34	17
Marriage et al. (2009)	Canada	Clinical	80	ASD	19–55	Adult: 16 % with ID	10	–	–
Gillespie-Lynch et al. (2012)	USA	Research sample	20	Autism	26.6 (3.8 SD)	Child: 54.7 (15.5 SD)	30	20	50

that individuals' placements over time, whether in schools or institutions, were associated with their outcome status.

A decade passed before another outcome study was published (Rumsey et al., 1985). This retrospective study concerned 14 men with a mean age of 28 who were recruited through a national search for eligible adult males with DSM-III autistic disorder in the US. Individuals with seizure disorders, identifiable causal medical conditions, or who were unable to discontinue current medications were excluded. The men were studied intensively in an inpatient setting over 5 days. Nine were "unusually highly functioning" with nonverbal IQ scores above 80 and well-developed language abilities. Stereotyped movements were observed on the unit in 86 % of the participants. Basic achievement was commensurate with measured IQ scores, but measures of adaptive functioning were far below expected, given the men's IQs, which is a robust finding from subsequent ASD research. Only one man was in a state institution.

Gillberg and Steffenburg (1987) studied outcome for a population-based sample of 23 people with ASD in late adolescence or early adulthood. As children, one-third obtained IQ scores in the mildly intellectually impaired range, and 26 % achieved scores in the normal or near-normal ranges. One-third had communicative speech at age 6. One person achieved a Good outcome and 44 % had Poor or Very Poor outcomes. Childhood IQ and use of communicative speech at age 6 were useful predictors of outcome status.

Kobayashi et al. (1992) conducted a follow-up investigation of 201 adolescents and adults identified with ASD in childhood through clinical services in Japan. Four of the people had died. The mean age for the remaining 197 young adults was 21. About one-fourth of the sample had an IQ score of 70 or better at age 6, and about 20 % were able to speak without echolalia at that age. Forty percent of the sample began school in a general education class, but only 27 % remained in general education at the age of 12. Outcome adjustment for roughly one-fourth of the sample was Good or better, and was Poor or Very Poor for 46 %. Childhood IQ was the only strong predictor of outcome in this investigation. Although there were similarities between the sample in this study and others reported, the outcome for these participants was better than in previous studies. The authors provided some possible explanations including sociodemographic factors in Japan, advances in public education standards for people with disabilities, intensive intervention histories, and a high proportion of people with ASD and average-range IQ scores at baseline.

In 1996, Ballaban-Gil, Rapin, Tuchman, and Shinnar reported on their study of outcome in 54 adolescents and 45 adults with ASD after an 18-year period. The follow-up procedure consisted of a 30-min telephone interview with caregivers for the members of the sample. Three people had died at the time of the follow-up. Two were described as no longer having any social deficits. Behavioral difficulties were reported for 69 % of the sample, and 40 % of the adults were prescribed medications aimed at controlling behavior. Thirteen adults were described as high-functioning.

Howlin, Mawhood, and Rutter (2000) compared outcomes for 19 men diagnosed in childhood with autism. Participants were 7–8 years old at the time of the childhood assessment and were identified through their involvement in hospitals or

special school programs in the community. They were 23 years, 9 months old on average at the time of the adult assessment. Roughly three-fourths of the men continued to exhibit severe social difficulties in adulthood. Only one-fourth was rated as exhibiting minimal or no "autistic-type behaviors." Just over half of the men relied on others to schedule and organize leisure activities for them, and one-third was described as having no or very limited interests or leisure activities. Three-fourths of the sample experienced a Poor or Very Poor outcome and 16 % experienced a Good outcome or better. Analyses of childhood variables that were associated with adult functioning indicated that early language skills for these men were highly related to social functioning in adulthood.

In 2003, Engstrom, Ekstrom, and Emilsson reported on the outcome for 42 Swedish adults identified through public health service records with Asperger's disorder or so-called high-functioning autism. Eligible participants were over 18 years of age and had adult IQ scores of 70 or higher. Participants included 24 men and 18 women ranging in age from 18 to 49 years. Ten individuals had autism diagnoses, and 32 had Asperger's disorder diagnoses. The participants with Asperger's disorder had been diagnosed at a mean age of 28 compared to age 13 for the group with autism. From among the full sample, 16 were selected as a representative subsample that included people from both diagnostic groups, genders, and a range of ages. Participants with ASD and care providers responded to in-depth interviews designed to obtain a picture of the adult situation for these men and women. Only one adult required no support from others. Almost all participants were supported through pensions from the state. While virtually all of the sample required a high level of support, the authors noted this was a selected sample of adults with ASD who had been identified through public service records as having an ASD.

Howlin et al. (2004) studied adult outcome for 68 people with ASD who also had a childhood nonverbal IQ score of 50 or better. The mean age at the initial evaluation was 7 and at follow-up was 29 years. Average nonverbal IQ scores in adulthood were slightly below childhood scores. Almost all of the subjects were known to have attended compulsory schooling; however, only 22 % left school having achieved formal qualifications. At the time of the follow-up investigation, 23 people were employed. Eight worked in regular, independent jobs; one was self-employed as an artist but was unable to earn a living wage; and 14 worked in sheltered or supported employment. Twenty-seven people were occupied in general work/leisure programs at day centers for adults with disabilities. Outcome adjustment ratings for the sample included Good or Very Good outcomes for one-fourth of the sample and Poor or Very Poor outcomes for roughly 60 %. Childhood IQ was a useful predictor of adult adjustment in that those with childhood nonverbal IQ scores of 70 or more functioned more independently than those with scores below 70. A score of 100 or better did not increase the likelihood that a person would do well in adulthood. For those capable of completing a childhood verbal IQ measure, the combination of verbal and nonverbal IQ scores in childhood provided a more precise indication of outcome classification, with scores above 70 in both domains yielding the greatest likelihood of a Fair outcome or better. Language level at age 5 was useful in

predicting overall outcome and residential status, but none of the other outcome variables studied had predictive utility.

Billstedt et al. (2005) followed up with members of three population-based studies of autism in Sweden, for a total sample of 120, after a period of 13–22 years. Participants ranged in age from 17 to 40 years and included 84 men and 36 women. Six participants had died at the time of the follow-up assessment, and only six participants from the original sample declined to participate. Outcomes were rated as Poor or Very Poor for 78 %. No participant was rated as having an outcome better than Fair. Only four adults were independent, and these individuals were described as "leading fairly isolated lives." Sixty-two of 73 participants examined for current diagnostic status continued to meet criteria for autistic disorder, and one person no longer met diagnostic criteria for any ASD. An overall downward shift in measured intellectual ability was reported. In childhood, 46 % of the sample had scores in the severe range of intellectual disability compared to 71 % at follow-up.

Eaves and Ho (2008) followed 48 individuals with ASD from childhood to adulthood in Canada. Eight of the participants had a childhood IQ score above 70. All participants received special education support in childhood, and 30 % engaged in some kind of post-secondary educational program. Overall outcome adjustment ratings were that 21 % had Good or Very Good outcomes and 46 % had Poor outcomes. Almost 80 % received a government disability pension and used the services of social workers. Also in 2008, Cederlund et al. released their study of outcome for 70 adults with autism and 70 adults with Asperger's disorder. Twenty-seven percent of this sample obtained an outcome categorization of Good, and only two people fell within the Poor category. There were no participants with Very Poor outcome ratings.

Our group (Farley et al., 2009) studied 41 adults who had been identified through a population-based study of ASD in Utah in the 1980s. All of these individuals had historical IQ scores of 70 or greater. Mean age at the first assessment was 7 years and in adulthood was 32 years. Outcome adjustment was better for this sample than previous samples. No systematically collected prognostic factors could be found to explain the difference, but anecdotal information suggested that the relative advantages experienced by the sample we studied over others could be related to the social supports experienced by most of the sample who were members of the Church of Jesus Christ of Latter-Day Saints (LDS Church) in Utah. LDS Church members tend to have large families and organize their religious communities according to the geographical location of their residences, so that in areas that contain a high density of LDS Church members children attend school and church activities with their neighbors. The members of individual congregations, therefore, tend to grow up having frequent interactions with the same community of individuals, with numerous inter-familial relationships due to family size. Participants in our sample routinely reported having found work, friendships, and roles in social groups through their relationships with other members of their church group.

A Canadian sample of 80 adults was identified through clinical diagnostic records, and outcomes were examined through chart reviews (Marriage et al., 2009). The investigators examined outcomes for 45 adults who were diagnosed before

18 years of age compared to 35 adults who were diagnosed in adulthood. As is often the case, individuals with comorbid intellectual disability experienced limited outcomes in adulthood. For those with normal range IQ scores, no differences were detected when comparing those diagnosed before 18 versus those diagnosed later. The investigators looked at a subgroup of individuals with normal range IQ scores who were over 25 years of age. Dividing this subgroup further based on whether they were diagnosed before or after age 18, they found that group diagnosed in adulthood had achieved more in terms of employment and independent living status. The authors suggested that the differences between these groups may be attributable to the fact that these subgroups had a 10-year age difference (average age of 29 for those diagnosed in childhood compared to an average age of 39 for those diagnosed as adults) that may have accounted for the relative increase in achievement levels for those diagnosed as adults. The authors speculated that perhaps having an additional 10 years to develop and achieve normative goals of adulthood offered an advantage to one group.

In a recent study of 20 US adults first examined under 4 years of age, Gillespie-Lynch et al. (2012) analyzed outcomes at an average age of 26 years. This was the fourth data collection point from this sample, with others occurring at average ages of 11 and 18 years. On average, participants had an average mental age of 2 years when they were almost 4 years old and 8 years when they were 18 years old. There was a trend toward reduction in ASD symptoms and improvement in adaptive functioning scores over time. Outcomes were rated as Very Good or Good for 30 % and Poor for 50 %. Early childhood language ratings and IQ scores predicted adaptive functioning in adulthood for this sample. A unique strength of this study was the nature of systematic data collection in early childhood that included specific metrics on the use of joint attention communication strategies. Initiation of joint attention, a voluntary communicative behavior, was not associated with adult variables, but response to joint attention, an involuntary communicative behavior, predicted adult social skills, ASD symptoms, and nonverbal communicative behavior.

Change in ASD Symptoms

Adults with ASD, as a group, exhibit reductions in the number and severity of ASD symptoms over time (Billstedt et al., 2005; McGovern & Sigman, 2005; Rumsey et al., 1985) although individuals may not exhibit notable improvements (Shattuck et al., 2007). In two investigations (Piven et al., 1996; Seltzer et al., 2003), researchers examined the durability of ASD symptoms using the ADI-R to collect detailed information on childhood and current symptom presentation. Almost all participants in both studies met full lifetime criteria for autistic disorder, but considerably fewer met criteria based on their current symptom presentation. Many of those who did not met the full criteria at the time of the investigations still exhibited impairments at or above the diagnostic threshold in two of the three behavioral domains. The authors noted that the ADI-R is designed to detect autism in young children and

may not capture essential features in older people (Seltzer et al., 2003). Participants continued to experience clinically significant challenges in daily functioning as adults; therefore, childhood behaviors must be taken into account in diagnosis. Piven et al. (1996) emphasized the lifetime nature of these conditions in spite of notable symptom improvement.

Studies of social functioning in adults with ASD have illustrated lifelong, functional impairments for participants in social reciprocity and development of social relationships even though they exhibit substantial improvements in social abilities over time. Well-developed language skills were associated with better reciprocal social functioning in one study (Shattuck et al., 2007). McGovern and Sigman (2005) studied symptom changes in 48 late adolescents and early adults and reported large improvements on the ADI-R Social domain score. Participants' lifetime mean scores were 12.93, with a current mean of 8.48. The authors observed significantly more improvement in the social abilities of individuals with IQ scores at or above 70. Howlin (2003) studied adult social functioning for a group of individuals with autistic disorder and average-range intellectual abilities. The group's mean ADI-R Social domain score in adulthood was 11.09, surpassing the ADI-R threshold of 10 for social impairments suggestive of autistic disorder. Similarly, Piven et al.'s (1996) study of 38 adolescents and adults with autistic disorder and near-average or average range intellectual abilities yielded a current mean ADI-R Social domain score of 12.1. This score was a significant improvement over childhood mean score of 21.0 but still above the threshold for social characteristics of autistic disorder.

Like social abilities, communication skills typically improve by adulthood (Piven et al., 1996). Fifty-four percent of the adolescents examined in the outcome study by Rutter et al. (1967) exhibited improvements in communication skills. Significant improvements in verbal communication abilities have been reported on the ADI-R, although findings related to nonverbal communication have been mixed. McGovern and Sigman (2005) reported improvements in group scores for verbal individuals from a lifetime mean of 8.06 to a current mean of 3.56. Nonverbal individuals also demonstrated significant gains as a group, with a lifetime nonverbal communication mean score of 6.23 that diminished to a current mean of 3.82. These follow-up mean scores reflect communicative skills that no longer meet the ADI-R threshold for communication. Shattuck et al. (2007) reported on symptom change in 241 people aged 10–52, indentifying improvement in verbal communication but no improvement over a 4–5 year period for the sample in nonverbal communication skills.

Two outcome studies used information from assessments and caregiver interviews to code the overall language functioning of adults with ASD. Howlin et al. (2004) determined that 43 % of their sample demonstrated no or very little abnormality in adulthood in terms of speech functioning, and 43 % showed only mild abnormality. Use of language was more impaired, however, with only 41 % having no or mild impairments. Language ability was similar for the sample studied by Kobayashi et al. (1992), with 47 % giving evidence of no or mild impairments in the use of language.

Stereotyped or repetitive behaviors and restricted interests also persist into adulthood, according to all of the outcome studies in this review. Improvements are quite

common, however. Perhaps because they are behavioral excesses, repetitive behaviors appear amenable to intervention targeted at cessation, at least in public. Rumsey et al. (1985) obtained detailed information on stereotyped or repetitive behaviors and restricted interests in 14 men through informant reports and 5-day observations on an inpatient unit. Additional data were collected through participant and caregiver interviews. A substantially higher proportion of restricted interests and repetitive behaviors were observed over the course of their stay than could be recorded in a single testing session. The authors reported that it seemed that some men, on recognizing that they were observed to engage in these behaviors, gave the impression of being ashamed to have been seen. Although this study reflects rates that are higher than is usually observed during brief assessments, caregiver reports indicated that these behaviors occur even more often at home than was recorded during the data collection period.

Results from studies using the Stereotyped Behaviors and Restricted Interests Domain of the ADI-R suggest that these behaviors appear equally in adult men and women with AD. Both genders demonstrate improvements in these areas by adulthood (Piven et al., 1996), and adults with IQ scores of 70 or better appear to improve much more than do those with lower IQ scores. McGovern and Sigman (2005) reported a mean decrease on this domain from 6.02 to 4.36. The outcome figure exceeds the ADI-R threshold of 3 and represents relatively less improvement in this area than in the social and communication domains in this sample. Howlin (2003) reported a similar domain score of 4.81 in her sample of adult males with autism.

A recent study of differences in restricted interests and repetitive behaviors with over 700 people with ASDs demonstrated that older individuals exhibited significantly fewer of these behaviors than younger people after controlling for gender, intellectual disability, and the use of psychotropic medications (Esbensen, Greenberg, Seltzer, & Aman, 2009). The sample consisted of roughly even groups of children, adolescents, and adults. About 60 % of the sample had comorbid intellectual disabilities, and 80 % were males. Adults with intellectual disability exhibited high levels of restricted interests and repetitive behaviors in comparison to younger people, while adults with normal-range IQ scores showed fewer of these behaviors than children did. Specifically, participants with intellectual disability had more severe stereotyped movements and more self-injury, but they did not exhibit higher levels of rituals, insistence on routine, compulsions, or restricted interests than other adults. For the entire sample, restricted interests decreased across age groups more than did other types of behavior within this domain.

Sensory Processing

While not a core diagnostic domain at this time, difficulties processing sensory information are common in people with ASD and considered an associated feature according to DSM-IV (APA, 1994). In a study of sensory processing difficulties in

18 adults with ASD and normal-range IQ scores aged 18–65, Crane, Goddard, and Pring (2009) found that, compared to matched controls, adults with ASD reported more experiences with low registration (i.e., responding slowly or not noticing sensory stimuli), sensitivity to sensory input, and avoiding sensations. All but one person reported extreme scores in at least one area. The author noted that results from a previous study (Kern et al., 2007) reflected fewer sensory processing differences in adults than were identified in this study, but ratings in the previous study were made by informants rather than by the individuals with ASD. Crane suggested that the difference in results may be due to more behavioral control in response to sensory processing problems that adults may develop over time, which could lead informants to be unaware of the levels of difficulty adults with ASD experience.

Social Relationships in Adulthood

Most outcome studies indicate that few adults with ASD develop significant relationships outside of their families of origin. This finding is an example of the cohort effects that are likely to surface in future research as adults with previously undiagnosed ASD are increasingly recognized. Fombonne (2012) noted that parents, typically fathers, sometimes report their own ASD symptoms when their child is undergoing diagnostic evaluation, and in our clinic we have had a number of married adults who often have one or two close friends present for evaluation, receiving a diagnosis on the autism spectrum. It is likely that the majority of adults with ASD who also have normal range intellectual abilities have not been diagnosed, and many of these individuals may have married or developed other close relationships outside of their families of origin. The number of adults seeking a diagnosis has greatly increased (Happe & Charlton, 2012).

In terms of outcome studies to date, very few adults with ASD have been reported to have successful, long-term romantic relationships (Howlin, 2003; Howlin et al., 2004). Some outcome studies indicate that no participants or only one participant has been involved in a romantic relationship (Howlin et al., 2000; Rumsey et al., 1985). One-third to half of adults in outcome studies have friendships outside of their families (Eaves & Ho, 2008; Howlin et al., 2000). Almost 75 % of family members reporting on the sample described by Eaves and Ho (2008) indicated that they enjoyed good to excellent relationships with their relative with ASD. Similar results have been found in other studies of adults with AD (Howlin, 2003; Howlin et al., 2000, 2004; Orsmond, Krauss, & Seltzer, 2004). Females have reportedly experienced greater success with peer relationships than males (Engstrom et al., 2003; Orsmond et al., 2004; Piven et al., 1996). Between 10 and 30 % of adults in recent studies (Eaves & Ho, 2008; Engstrom et al., 2003; Farley et al., 2009) had experience in a romantic relationship.

Education and Employment

Adult studies of ASD universally reflect a low level of employment and limitations in academic achievement after high school for participants. Approximately 15 % of adults with ASD studied in outcome research attend post-secondary education programs (Ballaban-Gil et al., 1996; Farley et al., 2009; Kobayashi et al., 1992; Rumsey et al., 1985; Szatmari et al., 1989; Venter, Lord, & Schopler, 1992). Employment situations for adults with ASD tend to be insecure and below what is expected based on measured intellectual ability. Many outcome studies include a large number of individuals with comorbid intellectual disability, thus reducing the proportion of participants who would be expected to work in the open marketplace. Even after accounting for these individuals, many participants spend their days at home without any structured activities.

Seven of the older adolescents in Rutter et al.'s (1967) study were employed in regular or volunteer work, and seven others spent their days at home without any plans for the future. Problems with concentration and work habits were noted to be the reason most of their 38 participants were unemployed. Only one of the 32 individuals followed by Lotter (1974) was employed. Twelve were in structured daytime programs, and two spent their days at home without any structured activities. Half of that sample was institutionalized.

Roughly one-third of adults with normal-range IQ scores in outcome studies are employed, inclusive of regular, full-time work, part-time or volunteer work, supported employment, and sheltered employment. Four men in one study of 14 were employed, with three in low-level, repetitive jobs, and one working as a taxicab driver (Rumsey et al., 1985). One-quarter of the 201 adults in the Japanese study by Kobayashi et al. (1992) were employed or in post-secondary education programs, and one-fourth of the adults in another study were gainfully employed or in sheltered employment (Ballaban-Gil et al., 1996). Howlin et al. (2004) conducted a detailed study of outcomes for 68 adults with childhood nonverbal IQ scores of 50 or better and found that 23 were employed across the range of employment options. Almost half were occupied in day centers for adults with disabilities. In our study (Farley et al., 2009) almost 40 % of the participants pursued post-secondary education or technical training, and half of the participants were in full- or part-time paid employment on the open market. Only 10 % were without any daytime occupation.

Residential Status

Most adults with ASD in the USA live with their parents, siblings, or other relatives (Gerhardt, 2009). This is true for participants in longitudinal and cross-sectional studies of adults with ASD. In the 1985 study by Rumsey et al., over half of the adult participants lived with their parents, and only one man lived in his own apartment.

Sixty-nine percent of the 90 adults studied by Ballaban-Gil et al. (1996) lived with their parents, 23 % were in residential placements, and 4 % lived independently. Similar results are reported for other studies (Eaves & Ho, 2008; Engstrom et al., 2003; Farley et al., 2009; Howlin et al., 2000) which is a significant improvement over previous eras during which over half of adults with ASD were institutionalized. Based on our recent experience with a large sample of adults with ASD, we recognize the value of a full range of residential care options for adults with ASD. A few individuals with significant comorbid psychiatric problems require highly controlled environments for their own health and safety. The evidence clearly reflects the fact that in a majority of cases today, parents and other family members continue to support their adult relatives with ASD in terms of housing.

This situation may be very difficult for some families, but there are also some benefits. Krauss, Seltzer, and Jacobson (2005) conducted a detailed study of residential situations for 133 adults with ASD and the experiences of their caregivers. Over 60 % of these adults lived outside of their family homes. Those who lived in other settings moved out in their mid-20s. Most of the benefits reported for the family groups of the adults living at home accrued to their families, while most of the benefits reported for those living in other settings were enjoyed by the adults with ASD. Caregivers reported on experiences of emotional distress within their families. When adults with ASD continued living in the family home, distress was experienced primarily by family members. When the adult with ASD was living in a placement outside of the family home, most of the reported distress was experienced by mothers who were troubled by guilt, worries, and missing their adult children with ASD. Regardless of residential situation, most families maintained close and frequent contact with their adult children. A larger proportion of females remained at home with their families than males.

Comorbid Psychiatric Conditions

Most studies of adult ASD outcome include information about comorbid medical conditions, which are common in this population (Mazefsky, Folstein, & Lainhart, 2008). Analyses of specific contributions these disorders make to restrictions in overall outcome have not been conducted (Danielsson, Gillberg, Billstedt, Gillberg, & Olsson, 2005). One indicator of the presence of significant co-occurring psychiatric and medical diagnoses is the frequency of prescriptions for anticonvulsant and psychotropic medications. However, relying on this information could overestimate the true prevalence of comorbid psychiatric conditions, particularly among nonverbal individuals who exhibit difficult behaviors that result from untreated medical problems or unsatisfactory environmental conditions. Roughly 40 % of participants in outcome studies have been prescribed medications for psychiatric conditions or to control behavior (Ballaban-Gil et al., 1996; Billstedt et al., 2005; Eaves & Ho, 2008; Farley et al., 2009). Virtually all Axis I disorders have been reported in adults

with ASD (Eaves & Ho, 2008; Farley et al., 2009; Hofvander et al., 2009; Szatmari et al., 1989; Tsakanikos, Underwood, Kravariti, Bouras, & McCarthy, 2011).

In Billstedt et al.'s (2005) population-based study of 114 adults with ASD, eight were described as having psychosis for which all were prescribed lithium. Only one person was identified with depression. One person had Tourette's disorder, but almost one-fourth of the sample experienced periodic tics that did not meet full criteria for Tourette's. One-third was prescribed psychotropic medications, but all participants in the study were described as having significant behavioral problems. Half of the sample had a history of self-injury, and over 40 % had severe problems with violent behavior. Overall, this sample had the most limited outcomes of those reported after the 1970s.

A large proportion of individuals with ASD suffer from a comorbid mood disorder. In a study of 35 individuals with Asperger syndrome, Ghaziuddin, Weidmer-Mikhail, and Ghaziuddin (1998) found that affective disorders were the most common type of psychiatric condition co-occurring in adults, affecting over half of their sample. Figures from adult outcome samples range from 1 to 30 % (Billstedt et al., 2005; Farley et al., 2009). Anxiety disorders are also present in a large proportion of adults with ASD. Rumsey et al. (1985) determined that 50 % of their sample was suffering from chronic, generalized anxiety which they suggested could account for the attention difficulties observed in one-fifth of the sample. Another study of adults with ASD and average-range IQ scores concluded that 40 % of their sample had OCD or chronic anxiety (Szatmari et al., 1989). Figures from other outcome studies are much smaller; however, these results may be confounded by the presence of ritualistic characteristics and hyperactivity commonly associated with ASD (Ghaziuddin et al., 1998).

Hyperactivity and short attention span are common in people with ASD. These have been most commonly noted in children, yet some adults present with behavioral characteristics of attention deficit-hyperactivity disorder (ADHD) as well (Ghaziuddin et al., 1998). Forty (33 %) of the adults in the study by Billstedt et al. (2005) presented with hyperactivity.

Psychiatric conditions evident in a small number of people with ASD include tic disorders, psychotic features, and catatonia. Almost 20 % of the sample examined by Billstedt et al. (2005) demonstrated tics and 10 % of the adults studied by Eaves and Ho (2008) had Tourette's disorder. One of the 15 adults in another investigation presented with Tourette's disorder (Ghaziuddin et al., 1998). A small number of individuals with ASD genuinely have co-occurring psychotic conditions. Eight percent of the sample in the study of adults with ASD conducted by Billstedt et al. (2005) and 38 % of those examined by Szatmari et al. (1989) had characteristics of psychosis. Catatonia is another type of psychiatric disturbance that is rarely observed, but notable, in ASD. One of the 15 adults studied by Howlin et al. (2000) had a sudden-onset catatonic episode during puberty. Billstedt et al. (2005) reported a much higher percentage (12 %) in their sample of 120 adults.

While not psychiatric disorders in their own right, maladaptive behaviors are significant deviations from expected behavior for a person's developmental level. They are often disruptive and sometimes dangerous. Examples include

self-injurious behaviors, feeding and toileting problems, and aggression. Maladaptive behaviors are frequently observed in people with ASD of all levels of age and ability. In general terms, maladaptive behaviors have been reported in up to 69 % of adults with ASD with no overall difference in frequency between males and females (Ballaban-Gil et al., 1996; Eaves & Ho, 2008). Maladaptive behaviors may be relatively infrequent in adults with ASD and average-range IQ scores but may be severe enough to preclude acceptance into general social settings over time (Rumsey et al., 1985). Self-injurious behaviors were reported to have occurred in 50 % of the sample studied by Billstedt et al. (2005), and have been reported to be more common in females than in males (Ballaban-Gil et al., 1996). Difficulties with toileting and feeding appear to persist in lower functioning individuals, but difficulties with compulsive rituals may develop around these tasks in higher functioning adults as well. Aggression among adults is rarely designed to harm others, but property damage or harm to self may occur intermittently, sometimes in response to unimportant changes or problems in the environment (Rumsey et al., 1985).

Chronic Medical Conditions

Almost 20 % of individuals with ASD experience comorbid seizure disorders (Farley et al., 2009; Fombonne, 1999; Kobayashi et al., 1992). These disorders occur more frequently in individuals with ASD and ID. The onset of seizures typically occurs early in childhood (i.e., before age 2) or in adolescence (Danielsson et al., 2005; Kobayashi et al., 1992). Seizures remit in a fraction of those afflicted (Danielsson et al., 2005). Nine percent of a sample of adults with ASD and average-range IQ scores was taking antiepileptics (Howlin et al., 2004).

Among individuals with ASD and comorbid intellectual disabilities, problems with eating and digestion may be more common. Fodstad and Matson (2009) examined 60 such adults and found that almost 40 % had gastroesophageal reflux and 80 % had regular problems with constipation. Over one-fourth of these adults had cardiopulmonary conditions and 10 % had renal disease. They concluded that the frequency of problems related to eating was low, but the intensity of problems, when they occurred, was quite severe.

Roughly 20 % of cases of ASD are associated with a known syndrome. Twenty-three percent of a population-based sample of 120 adults had syndromes known to be associated with ASD, including fragile X syndrome and tuberous sclerosis (Billstedt et al., 2005). Half of this sample also had "major medical problems necessitating regular follow-up." In our study of 41 adults, 17 % had sleep disturbances, but only 5 % were under treatment (Farley et al., 2009). Another 17 % reported chronic allergies. Other chronic medical problems that were reported were those common among the general population, including chronic back pain, hemorrhoids, thyroid disorder, anemia, gout, flat feet, and high blood pressure. Over 40 % of the sample studied by Eaves and Ho (2008) was overweight.

Gender Differences

Women are underrepresented in adult outcome studies, in general, and it is therefore difficult to draw conclusions about women with ASD based on adult outcome studies at this time. Most reports suggest no or minimal differences between outcomes for genders (Billstedt et al., 2005; Kobayashi et al., 1992). The most consistent findings from studies of gender differences have been related to psychiatric symptoms. Two studies have demonstrated that women tend to have more problems with self-injury (Ballaban-Gil et al., 1996; Esbensen et al., 2009).

In a recent study of the gender differences in symptoms of autism and symptoms of anxiety and depression, investigators examined 62 men and women ages 18–45 with diagnoses of autistic disorder or Asperger syndrome and IQ scores in the normal range (Lai et al., 2011). Males and females were matched for age and IQ. The samples were similar on ratings of childhood ASD symptoms as assessed with ADI-R. Results showed that women exhibited fewer symptoms of ASD in behavioral observations, but self-reported higher levels of lifetime ASD symptoms. The investigators suggested the females exhibited fewer symptoms but perceived more problems, with both findings possibly due to a heightened awareness of social communication behaviors. The women were also described as having more lifetime problems with sensory stimuli than men. High levels of co-occurring psychiatric symptoms in the areas of anxiety, depression, and obsessive–compulsive behaviors were observed, with insignificant differences between sexes in specific symptom areas.

Involvement with Law Enforcement

Parents of adolescents and adults with ASD often express concern for their family members in relation to involvement with law enforcement agents (Howlin, 2002). This concern is being addressed actively through efforts to educate law enforcement officers and agents of the courts by several advocacy groups. Allen et al. (2008) examined the cases of 33 individuals with Asperger's disorder and discovered that most engaged in offending behavior that was related to interpersonal problems including social or sexual rejection, bullying, or family conflict. Drug offenses, theft, fraud, sexual offending, and motor offenses are among the least common reported for individuals with ASD, supporting the argument by many experts in the ASD field that offending behavior in ASD populations was likely to result from coercion by others, misinterpretation of social situations, or obsessive interests, while many with ASD may be protected by the frequently noted propensity for rule-bound behavior. Ten percent of the adults with Asperger's disorder studied by Cederlund et al. (2008) had been involved with law enforcement officers, but the remainder was described as very law-abiding. None of the individuals in their lower-functioning sample with autistic disorder had committed legal offenses.

Almost one-third of the adults we studied (Farley et al., 2009) had experienced involvement with law enforcement officers for infractions after childhood, but these were related exclusively to social misunderstandings, "suspicious" behaviors deriving from special interests, and participants being coerced to engage in antisocial behavior by peers.

Costs of Autism in Adulthood

Early adulthood appears to be the second most expensive time in the life of a person with ASD from a societal perspective. Ganz (2007) estimated the societal costs of ASD across the lifespan, calculating a total per capita societal cost for an individual with ASD at over $3 million. The most expensive period was early childhood, at which time many children are undergoing diagnostic studies, receiving medical treatments, and participating in intensive intervention programs. Costs for young adults (ages 23 through 27) were estimated to be $404,260 (in 2003 dollars). Ganz calculated direct medical, direct nonmedical, and indirect costs. Direct medical costs are expenses incurred in the course of medical care, and these tended to be lower for adults than other age groups. Direct nonmedical costs include adult support services and employment services, as examples. This life period often involves much trial-and-error while families attempt to identify services that will result in a good fit with their son or daughter. Direct nonmedical costs were higher in this age group than any other, estimated at $27,539 over this 5-year period. Indirect costs mainly comprise lost productivity costs, as when family members must leave work or reduce hours in order to support their family member. These costs are also the highest for this age group because adult children may remain dependent on their parents, but are also technically old enough to enter the workforce. Therefore, lost productivity costs are calculated for parents as well as the young adult, a phenomenon unique to this life period. Societal costs diminish as adults with ASD age, so that someone aged 48 through 52 incurs less than half the cost of someone aged 23 through 27. Costs, for people in their late 50s and older, drop precipitously.

Investigators have examined the differences in costs of vocational rehabilitation (VR) or employment support services in the USA and England for adults with ASD. Using data from 2002 through 2006, Cimera and Cowan (2009) analyzed data from the U.S. Rehabilitation Services database for people with a range of disability classifications. They determined that rates of use by people with ASD rose over the period from 0.24 % of the VR client population in 2002 to 0.66 % of the client population in 2006. Clients with ASD were the second most costly group to serve; however, costs increased over the period for other disability classification groups while they decreased for clients with ASD. The authors speculated that VR counselors may have been more adept at supporting clients with ASD given the increasing rates of these clients over time, leading to more efficient use of resources.

Outcome in Late Life

Virtually nothing is known about ASDs in late life. Questions at the forefront about this period are related to brain changes, the transfer of care from parents to other family members or human service agencies as parents become unable to care for their adult children through illness or death, and the adequacy of existing services to care for this population. There are many questions about the nature of changes in the brain in adults ASD as they approach old age. We do not know whether or not they experience memory problems at a similar rate to adults in general population, nor whether they may experience earlier onset of dementia and increased rates of dementia as experienced by adults with Down syndrome (Mukaetova-Ladinska, Perry, Baron, & Povey, 2012). Mukaetova-Ladinska et al. (2012) also described limited knowledge in the field related to concerns for adults with limited abilities to articulate their experiences and needs when their parents, who may understand these adults best, are no longer able to care for them. Adults with ASD may have multiple comorbid medical and psychiatric problems that they may not be able to communicate to providers. We do not know whether existing services are ready in terms of clinical capability, numbers, and geographical distribution of care sites to care for these adults. There are also questions about the preparedness of caregivers to hand over responsibility for their adult children or wards before they are unable to provide care. Parents are likely to have ambiguous feelings, anxiety, and uncertainty about when and how to transfer care. There may be guilt, sadness, and fear about no longer having the energy or capacity to provide for their adult child. There may also be confusion and limited resources to organize the legal and financial arrangements necessary to develop a plan for transfer of care. An important area for social science research is understanding when and how these changes need to occur for adults with ASD and their current and future caregivers to accommodate transfer of care that is minimally disruptive for all concerned.

Summary and Future Directions

Despite the fact that ASD is a heterogenous collection of conditions, the results of these studies point to several consistent findings. Early childhood IQ in the near-normal or normal range and communicative speech before 6 years of age appear necessary to have a chance at adult independence. Educational experiences, comorbid psychiatric conditions, and early childhood variables (e.g., response to joint attention) may also be significant in predicting adult outcomes. ASD symptoms diminish over time in all domains, most notably in individuals who do not have comorbid intellectual disability. There are subgroups who experience a marked change in developmental trajectory in adolescence or early adulthood. Outcomes for the majority individuals with clear ASD in childhood appear to be limited, in terms of Western cultural interpretations of adult success, for roughly 60 % of adults

with childhood diagnoses of ASD. Comorbid psychiatric conditions occur at a high rate for adults with ASD. Academic achievement and maintenance of permanent employment situations at a level commensurate with measured IQ is rare for this population at present, and attainment of truly reciprocal social relationships is rare. Adaptive behavioral functioning is also low in relation to measured intellectual ability. There are probably a large number of adults with ASD, as currently defined, who have not been formally diagnosed. Some of these adults may be achieving at much higher levels than have been reflected in the current literature on adult outcomes for ASD. This is suggested by clinical experience of parents who note their own symptoms when their children are being diagnosed as well as by adults who present for evaluations who are employed and married. These findings are important but only a coarse-grained picture of the natural course of ASD. Future discovery of brain pathophysiologic mechanisms will allow for dissection of more homogenous subtypes with possibly distinctive outcome trajectories. Current progress in genetics and brain imaging may inform future outcome studies. Many questions have yet to be answered before we understand the true course(s) of these disorders and how best to support individuals with ASD and their families, clinically, educationally, and through social services.

Other childhood variables may predict adult outcome, including exposure to specific treatment approaches and "red flag" behaviors. Little is known about the nature of development of comorbid psychiatric conditions. They may result from biological mechanisms, repeated negative social experiences, maladaptive thoughts, or a combination of these. We do not when these processes begin to occur or when to begin intervening. Systematic studies of the use of psychotropic medications and current individual or group therapies are limited. Similarly, we do not yet understand when changes in developmental trajectory begin or why they occur. There is limited information about the population of adults meeting current diagnostic criteria for ASD, as many are probably undiagnosed.

Objective outcomes for adults with ASD studied to date appear limited, but the subjective quality of their lives, from their perspectives and those of their caregivers, is not well understood. This is true for adults at all levels of intellectual and functional abilities. There are efforts underway to understand how to support adults with ASD in post-secondary settings and in preparation and maintenance of employment. Intervention programs to prepare adolescents and adults with ASD with "soft skills" for the workplace are needed, in addition to model programs to support securing and maintaining employment. There are some current program models to educate employers about individuals with ASD in terms of their unique strengths and possible needs for environmental supports.

Future research efforts in the social domain are needed to understand how to support individuals with ASD in learning new social skills to develop satisfying friendships and romantic relationships. There is also a need to develop therapeutic models for couples where there is an adult with ASD, and possibly children with ASD in the family.

Development of models to promote adaptive functioning skill development is also needed. Adults with ASD may have the fundamental intellectual capacity to

drive, but few actually do, often for fear of endangering others. Educational programs that prepare adolescents and adults with ASD to be comfortable driving, to go shopping for food for the coming week, to cook, or to manage their personal hygiene in a socially normative manner are all needed.

Other important areas for research are related to brain changes or development of medical conditions that may occur in late adulthood. We do not know what services are likely to be needed by this population and whether existing services can accommodate future needs. Research into transfer of care from parents to other support persons, including planning approaches and therapies for adults with ASD, their current caregivers, and future caregivers, is essential. While much remains unknown about the natural progression of ASD across the lifespan, there is a high level of commitment and interest from research and advocacy organizations to resolve the gap in understanding. It is likely that answers to these and other questions will come forth in the next decade.

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Chapter 12
Medical and Health Problems in Adults with High-Functioning Autism and Asperger Syndrome

Lillian Burke and Kevin P. Stoddart

Adults on the autism spectrum experience a wide range of medical and health problems—some at a higher prevalence compared with the general population. Although these problems can significantly affect quality of life, information on medical comorbidities for this group is sparse, and general knowledge of disorders associated with autism spectrum disorder (ASD) in community-based medical settings is lacking. In this chapter, we review medical and health problems experienced by adults with ASD. We begin this discussion by examining possible risk factors associated with health problems in this group, in addition to the current literature on prevalence rates of specific disorders.

The focus of this chapter is on those who have historically been identified with "high-functioning autism" or Asperger syndrome (AS). This cluster of individuals has relatively good language development and near-average to above-average intelligence. Their primary challenge is social: they have problems understanding social rules and expectations, difficulties conversing in a reciprocal manner, and may experience high social anxiety—sometimes leading to social avoidance. They exhibit characteristics such as excessive interests in certain subjects, strict adherence to routines, hypo- or hypersensitivities, or obsessive and/or compulsive features. Because of the general lack of professional knowledge about these adults and inadequate access to services, many are diagnosed in adulthood (Stoddart, Burke, & King, 2012). For a community-based sample in Canada, 48 % of individuals with "high-functioning autism" and AS were not diagnosed until they were 21 years or older (Stoddart et al., 2013).

L. Burke, Ph.D.
The Redpath Centre, Toronto, ON, Canada
e-mail: lillian.burke@redpathcentre.ca

K.P. Stoddart, Ph.D. (✉)
The Redpath Centre and University of Toronto, Toronto, ON, Canada
e-mail: kevin.stoddart@repathcentre.ca

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Empirical literature reports the co-occurrence of a number of classes of disorders that are associated with ASD including neurological, digestive and gastrointestinal, metabolic, autoimmune, and genetic disorders. Some diseases seem to occur within families, in the absence of a known genetic vulnerability. Others, such as epilepsy, present with higher frequency in those with ASD and comorbid intellectual disabilities. Another group of conditions appear to be random and may be, in part, attributable to other ASD-related features such as concurrent idiosyncratic sensory processing (e.g., heightened sensitivity to pain) and mental health struggles (e.g., bouts of diarrhea related to anxiety).

Health Risk Factors in Adults with ASD

> What am I to do? To have anything like a reasonable quality of life, my life is abominably high-maintenance. I can't find a medical doctor who is willing to work with me without the drugs that I get all the side-effects for, unpredictable intended effects, and wild-card effects that don't show up in the literature at all. I don't know how to live in this world, never mind participate in it.

As reflected in this quote from a woman with ASD, research and professional education on medical and health problems experienced by this patient group have been largely been neglected. We found a dearth of studies addressing the health needs of those on the milder end of the spectrum compared with an increasing body of literature for this group related to social, emotional, psychiatric, communication, educational, and employment needs. More important, members of the multidisciplinary team needed to support adults with ASD are left with few guidelines as to how to recognize and address these medical and health concerns in their practices.

Although it is not possible to determine if ASD *itself* gives rise to increased mortality in this group, the specter has been raised and examined in numerous reports. Mortality studies in ASD provide us with some clues about significant medical concerns for this group and underscores the necessity of recognition and treatment. A recent population-based mortality study in Sweden found an almost sixfold increased mortality rate among individuals with ASD, as compared to the general population. Of nine deaths reported, four were related to "sudden unexpected death in epilepsy," two to "cerebral infection/malignancy," two to accident, and one to cardiac insufficiency (in an individual with Trisomy 13; Gillberg, Billstedt, Sundh, & Gillberg, 2010). In a California study examining the deaths of 202 individuals, major causes of death included circulatory problems ($n = 22$), cancer ($n = 21$), seizures ($n = 15$), congenital abnormalities ($n = 16$), drowning and suffocation ($n = 18$), respiratory problems ($n = 13$), digestive ($n = 13$), and diseases of the sensory and nervous systems ($n = 10$). The standardized mortality ratio (SMR) for those with no or mild mental retardation was elevated for seizures (22.6) and nervous and sensory

diseases (4.8). Overall, higher rates of mortality occurred in those with severe intellectual disability, although individuals with all levels of IQ were affected with an SMR of 2.4 (Shavelle, Strauss, & Pickett, 2001). Finally, a review of a clinical sample of 341 in Denmark followed for 24 years found the average age at the death of 12 individuals was 22 years; 9 of the 12 individuals had medical comorbidities. Both severe retardation and normal intelligence were associated with high risk of death (Iasger, Mouridsen, & Rich, 1999).

Below, we briefly review variables that may be risk factors for this cohort, based on our clinical experience and review of the existing research. The social determinants of health (such as race, gender, education, and income) are relevant for the general population and for individuals with disabilities (WHO, 2011a, 2011b). Discussion of social determinants is beyond the scope of this chapter; however, we believe they are also highly applicable to adults with ASD. Empirical exploration of the determinants of health is critically needed for this patient cohort, both in developed and developing countries. We highlight only the most significant risk factors relating to health and wellness here: aging, medication use, features characteristic of ASD, genetics, and poor cross-systems knowledge exchange.

Risks Associated with Aging

Until recently, the research examining health issues in those with ASD has focused on children. Some medical disorders may not present until adulthood, or perhaps have been present since childhood but not diagnosed until adulthood. It has been suggested that adolescence is a period when an individual with an ASD is at increased risk for developing health problems such as seizures and gastrointestinal problems (Kring, Greenberg, & Mailick Seltzer, 2010).

The risks associated with individuals with aging and milder ASD is a relatively unexplored area (Povey, Mills, & Gomez de la Cuesta, 2011). We are identifying many individuals with ASD in later life (50 years and over) as are others around the world (James, Mukaetova-Ladinska, Reichelt, Briel, & Scully, 2006). Some of these are older family members of those previously diagnosed with ASD (Ritvo, Ritvo, Freeman, & Mason-Brothers, 1994).

Furthermore, services and supports for adults with ASD are often lacking, and intervention, especially in "milder" ASD, may occur in later life only. Increasing attention is also being given to disease presentation and prevention in older individuals with developmental disabilities generally, and in older adults with ASD specifically (Povey et al., 2011; Stoddart, 2005, 2006), as more individuals with developmental disabilities are living longer and reaching older age. A working knowledge of ASD has yet to be widely disseminated into the sector caring for aging individuals and vice versa, which leads to systemic and practice-related vulnerabilities for older adults living with ASD.

Risks Associated with Medication Use

Medication use is common, and often long term, in individuals with ASD. In our recent study of 480 youth and adults with ASD, we found that there was a high rate of medication use, despite this being a relatively young sample. They ranged in age from 16 to 66 years, with an average of 29.11 years—80.6 % were 40 years or younger. The mean number of medications used per individual in this study was 1.65 (SD = 1.76) with 63.1 % taking at least one medication; some were taking as many as six or seven. "Medication use was correlated with age ($r = 0.220$; $p < 0.001$), number of physical illnesses ($r = 0.348$; $p < 0.001$), and number of psychological diagnoses ($r = 0.283$; $p < 0.01$)" (Stoddart et al., 2013, p. 25). Multiple medication use may be an artefact of poor physician monitoring, lack of awareness of multiple prescribers, poor patient follow-up, unmanaged behavioral problems, and unavailability of alternative treatment approaches.

The long-term effects of medication are an ongoing concern of prescribers and patients. Second generation antipsychotic medications are increasingly being used with children and adolescents presenting with psychiatric and behavioral difficulties, and there is some evidence that this may result in metabolic and endocrine disturbances (De Hert, Dobbelaere, Sheridan, Cohen, & Correll, 2011). Some adults may understandably be alarmed by the side effects of medications listed on patient information sheets or the Internet physiologically sensitive to, or hypervigilant about adverse reactions. A history of idiosyncratic or even paradoxical responses to medications may precede patient concerns (Sloman, 2005; Stoddart et al., 2012; Towbin, 2003).

Many individuals on the spectrum and their families would prefer to use naturally occurring substances or *Complementary and Alternative Medicines* (CAMs). Two examples from our practice are the use of melatonin for improving sleep and marijuana/tetrahydrocannabinol (THC) to treat anxiety, insomnia, or pain. Other CAMs which have been noted in the literature include multivitamins, gluten-casein free diet, vitamin B6, and magnesium; reviews of efficacy and safety are just emerging (Akins, Angkustsiri, & Hansen, 2010; Anagnostou & Hansen, 2011). In their review of medical treatment and CAMs, Anagnostou and Hansen note "…healthcare professionals need strategies and tools to help families negotiate the many available CAM treatments and make decisions based on current safety and efficacy" (p. 623).

Risk Associated with Sensory, Executive Function, Mental Health, and Social Problems

Many of our patients are at risk of inadequate or improper medical care because of features associated with ASD. For example, sensory processing concerns are not generally thought of in relation to medical disorders. However, hypo- or hypersensitivity can play a role in the detection and retreatment of health concerns. We recently learned of a woman with high-functioning autism that did not report on

pain in her abdomen as early as others might have. Unfortunately, she was diagnosed with cancer and before treatment could begin, succumbed to the illness. Some authors have suggested that *high* levels of sensitivity may be related to the unusual way those with chronic fatigue syndrome (CFS) and fibromyalgia process physical responses.

Second, clinical experience tells us that despite having average or above-average intelligence, individuals with ASD still struggle with planning, initiation, problem solving, and sequencing life's demands. Many have difficulty finding and using services and supports (Stoddart et al., 2012, 2013). In higher-functioning individuals with average to above-average IQs, there is often a "cloak of competence" (Egerton, Bollinger, & Herr, 1984) or an assumption of competence when it comes to these basic life skills. Adults who are highly accomplished in their work may have basic problems with organization at home, or for tasks which are of less interest. Not surprisingly, these executive functioning problems carry over into medical and health care. Simply finding and arriving at a specialist clinic on time can be a challenge. In an overburdened medical system, the patient who misses a specialist appointment is either dropped from the referral list or put back at the bottom of a long waiting list for nonlife-threatening illnesses.

Third, social interaction also affects contact and interactions with medical personnel. Individuals with ASD may be reluctant to raise "private" medical issues with their family doctors such as birth control, irregular menses, or bowel problems. one young man we saw in our clinic was experiencing significant genital discomfort, which resulted in him losing his employment, but he refused to raise this with his doctor, or subject himself to a medical exam. As well, our patients appear socially odd or awkward, thereby reducing their credibility when reporting symptoms.

Fourth, we know that anxiety and depression are commonly seen in individuals with ASD. These symptoms may contribute to difficulties accessing medical services and supports, especially in cases of extreme social anxiety, requirement of meeting strangers, making appointments by telephone, or sitting in a crowded waiting room with (usually ill) strangers. Patients with a known history of anxiety disorders, (traits of) obsessive compulsive disorder, and hypochondriasis may also be viewed as unreliable and anxious-prone informants in a medical examination.

Risks Associated with Genetic Vulnerability

There is a body of literature suggesting that some of the disorders seen in those with ASD may have a familial link, having been present in the mother during pregnancy, having a pattern of occurrence in families, as well as being identified in childhood (Gillberg, Gillberg, & Kopp, 1992; Hoshiko, Grether, Windham, Smith, & Fessel, 2011). It is well established that ASD presents more often in families where an ASD has already been identified, and characteristics of AS/ASD are often noted in other family members (Burke, 2005). It is also reported that mental disorders such as mood disorders, which are present in family members, may also present in a child with an ASD, suggesting possible heritability (Attwood, 2007).

While we have come to view AS and autism as part of the same family of disorders, and in North America are moving to a diagnostic system that does not distinguish between the disorders beyond severity, many clinicians and researchers have cited features which suggest the disorders are distinct. Genetic research examining gene regions within families indicate occurrence of both AS/ASD-shared as well as AS distinct regions (Salyakina et al., 2010). Recent findings from genome research which looked at single-nucleotide polymorphism (SNP) of five mental disorders suggest associations across the disorders. Those investigated were ASD, ADHD, bipolar disorder, major depressive disorder, and schizophrenia (Cross-Disorder Group of the Psychiatric Genomics Consortium, 2013).

The above research indicates transmission of features of ASD may be specific to an ASD diagnosis, may cross within the ASD family, or may cross other mental or neurologically based disorders. It would seem reasonable, then, that medical and health issues may also be part of the presentation of an ASD, as are seen in many other syndromes, and that these may also be genetically transmitted. It would therefore be important for families to gather information, not only related to features of ASD within family members but also related to mental and physical health concerns. Further, medical practitioners should ensure symptoms of health disorders are thoroughly investigated. Interestingly, the National Autistic Society in the UK has introduced a health family tool to assess not only an individual's health but also their family's health history which will allow knowledge of diseases, not necessarily ASD-related or more common in ASD, but that run in families such as diabetes, heart disease, and cancer (Povey et al., 2011).

Risk Associated with Poorly Informed Medical Systems

The knowledge of healthcare providers in the community is limited when it comes to knowledge of higher incidence disorders in ASD. Chronic disorders from childhood will continue into adult years, even if they are controlled through medication or other forms of treatment. The experiences of children and youth with ASD and their families are surprisingly poor, even in specialist pediatric hospitals (Muskat et al., 2012). The carry-over of these poor or even traumatizing experiences is often voiced by older youth and adults long after these episodes.

In our practices, many adults, without the benefit of an ASD diagnosis, were previously diagnosed with a series of seemingly unrelated medical problems. When they are finally diagnosed with an ASD in later life they appear "relieved" to discover that many of the medical issues that they have struggled with their entire lives are common for individuals with ASD. These include allergies, dietary restrictions, gastrointestinal issues, and hormonal problems. In some cases, knowing this, they can access medical practitioners with experience in ASD, or benefit from information that they access on their own. We review many of these higher risk clusters of disorders below.

In practice, we routinely ask about co-occurring medical issues in both diagnostic and treatment appointments and ensure that they are being addressed (Stoddart, Burke, & King, 2012). Although we lack sophistication in our current understanding of health issues and adult ASD, in the future we can theoretically use our knowledge of high prevalence medical issues to assist in the diagnostic process, and in implementing more focused treatments for these comorbidities.

Individuals with ASD and their families have reported difficulty obtaining appropriate health care or having their symptoms resolved (Stoddart et al., 2013). Graetz (2010) has suggested that there are not enough medical practitioners who understood the needs of their clients on the spectrum. Barnhill (2007) discussed physical health of adults with AS, indicating some may have chronic aches, pain, and fatigue which impact on other areas of life. She noted her own son had such experiences, and had difficulties identifying his complaints, making it challenging for his physician to offer appropriate treatment.

Further, in the absence of centralized medical management, electronic records exchange, and largely community-based decentralized services for adults with ASD, individuals are challenged to understand what knowledge care providers require, may make assumptions that general practitioners or specialists are knowledgeable about particular issues, or that they are able to follow through.

In a comparative study of individuals on the autism spectrum and those who were unaffected, those on the spectrum reported significantly greater unmet health needs, less patient-provider communication, and less resolution of symptoms of chronic health problems. Participants in the survey were primarily those with a diagnosis of AS (Nicolaidis et al., 2013). Through a Connecticut study, physicians were asked about their experiences with adults on the autism spectrum; 40 % of the responding physicians indicated they did see adults with ASD. Most patients did not live independently and did not, or could not, follow medical recommendations on their own. Of the responding physicians, only 36 % had received training related to serving adults with ASD; half of the respondents indicated they would like training (Bruder, Kerins, Mazzarella, Sims, & Stein, 2012).

Prevalence Research and Methodological Considerations

It is important that we understand the likelihood of co-occurrence of certain medical and health issues in those with ASD as well as the impact these disorders have on the individual. This will allow physicians to be more cognizant of potential investigations that may be necessary as well as ensuring there are appropriate interventions available. It will also allow individuals and their families to ensure they seek appropriate care when certain symptoms are present. The medical and health issues we review reflect recent studies reporting the presence of these disorders in adults on the spectrum. However, in discussing the specific disorders, some of the research may primarily have been carried out with children or youth.

Often studies reviewed combine adults across functioning levels, with or without intellectual disability, or do not specify functioning levels, so that it is not clear what factors might actually be predictors of health or medical disorders in those on the spectrum. Other factors such as age, access to healthcare, age of diagnosis, and other risk factors articulated in the last section are not necessarily noted. Many have previously discussed the wide heterogeneity of ASD (Stoddart et al., 2012; Willemsen-Swinkels & Buitelaar, 2002). The possibly wider range of presentation and functioning in adulthood has important implications for research and service provision (Stoddart et al., 2013). Shattuck and colleagues argue: "Although few studies have analyzed the implications of the heterogeneity of both abilities and challenges exhibited by people on the autism spectrum for service provision, such heterogeneity is vast [and] has significant implications for service needs" (Shattuck et al., 2012, p. 289) and for our purposes, healthcare and medical management.

A number of disorders, including those which are genetic, metabolic, as well as other developmental syndromes, have been found to exist in people who exhibit more severe symptoms of autism (Miles, McCathern, Stichter, & Shinawi, 2010). Some of these include Fragile X, tuberous sclerosis, neurofibromatosis, hypomelanosis of Ito and Moebius syndrome, phenylketonuria, adrenylosuccinate lyase deficiency, creatine deficiency, Smith-Lemli-Opitz syndrome, Angelman syndrome, and Landau-Kleffner syndrome (Gillberg, 1992; Miles et al., 2010).

Gillberg and Ehlers (1998) suggest that fewer than 15 % of those on the milder end of the spectrum will present with comorbid medical conditions. Those most likely to occur include fragile X, neurofibromatosis, and tuberous sclerosis. In 2000, Gillberg and Billstedt proposed the following prevalence rates of disorders concurrent with an ASD: epilepsy (30 %), anorexia nervosa (28 %), tuberous sclerosis (2–9 %), fragile X syndrome (2–10 %), and Thalidomide syndrome (4 %).

A recent large-scale review was conducted over four hospitals in the USA, including one pediatric setting (Kohane et al., 2012). Records of 14,000 individuals with ASD under the age of 35 were studied and the prevalence of comorbidities examined. Coexisting disorders in those under and over the age of 18 years were also compared. Among the identified comorbid physical health issues in children and young adults with ASD were: epilepsy (19.4 %), bowel disorders (11.7 %—excluding inflammatory bowel disease or IBD), CNS anomalies (12.4 %), autoimmune disorders (0.7 %—excluding IBD and Type 1 diabetes), diabetes mellitus Type 1 (0.8 %), IBD (0.8 %), and sleep disorders (1.1 %). When compared to prevalence of these disorders in the general population, all but autoimmune disorders was found to be greater. When age was examined, those over age 18 had a higher incidence of diabetes mellitus Type 1 and IBD, while occurrence of the other noted disorders did not vary. This study also confirmed previous research indicating presence of "single-gene" disorders associated with ASD, specifically fragile X syndrome, tuberous sclerosis, Down syndrome, and muscular dystrophy. The authors noted that occurrence of each individual disorder was at a low prevalence rate, although collectively, they might exceed 20 %.

Other research examined records from a national insurance database in Taiwan over a 14-year period and identified a higher incidence of allergic and autoimmune

disorders in those with ASD than those found in a matched control group (Chen et al., 2013). Among the specific disorders occurring at an increased level were asthma, dermatitis, urticaria, allergic rhinitis, and Type 1 diabetes. A trend was found for concurrent ASD and Crohn's disease. The sample included individuals across functioning levels.

In an American study, individuals with ASD ranging in age from 10 to 53 (Mean = 22) were followed over a 5-year period. Over 80 % of the parents rated their child's health as good or excellent. Researchers found the most common health problems reported were difficulty sleeping (70 %), gastrointestinal complaints (58 %), breathing (asthma/allergies) problems (32 %), and seizure disorder (25 %). Other issues included problems with feet, teeth, high cholesterol, and migraine headaches. Medications were prescribed for anxiety, depression, seizures, behavior, breathing problems, gastrointestinal difficulties, sleep, hormonal issues, attentional issues, and skin problems (Seltzer & Wyngaarden Kraus, undated).

In Canada, Mousseau, Ludkin, Szatmari, and Bryson (2006) examined the quality of life of 19 "high-functioning" (i.e., IQ > 70) men with ASD with an average age of 30.8 years. The number of times per year the participants contacted healthcare professionals ranged from 4 to 67, with an average of 24. Body Mass Index was calculated with an average of 28.21 (i.e., average "overweight"). In another study of individuals with AS (Balfe & Tantum, 2010), reports of physical complaints included vision problems (24 %), hearing problems (24 %), involuntary movements (36 %), genetic problems (16 %), and neurological problems (16 %): 54 % of individuals took medication.

In our early study of adults (20+) with ASD, accessing services in a developmental service agency, 100 clinical files were reviewed (Stoddart, Burke, & Temple, 2002). In total, 32 (32 %) had a chronic medical issue including epilepsy ($n = 9$), cerebral palsy ($n = 5$), fragile X syndrome ($n = 5$), hearing/vision impairment ($n = 4$), head trauma ($n = 2$), and neuroleptic malignant syndrome ($n = 2$). Individual cases were identified with diabetes, asthma, hydrocephalus, thyroid disorder, ulcerative colitis, organic brain disorder, physical mobility problems, and temporal lobe dysgenesis.

In our recent study of 480 youth (16+) and adults with ASD in the community (Stoddart et al., 2013), we asked respondents to list up to three medical or health conditions. Approximately half of the sample were diagnosed with "high-functioning autism" or AS. A total of 296 conditions were named by respondents, and we grouped these into categories. In total, 176 (36.7 %) respondents identified at least one medical or health condition. Of the entire sample, 10.62 % reported brain and spinal cord disorders (e.g., epilepsy, brain injury), 9.79 % reported digestive system disorders (gastroesophageal reflux disease [GERD], irritable bowel syndrome [IBS], Crohn's), and 9.38 % noted lung and respiratory disorders. Hormonal and metabolic disorders and musculoskeletal disorders were each reported in 6.46 % of the sample. Sleep disorders occurred in 2.92 %; 2.50 % indicated they experienced skin disorders and weight disorders. "There was no relationship between numbers of illness reported for each person and diagnosis or gender. However, there was a weak but significant correlation between number of illnesses and age ($r = 0.250$; $p < 0.01$)" (p. 24).

Genetic Disorders

There is increasing evidence that ASD has a genetic etiology, which may be influenced by environmental factors. Genetic testing is not always carried out with those diagnosed with an ASD, in our experience. However, it is reported that 5–9 % of those with an ASD has an identified chromosomal abnormality, and a vast number of chromosomes have been identified in case studies (Spence, Sharifi, & Wiznitzer, 2004).

Early evidence and interest in genetics came from twin studies, from studies showing the reoccurrence of ASD within families, and from case reports of coexistence of ASD with other genetic disorders. The higher incidence of ASD in males suggests a relationship to sex chromosomes. These factors have led to broad spread genome research (Klauck, 2006). While initially researchers believed one or two genes would be identified as causative factors in ASD, recent research suggests that "several hundreds of loci are likely to contribute to the complex genetic heterogeneity of this group of disorders" (Schaaf & Zoghbi, 2011, p. 806). This would seem to explain the great variety in presentation of those on the spectrum, as well as the large number of disorders that share features with ASD. While the genetic research will not be reviewed further in this chapter, some of the specific disorders will be discussed as will the medical concerns that are consequences of such disorders.

Fragile X Syndrome

Fragile X (FrX) occurs at a rate of 1:3,200–4,000 males and 1:6,000 females (Sherman, 2002) and results from mutation of the FMR1 gene on the X chromosome, preventing the gene from producing adequate FMR protein (FMRP; Denmark, 2002; Garber, Visootsak, & Warren, 2008; NICHD, 2003). As it is carried on the X chromosome, affected females show less severe symptom because they typically have one unaffected X chromosome (NICHD, 2003). The gene can be passed on without presentation of symptoms, resulting in some families being unaware that they carry the disorder. Those with FrX exhibit behavioral difficulties, learning challenges, and associated mental health problems, in addition to physical health characteristics. Physical features and health characteristics include a high palate, prominent jaw, long face, course features, large ears, increased head circumference, poor muscle tone, orthopedic problems, heart murmur, seizures, ear infections, vision problems, gastroesophageal reflux, and epilepsy (Garber et al., 2008; NICHD, 2003; Roberts & Kagan-Kushnir, 2005).

FrX has been associated with ASD (Denmark, 2002). Some have estimated that 30 % of those diagnosed with FrX have a concurrent diagnosis of ASD (Holden & Liu, 2005). While most of the professional literature examines the relationship between FrX and more severe subtypes of ASD, there is some suggestion of AS occurring with X chromosome atypicalities (Searcy, Burd, Kerbeshian, Stenehjem, & Franceschini, 2000), and we have observed this in practice.

Neurofibromatosis

Neurofibromatosis (NF1), also known as von Recklinghausen's disorder, is caused by mutations on the 17th chromosome (17q11.2). The gene involved in NF1 regulates neurofibromin, a protein believed to suppress the development of tumors. In NF1, typically benign tumors develop in the central nervous system as well as other parts of the body, and abnormalities in skin pigmentation occur. Additional features may include increased head circumference, learning challenges, hyperactivity, seizures, and skeletal problems such as scoliosis (Mouridsen & Sorensen, 1995; Williams & Hersch, 1998). Williams and Hersch (1998) estimate that 70 % of those with NF1 will have a neurodevelopmental disorder, including learning disability, ADHD, and ASD. Dodd (2005) proposed in those who have AS, there is a slight increase in occurrence of neurofibromatosis compared to the general population.

Duchenne's Muscular Dystrophy

Duchenne's muscular dystrophy (DMD) is an X-linked disorder in which a gene mutation reduces the production of dystrophin, a protein providing stabilization of skeletal muscles. Dystrophin is typically found in the central nervous system. In males who have DMD, concurrent diagnoses of ADHD, ASD, Dyslexia, and OCD have been reported (Hendriksen & Vles, 2008). Poysky (2007) suggests the incidence of DMD in those with ASD is higher than in the general population.

Tuberous Sclerosis Complex

Tuberous sclerosis complex (TSC) is an inherited disorder in which a gene mutation reduces the availability of proteins that act to suppress tumors. The tumors contain overgrowth of nerves or connective tissue. Individuals with TSC have skin-related symptoms, such as light patches and growths. The impact of the resulting tubers is dependent on where the tubers develop. For some, growths develop on the kidney, eye, heart, or lung (Yates, 2006). Cortical tubers are related to epilepsy. Cortical tubers that grow in the temporal lobe appear to be present in individuals with ASD (Bolton, Park, Higgins, Griffiths, & Pickles, 2002). Behaviorally, individuals with TSC are prone to hyperactivity and sleep disturbance (Mahoney, 2002). While less than 4 % of individuals who have autism are diagnosed with TSC, as many as 50 % of individuals with TSC present with features of an ASD (Wiznitzer, 2004). Depending on the degree of impairment, this may include those with AS or milder forms of ASD.

Neurological Disorders

ASD is a neurodevelopmental disorder. Despite the inherent implication of this for brain function in ASD, there are additional neurological conditions which appear to coexist with ASD. The most commonly discussed are seizure disorders/epilepsy, and tic disorders, including Tourette syndrome. Some with ASD also report migraine headaches. Genetic disorders noted above may also have neurological implications.

Epilepsy/Seizure Disorders

Early research of those with autism identified the co-occurrence of epilepsy, and estimates suggest that 40 % of those with an ASD will develop epilepsy (Taylor, Neville, & Cross, 1999). While little research has occurred in those with epilepsy who are on the milder end of the autism spectrum, such as those with AS, Berney (2004) estimates the risk to be lower for those with AS than autism. He estimates 5–10 % in AS, with a later onset.

A review of the literature, revealed single case studies in which individuals presented with comorbid epilepsy and AS (Burgoine & Wing, 1983; Jones & Kerwin, 1990; Warwick, Griffith, Reyes, Legesse, & Evans, 2007). In a study of individuals with ASD being evaluated as candidates for epilepsy surgery, eight of the 19 had AS (Taylor et al., 1999). In a review of 100 cases of males with AS, Cederlund and Gillberg (2004) identified clinical epilepsy in four, with an additional 20 showing atypical EEGs.

An investigation of the relationships between hypothalamic hamartoma (HH) and psychiatric disorders was conducted by Ali, Moriarity, Mullatti, and David (2006). The authors note that HH has previously been identified as a cause of seizures with associated behavioral difficulties including aggressive behavior: "it is the HH that is the source of the seizures, and it is considered to be intrinsically epileptogenic" (p. 112). Ten patients were reviewed, all adults without cognitive impairments. Of these, five individuals were identified with feature of AS.

Tics and Tourette Disorder

Tourette disorder (TD) is a neurological disorder in which an individual exhibits motor and vocal tics or involuntary movements/sounds (Jankovic, 2001). The incidence of TD is higher in males than females, and onset occurs before age 18, with typical onset between the ages of 3 and 8 years. TD may present concurrent with other disorders such as ADHD and OCD.

An association between ASD and tic disorders, including TD, has been established in the literature over the past three decades (Baron-Cohen, Mortimore, Moriarty, Izaguirre, & Robertson, 1999; Epstein & Salzman-Benaiah, 2005; Kerbeshian & Burd, 1996; Marriage, Miles, Stokes, & Davey, 1993; Ringman & Jankovic, 2000; Sverd, 1991). Epstein and Salzman-Benaiah (2005) emphasize the considerable overlap of symptoms of AS and TS. Baron-Cohen et al. (1999) reported the occurrence of tic disorders in 6–8 % of their ASD sample. Freeman et al. (2000) reported a prevalence of 4.5 % in an ASD sample. In a review of 60 women on the milder end of the autism spectrum (Burke, Stoddart, & Abdelsayed, 2012), 8 % identified themselves with a diagnosis of TD.

Hormonal and Metabolic Disorders

There are many studies in the research literature which suggest a familial presence of metabolic or autoimmune disorders that may be related to the occurrence of an ASD in that family. It is purported that presence of metabolic conditions during pregnancy, such as diabetes, may increase the possibility of the child having a neurodevelopmental disorder, including ASD (Krakowiak et al., 2012). Adams et al. (2011) suggest that concurrence of metabolic disorders with neurodevelopmental disorders such as ADHD, intellectual disabilities, and learning disorders, has received increasing attention. They propose that metabolic and nutritional concerns are also relevant for those with ASD. Metabolic disorders are reported in the literature in those with ASD, although Spence et al. (2004) suggest the incidence is likely less than 5 %. Increasingly however, studies of health issues in those with ASD contain reports of hormonal and metabolic disorders (Seltzer & Wyngaarden Kraus, undated; Stoddart et al., 2013), suggesting a need to continue to examine this relationship.

Thyroid Disorders

Thyroid hormones impact on the development of the central nervous system during pregnancy. Some have hypothesized that autism may be related to the level of thyroid hormone. An early report of a small sample of children with ASD symptoms suggested a link between CNS damage and hypothyroid. The children were either born with a hypothyroid condition or it was noted that their mothers were believed to experience hypothyroid during pregnancy (Gillberg et al., 1992). Other research found a relationship between regression in children with autism and familial autoimmune disorders, specifically thyroid disease (Molloy et al., 2006). More recent studies have continued to make an association between low thyroid hormone (T4)

and the risk of having an ASD (Hoshiko et al., 2011). A high incidence of thyroid disease in adults on the milder end of the autism spectrum has been noted in our clinical practice and has significant implications for the understanding and treatment of mood dysregulation, such as depression.

Diabetes

An individual's risk of having diabetes increases if other family members have the disorder (American Diabetes Association, 1999). There are two types of diabetes, referred to as Type 1 and Type 2. Type 1 diabetes is a significant and chronic disorder. While historically considered a disorder of childhood, more recent information indicates occurrence in adults is comparable to that in children (Devendra, Lui, & Eisenbarth, 2004). There are two forms of Type 1 diabetes: type 1A is "immune mediated," while type 1B is due to deficiency of insulin (Devendra et al., 2004). In Type 1A, insulin is destroyed due to the response of the immune system. It is noted that similar autoimmune responses can also be seen in disorders of the thyroid or lupus (American Diabetes Association). Type 1 diabetes has been reported as one of the disorders which may co-occur in those on the autism spectrum.

When considering the research related to diabetes and ASD, in a large sample of children, an increased risk of ASD was found in families where there was a history of Type 1 diabetes (Atladottir et al., 2009). Another study reported that children with ASD were overrepresented in patients seen at a hospital diabetes clinic (Freeman, Roberts, & Daneman, 2005). In attempting to explain this relationship, these authors made reference to the reported relationship between familial autoimmune disorders and ASDs.

In addition to Type 1 diabetes, a case study by Raja, Azzoni, and Giammarco (1998) reported on an individual with AS who presented with neurogenic diabetes insipidus (NDI) as well as polydipsia. NDI is caused by inadequate levels of antidiuretic hormone accompanied by water loss. The patient also had empty sella—"sella turcica that is filled with cerebrospinal fluid (CSF), while the pituitary gland is flattened" (p. 235). The authors proposed that empty sella should not be neglected as a possible cause of NDI, and evaluation of anterior pituitary abnormalities should occur.

Hypoglycemia

Hypoglycemia results from an imbalance in blood sugar and affected individuals may feel anxious or lightheaded (Lawton & Reichenberg-Ullman, 2007). Hypoglycemia is not uncommon in the general population, and so it's occurrence in those with ASD would not seem unusual. We believe it is important to include it in

this chapter, however, as many individuals with ASD do not have good eating habits. The person with an ASD may have significant sensory and environmental sensitivities and often suffers from anxiety. In those with ASD, indicators of hypoglycemia might include anxiety, hyperactivity, over-reactivity, mood swings, problems with speech, and apparent confusion. In addition to the person's physical discomfort, the impact of hypoglycemia for someone with ASD may be a behavioral presentation, often incorrectly interpreted by the individual or others (Lawton & Reichenberg-Ullman, 2007).

Adrenal and Cortisol Disorders

When an individual encounters a stressful situation, the hypothalamic-pituitary-adrenocortical (HPA) axis is stimulated. Cortisol is released into the bloodstream and various body systems become engaged to enable the person to manage the situation (Seltzer et al., 2009). In reference to those with ASD, Hamza, Hewedi, and Ismail (2010) stated: "The hypothalamic-pituitary-adrenocortical (HPA) axis deserves special attention, since it is the basis for emotions and social interactions that are affected in autism" (p. 71). The authors studied 50 children and adolescents with ASD compared to healthy matched controls. Within the sample, there was no history of adrenocortical dysfunction. Results showed individuals with autism to have lower basal cortisol (10 %) and lower stimulated cortisol (10 %): adrenocorticotropic hormone (ACTH) was higher in those with autism (16 %). IQ level did not appear to be a significant factor.

A review of the literature on adrenal and cortisol disorders shows additional research occurring in relation to discrete hormonal issues in those with ASD. For example, a recent study in Japan looked at young males who were drug-naïve and had no concurrent medical or genetic disorder. The investigators tested serum levels of anterior pituitary hormones and found significantly higher levels of ACTH, growth hormone (GH), and cortisol (Iwata et al., 2011). In another study, the plasma levels ACTH of adults with AS were compared to unaffected adults (Tani et al., 2005) and found to have high levels of ACTH.

Known behavioral responses to stress and difficult situations in those with ASD have led researchers to examine cortisol levels in response to possible environmental stressors. Spratt et al. (2012) found early morning urinary cortisol was not significant in children with autism, but hypersecretion occurred in response to a stressful situation. In another study, children at the milder end of the spectrum were put into social situations with familiar and unfamiliar others. While their self-ratings of stress showed no significant difference, there was a response in salivary cortisol (Lopata, Volker, Putnam, Thomeer, & Nida, 2008). In a study of adolescents with AS, cortisol awakening response (CAR) levels were found to be atypical when compared with peers (Brosnan, Turner-Cobb, Munro-Naan, & Jessop, 2009).

Addison's Disease

Addison's disease is an adrenal insufficiency which is underdiagnosed in general (Ten, New, & MacLaren, 2001). Presentation of Addison's disease can include significant weakness and fatigue. The impact of the adrenal insufficiency can also lead to anorexia, vomiting, dehydration, and hypoglycemia. These are features we have noted elsewhere as presenting in our clients, either individually or in relation to other disorders. An association between Addison's disease and diabetes was recognized in the 1960s (Bourne & Howard, 1963). Hyperpigmentation is also observed: Ten et al. (2001) note that this is caused by MSH and ACTH elevations. Addison's disease has been diagnosed in some individuals we have seen clinically. Monitoring of chat rooms and blogs by individuals on the spectrum shows that this association is reported by others. However, no peer-reviewed literature could be found investigating Addison's in those with ASD.

Autoimmune, Auto-inflammatory, and Musculoskeletal Disorders

A review of the literature revealed interesting discussions related to autoimmune, auto-inflammatory and musculoskeletal disorders, and possible relationships between these classes of disorders. For example, Jin et al. (2007) conducted research suggesting a relationship between vertiligo, a disorder affecting pigmentation of the skin and other autoimmune and auto-inflammatory disorders, such as rheumatoid arthritis, lupus, Addison's disease, and thyroid disease. Yunus (2012) classified several disorders as central sensitivity syndromes (CSS), including fibromyalgia syndrome (FMS), restless leg syndrome (RLS), CFS, and IBS. He noted that FMS is often present in disorders with "structural pathology," such as lupus, rheumatoid arthritis, osteoarthritis, diabetes mellitus, and emphasized that CSS disorders had a neurochemical basis and should not be considered as reflecting psychologically based complaints. A further relationship between these disorders relates to those of the digestive and gastrointestinal systems, and will be discussed later in this chapter.

It has been suggested that immune function genes which are part of the human leukocyte antigen region (HLA), represent an issue which needs to be researched more (Torres, Westover, & Rosenspire, 2012). The authors state that immune abnormalities in those with ASD have been reported for two decades. Among such abnormalities, they list 17 proteins which for which autoantibodies have been reported in serum of individuals on the spectrum, as well as altered cytokine levels and decreased lymphocytes. The authors further suggest that when considering genetic relationships to ASD, that HLA associations have the "highest genetically associated risk."

The effect of immune function on development of the central nervous system has been established. Further, some have posited a relationship between impaired

immune function and ASD, as well as familial autoimmune disease in those with ASD (Ashwood, Wills, & Water, 2006; Atladottir et al., 2009; Sweeten, Bowyer, Posey, Halberstadt, & McDougle, 2003). In a large sample of children who had a diagnosed ASD, there was a high incidence of mothers with a history of celiac disease and rheumatoid arthritis (Atladottir et al., 2009).

Rheumatoid Arthritis

Rheumatoid arthritis (RA) is a disorder affecting bones, joints, and muscles, and causing significant pain and restricted function. It can occur in childhood or adulthood. A number of conditions related to arthritis may be concurrent which can affect appropriate diagnosis. Brewer (1986) listed a number of diseases in children which he linked to the onset of chronic RA. Among these, he listed rheumatic fever, lupus, immune deficiency syndrome, Sjogren's syndrome, lymphoma, neuroblastoma, and IBD. Laiho and Meckelburg (2003) reported the presence of rheumatoid arthritis in a 19-year-old woman with AS as well as insulin-dependent diabetes mellitus.

Fibromyalgia Syndrome (FMS) and Chronic Fatigue Syndrome

Individuals with FMS experience musculoskeletal pain throughout the body as well as fatigue. It is believed that FMS is a "disorder of central pain processing," in which individuals responses to typical pain are elevated, and the person may experience pain in the presence of sensation which is typically not pain-producing (Clauw, 2009). Fibromyalgia syndrome has a prevalence of 0.5–5.0 % and is more common in women at a ratio of 4:1 (Rao, Gendreau, & Kranzler, 2008). The pain may cross body systems or may be focused on one area of the body. St. Amanda and Marek (1999) estimated that 60 % of those who have FMS, present with concurrent IBS. Some who have fibromyalgia may also experience skin disorders such as rashes, acnes, seborrhea, hives, and eczema. Fibromyalgia may be accompanied by fatigue, irritability, depression, problems with concentration, trouble sleeping, and sensory over-responsiveness, which are also features of CFS.

Many individuals we have with ASD or with a family member with ASD, report fibromyalgia. While no peer-reviewed documents could be found in the literature addressing a relationship between ASD and fibromyalgia (FMS), many blogs and websites were found with active discussions on this relationship. In the popular media, the relationship between FMS, CFS, and autism was queried following reports of positive effects to all three disorders related to a nutritional treatment (Teitelbaum, 2011). CFS is a disorder with no specific identified cause, although one proposed source is immunological. Those with CFS experience chronic fatigue that is not relieved through typical methods. Other symptoms include sensitivity to

sensory experiences (light, sound), digestive difficulties, muscle weakness, and depression.

In a study by Wilbarger and Cook (2011), women with FMS were found to have greater hypersensitivity to environmental stimuli as compared to women with rheumatoid arthritis or unaffected women. This would reflect the sensory processing issues experienced in those with ASD. A relationship was identified between FMS, CFS, and Attention Deficit Hyperactivity Disorder, as reported in a case review of adults in an outpatient setting (Young & Redmond, 2007). Leehey, Legg, Tassone, and Hagerman (2011) did identify FMR symptoms in carriers of FXMR1: FrX is often associated with ASD.

Gastrointestinal and Digestive Disorders

> Elimination is hard to talk about. I find the pain, noise, and stench my gut produces excruciating. I've figured things out well enough that it's only 2–3 days a week on average that I'm in discomfort…I may just have to live with walking this food and digestion tight-rope for the rest of my life. I can't predict which days it's not safe to stray far from a bathroom, as it seems to be driven by both internal and external chemistry. Only fasting calms things down, but I can't fast all the time.

The prevalence of gastrointestinal symptoms seen in both children and adults with ASD has led to a belief in a relationship between ASD and gastrointestinal (GI) disorders. GI problems have repeatedly been reported to occur in some children with ASD (Brown et al., 2010). Reported problems include heartburn, bloating and abdominal pain, food intolerance, gastritis, chronic constipation, and diarrhea (Erickson et al., 2005). In a study of 172 children and youth diagnosed with ASD, researchers found that 22.7 % experienced GI problems. No differences in rate of GI problems were discovered based on intellectual levels or ASD severity. Those subjects with GI problems were more irritable, anxious, and withdrawn (Nikolov et al., 2009).

In a review of the profiles of 60 women on the milder end of the spectrum, Burke et al. (2012) found 10 % of women reported significant gastrointestinal difficulties. In a survey of youth and adults with ASD by Stoddart et al. (2013), almost 10 % indicated digestive/gastrointestinal difficulties. In our clinical practice of adults on the milder end of the spectrum, many individuals have reported that gastrointestinal difficulties they experience have been present since childhood. Sometimes their complaints appear related to anxiety or stress. Many also report poor eating habits. Therefore, it is unclear whether gastrointestinal difficulties reflect an association with ASD, are the result of the lifestyles of those with ASD, or both.

While some of the literature indicates a concurrent presentation of ASD and GI disorders, others suggest a possible genetic linkage. For example, Campbell et al. (2009) looked at individuals with ASD and their families, and found that of their sample, gastrointestinal complaints occurred in 41 % of those with ASD, 24 % of their parents, and 9 % of siblings who did not have an ASD. These authors suggest that the association is genetic and have implicated an MET promoter variant.

Diet and Health

Conferences, books, and blogs can be found related to diet and health in those with ASD. This interest in diet, food sensitivity, nutrition, vitamin therapy, and many other food-related issues have been a topic of interest in relation to those with ASD for the past two decades or more. Some concerns reflect serious health issues or disorders. Issues of diet are sometimes an obsessive interest for those with AS. In some cases, families, desperate for solutions have become caught up in new interventions, often spend large amounts of money for unproven methods that may not only be ineffective but also be risky.

Beginning in the 1990s, research suggested those on the spectrum might be sensitive to foods containing gluten and casein. Gluten is based in grain and casein in dairy products (Lynch, 2004). Physical reactions to these products may include diarrhea, constipation, or gas, and either red face or pallor. Reports in the literature are not consistent in relation to prevalence of impact of food sensitivities. However, in our practice, we are told by individuals and families of the positive impact of withdrawing gluten and milk products, both behaviorally as well as medically. As well, probiotics are reported to increase positive bowel function and reduce discomfort.

Acid Reflux/Gastroesophageal Reflux Disease

GERD is identified by heartburn or regurgitation (Howden & Chey, 2003). Additional symptoms may include chest pain, sore throat, aspiration, and vocal changes. GERD results from acid and gastric material moving into the esophagus. More serious cases of GERD occur when the body's mucous is unable to protect against the amount of acid produced (Kahrilas, 2003). While GERD is common in the general population, it occurs in those with ASD at even a higher rate (Grandin, 2009). As GERD may initially present in children with ASD, it has implications for behavior and quality of life, as do other gastrointestinal disorders (Kring et al., 2010). However, it is a disorder we see commonly in individuals with ASD of all ages in our practice.

Inflammatory Bowel Disease

IBD refers to any condition in which there is inflammation occurring in the gastrointestinal tract. It appears to be genetically influenced: 10–20 % of those who suffer from IBD also have family members with an IBD (Steinhart, 2012). There are two disorders that are most frequently associated with IBD, Crohn's disease, and ulcerative colitis. Steinhart notes that for some time, it was believed that Crohn's disease

primarily affected the ileum or the last section of the small intestine. More recently, it has been identified that it can reflect inflammation anywhere in the tract. Ulcerative colitis refers to inflammation in the large intestine and rectum. Treatment of inflammation in affected areas will provide relief.

Irritable Bowel Syndrome

Irritable bowel syndrome refers to a common disorder which causes discomfort and "disordered" bowel habits (Spiller, 2005). Steinhart (2012) indicates there is often confusion between IBD described above and IBS. She states that with IBS, there is a need to "modify the motility of the tract or the transmission of pain impulses from the intestine to the brain" (p. 11). IBS presents more often in women (Spiller, 2005) and may occur with alteration in mood. Many individuals with ASD whom we see in clinical practice report that the diagnosis of IBS was given after investigation of other possible disorders and negative findings.

Gluten Intolerance

Celiac disease is an inflammation of the small intestine. It is caused by inability to tolerate gluten (Murray, 1999). It has been reported to occur at a higher than normal rate in those with Type 1 diabetes and thyroid disorders (Murray, 1999). It also occurs at a high frequency in those with Down syndrome and ASD (Percy & Propst, 2008). The noted authors report that it is one of the most prevalent medical disorders in North America, with a prevalence of 1:133. These authors indicate anecdotal information suggests those with ASD may benefit from a diet, free from gluten and dairy products.

Gilger and Redel (2009) noted that Asperger had suggested a relationship between autism and celiac disease. Based on their review of the literature, they suggest the rate of gastrointestinal problems in children with ASD to be between 9 and 84 %.

In our clinical practice, we have met individuals with ASD who received a diagnosis of celiac disease. We have met others who did not receive this diagnosis but did present with clinical symptoms. Both groups reported that dietary intervention decreased their discomfort.

Yeast Overgrowth

Individuals with ASD may experience elevated levels of yeast (Lynch, 2004; Shattock & Whiteley, 2002). Symptoms tend to be both behavioral and physiological. Physical indicators include headaches, rashes, and GI discomfort. Yeast may

also lead to irritability, confusion, and behaviors specific to the area of discomfort (Sicile-Kira, 2004). Sometimes dietary interventions are adequate. If stronger intervention is needed, some antifungal treatments may be effective in reducing problematic symptoms (Shattock & Whiteley, 2002).

Food Allergies and Sensitivities

The occurrence of food allergies in those with AS is not believed to be greater than is seen in the general population. However, there does appear to be a higher incidence of food sensitivities (Lawton & Reichenberg-Ullman, 2007). The noted authors indicate that if a person has food sensitivity, a behavioral reaction may be observed when the food is ingested, but conventional allergy testing will not confirm the sensitivity. They discuss ways to test for food sensitivity, including withdrawal of the food from one's diet.

Eating and Weight Disorders

Those with ASD may have atypical food preferences and habits (Attwood, 2007; Dominick, Davis, Lainhart, Tager-Flusberg, & Folstein, 2007). The authors noted that proposed reasons for eating preferences and behaviors may include gastrointestinal difficulties, causing avoidance of a food, sensory sensitivities, and issues related to a desire for sameness. Eating habits may be indicative of sensory preferences (taste, smell, texture) or habit, as well as reflecting a fad, hoarding behaviors, or pica. They may also signal a food sensitivity or allergy (Sicile-Kira, 2004). It is noted that sometimes individuals will crave foods they are allergic to, causing physiological discomfort and behavioral episodes. The phrase "white diet" describes the typical preference of some of those with ASD. Such a diet includes pasta, rice, processed chicken, white bread, and "junk food" which may cause difficulties with elimination and affect the balance of nutrients available to the body.

Eating Disorders

In the last decade or so, it has been reported that a higher than expected number of those with ASD have an eating disorder. This is particularly so for women with ASD (Attwood, 2007; Gillberg, 2002). Gillberg (2002) stated that while there is little research specific to the relationship between AS/ASD and eating disorders, there is substantial clinical evidence. He reported that some studies have shown women with anorexia nervosa had a high incidence of AS or of another ASD. Young men with AS who develop unusual eating habits and experience weight loss may also meet criteria for anorexia nervosa. Those on the autism spectrum may have

increased tendency toward obesity. Miles et al. (2010) suggest that medication side effects and inactive lifestyle may be implicated.

In a study of adolescents, a significant relationship was found between symptoms of eating disorders and features of ASD (Coombs, Brosnan, Bryant-Waugh, & Skevinton, 2011). In our practice, we have seen several cases of food refusal, excessive or obsessive exercise, binging and purging in adults with AS. A female we saw in practice was fed through a G-tube for over a decade, prior to her diagnosis of ASD and anxiety disorder. Some individuals or their families report that the adult does not have a sense of how much food to take, or to eat. Some state they do not realize that they have eaten enough until they feel unwell and others report never feeling satiated. Overeating may be understood as a response to anxiety, depression, or sensory-seeking behavior (in the case of salty foods, spicy foods, or carbonated beverages). It may also reflect obsessive concern about weight, Body Mass Index, muscularity, and engaging in repetitive exercise.

A study examined women in a clinical setting diagnosed with eating disorders (Wentz et al., 2005). The authors reported 53 % had at least one childhood onset neurological disorder, 27 % had tic disorder, 23 % had an ASD, and 17 % had ADHD. Kalyva (2009) reported on adolescent females who had been diagnosed with AS, compared with those who did not have a diagnosis. The girls and their mothers were asked to report on the girls' eating habits and attitudes. Adolescents with AS were found to be at greater risk for eating difficulties than those without AS.

Many of those we meet who have eating disorders present with atypical features rather than meeting clinical criteria for anorexia or bulimia. A number of these individuals have also experienced episodes of gastrointestinal difficulty, sometimes preceding onset of the eating disorder. The profile of these individuals raises an interesting parallel with the effects of starvation or semi-starvation as discussed by Garner (1998). He reports that after food deprivation, one may engage in binge eating, have emotional struggles, personality changes, present with signs of poor concentration and judgment, and show changes in social and sexual interest and behavior. This reflects the experience reported of our clients who have reduced food intake during gastrointestinal episodes and then engaged in extreme binging as well as experiencing the other noted symptoms, without immediate remission after the return to a typical diet. This suggests an unexplored area of investigation relating to eating-related difficulties for those with ASD.

Summary and Conclusions

Adults with "high-functioning autism" and AS experience significant medical and health issues. While the bio-psycho-social model of assessment and intervention is predominant in clinical practice, practitioners in the field of ASD seem to have overlooked the "biological" component in understanding and treating those on the spectrum. This may be due to the neurodevelopmental status of ASD, leading

clinicians to dismiss possible medical issues, the circular nature of some health disorders, lack of knowledge, and poor cross-sector dissemination of existing knowledge. There is certainly a dearth of research in relation to many of the disorders concurrent with ASD as reported by those affected; in fact, we have learned much from individuals whom we treat. As those with milder presentations may be seen in private practice settings, some health issues may miss the attention of researchers in academic, medical, and mental health institutions. Regardless of the reason for neglect of this issue, medical and health problems in those with ASD lead to emotional distress, physical discomfort, and reduced quality of life. It is therefore imperative that we address these through research, education, and development of guidelines for improved detection and intervention.

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Chapter 13
Unlawful Behaviors in Adolescents and Adults with Autism Spectrum Disorders

Marc Woodbury-Smith

Adolescents and adults with autism spectrum disorder (ASD) may come into contact with the criminal justice system (CJS) as victims, witnesses, or perpetrators of alleged criminal activity. It is crucial, therefore, that the CJS is able to respond appropriately when faced with such an individual, who may, if higher functioning, appear to all intents and purpose "normal." It is equally crucial that carers, families, and health professionals have an understanding of the factors that may lead to CJS involvement such that strategies can be put in place to reduce the risk of unlawful behavior. Whilst it is certainly true that people with ASD are vulnerable to being a victim of crime, much of the literature has been concerned with the risks of perpetration. This is driven, in part at least, by the potentially far reaching consequences for the individual who is accused of a crime. As will be discussed subsequently, despite the lack of clear scientific data regarding the epidemiology and etiology of unlawful behavior among people with ASD, many different factors related to the autism phenotype can theoretically impact on risk, and an understanding of these factors can reduce this risk. Understanding these risk factors can also inform the rehabilitation needs of such individuals, who may not necessarily benefit form the generic forensic mental health services. Moreover, for those already in the CJS, much can be done to ensure that their vulnerability is recognized and managed accordingly.

The aim of this chapter is to summarize the available evidence concerning unlawful behavior among adolescents and adults with ASD in a practically informative way. The term unlawful will be used as an all-encompassing term to capture any behavior that is a transgression of the laws of society (which may be referred to in other texts as "criminal" or "offending" behavior). Whilst these laws may vary from jurisdiction to jurisdiction, there are certain core "rights" and "wrongs" that are universally accepted and therefore are associated with severe consequences across the world. These are primarily those behaviors that result in a victim, i.e., result in

M. Woodbury-Smith, PhD (Cantab), MRC Psych (UK) (✉)
McMaster University, Hamilton, ON, Canada
e-mail: woodbur@mcmaster.ca

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harm to another person, and that are therefore deemed "morally" wrong. It is these behaviors, which include harassment and stalking, assault on others of a physical and/or sexual nature, as well as the more serious crime of murder, which will be the focus of this chapter. Other transgressions, such as criminal damage and theft (larceny) that may not necessarily directly harm another person physically but that almost certainly will result in sadness and/or distress on the part of the victim, will also be discussed. Much of the research literature is concerned with adults with a diagnosis of Asperger Syndrome, although the evidence discussed and its conclusions apply equally to other higher functioning individuals on the autism spectrum. In contrast, individuals with lower intellectual capacity are much less likely to be perpetrators of crime (although are probably more likely to be victims). However, for the sake of simplicity, the term ASD will be used throughout. Finally, by "higher functioning" I refer to those individuals whose intellectual capacity is in the normal range (i.e., they are higher functioning as compared with others on the autism spectrum).

Literature Overview

The risk of unlawful behavior among people with ASD became more widely apparent as a result of a series of case reports published in the literature in the 1980s and early 1990s (for example, Baron-Cohen, 1988; Chesterman & Rutter, 1993; Mawson, Grounds, & Tantam, 1985). Each of these described an individual with an ASD who had engaged in unlawful behaviors, including assault (Baron-Cohen, 1988; Mawson et al., 1985) and theft (Chesterman & Rutter, 1993). Over the next two decades many further case reports were published, each arguing that the unlawful behavior described was in some way a consequence of the ASD (discussed in Woodbury-Smith et al., 2005). Other potential causes, such as mental health comorbidity (Palermo, 2004), have also been put forward as potentially significant etiologically, although this literature is much smaller.

Of course, case reports are problematic from a scientific point of view. For example, they offer no information about the prevalence of the behaviors described, and suffer from extreme publication bias, such that only the most "interesting" or "unusual" cases are described, hence limiting any generalizations that can be made and offering little useful information about risk among the wider ASD population. One benefit of case studies, however, is that they can raise potential hypotheses concerning the risk factors for the behavior observed in the individual described. So, for example, Mawson et al. (1985) hypothesized that a sensitivity to certain stimuli, notably babies crying, resulted in irritability and hyperarousal culminating in attacks on others. Baron-Cohen (1988) similarly described assaultative behavior, but he hypothesized that this was occurring in the context of a poorly developed theory of mind, whilst other case reports have described certain behaviors occurring in the context of an obsessive pursuit of an interest (discussed in Woodbury-Smith et al., 2010). These case reports have also offered some insight into the management of the cases described, which has varied between incarceration in jail according to the criminal

law of the jurisdiction, incarceration in psychiatric hospitals using the provision of mental health law or court diversion, and management in the community with access to generic or specialist mental health services (Dein & Woodbury-Smith, 2010).

In addition to case reports, case series have also been published (Murrie, Warren, Kristiansson, & Dietz, 2002). Notable is the original work of Asperger himself (Asperger, 1944, translated in Frith 1991). When Asperger described a group of boys with core deficits in social interaction, communication, and inflexible patterns of behavior, he additionally commented on other aspects of their behavior. For example, Fritz V. "never got on with other children [and] quickly became aggressive and lashed out with anything he could get hold of (once a hammer) regardless of the danger to others" (Asperger, 1944, p. 40). Another patient, Harro L., was referred by his school because of his "savage tendency to fight" (Asperger, 1944, p. 51); Asperger commented that "little things drove him/her to senseless fury, whereupon he attacked other children" (Asperger, 1944). Similar conduct-disordered behaviors were seen in Asperger's other patients. Asperger believed that such "autistic acts of malice" (to use his terminology) reflected a limited ability to reflect upon how much they hurt others, an indication of a poorly developed ability to empathize.

A review has been undertaken of the clinical records of cases seen by Asperger in his clinic in Vienna during the 1960s and 1970s (Hippler & Klicpera, 2003). This review identified more detailed information about behavior. Of the 46 children whose files were available for examination, seven (15 %) had been admitted to the ward because their behavior was no longer acceptable at school and exclusion was imminent. Asperger described the occurrence of "autistic malice" in seven patients (15 %). These children were described as showing intentional acts of malice, "with malicious pleasure and apparent pride in what they had done. Some of the children were said to experiment on others, that is, they seemed to do things on purpose to see how others reacted or to provoke a certain reaction" (Hippler & Klicpera, 2003, p. 294).

Wing (1981), whose characterization defined our subsequent conceptualization of Asperger syndrome, described a series of 34 cases of adults who were phenotypically similar to those described by Asperger. In her account, she made specific mention of a small number of individuals who had engaged in problematic behavior, noting that "a small minority have a history of rather bizarre antisocial acts, perhaps because of their lack of empathy" (Wing, 1981, p. 116). This was true of four of the cases she described. One child, for example, with a special interest in chemistry, injured a colleague during the course of a "scientific" experiment. She also described more specifically how a lack of social understanding could lead to contact with the CJS. For example, "he has no idea of how to indicate his interest and attract a partner in a socially acceptable fashion. If he has a strong sex drive, he may approach or touch or kiss a stranger, or someone much older or younger than him/herself and as a consequence find him/herself in trouble with the police" (Wing, 1981, p. 116). The case series of adults with schizoid traits described by Tantam (1988), many of whom overlapped phenotypically with Wing's, included a small number with antisocial and violent behaviors. Similarly, Wolff's longitudinal study of loners emphasized the clinical overlap with Asperger's, and among those individuals described, a small number had presented with antisocial traits (Wolff, 2000).

Prevalence of Unlawful Behavior

Insight into the numbers of individuals with ASD managed within secure mental health facilities was provided by two studies that attempted to measure the prevalence of Asperger Syndrome in maximum secure psychiatric hospitals ("Special Hospitals") in England and Wales (Hare, Gould, Mills, & Wing, 1999; Scragg & Shah, 1994). Both studies found that the prevalence in these hospitals was higher than the community prevalence figure, ranging between 2.4 and 4.8 % according to the stringency of diagnostic criteria used. In contrast, however, the only study of the prevalence in the Scottish State Hospital (maximum secure), Carstairs, identified no cases (Myres, 2004). This same study also investigated the prevalence of ASD in the prison population of Scotland and found two cases, representing 0.03 % of the prison population. Unlike the other two studies, however, this study was based on staff-reported diagnoses rather than a total population screening and diagnosis approach. Nonetheless, this is the only study at the time of writing that has measured prevalence in prisons. It is also important to note that although the proportion formally identified was small, the perception among prison respondents was that this represented only a proportion of a larger number of prisoners who possibly had ASD, but who had not been assessed or diagnosed.

Based upon these data, it seems reasonable to conclude that a small, yet significant, number of individuals with ASD engage in unlawful behaviors of a severity that warrants incarceration. Although the figures may be higher than the population prevalence, little is known about the true prevalence in jails, which, if all individuals are being diverted to mental health or community care, may be significantly lower, as evidenced by Myres' study. The quoted prevalence figures may also be a consequence of the methods of ascertainment employed, and the diagnostic practice used at the time, which differed somewhat from current methods.

There are also no epidemiological community studies of unlawful behavior in ASD. One study did attempt to measure the prevalence of offending in an "administrative" community sample of 30 adults with Asperger Syndrome using a self-reported offending questionnaire and a matched non-ASD comparison group similarly recruited in the community (Woodbury-Smith, Clare, Holland, & Kearns, 2006). Self-report was further validated by official criminal justice data for each participant. The researchers found that both self-report and official data were consistent with a low rate of law breaking among the ASD group, and significantly lower than the non-ASD comparison group. There were some differences between groups, however. For example, the ASD group were less likely to have used illicit substances but more likely to have engaged in behavior categorized as "criminal damage." Moreover, they tended to have a greater history of violent behaviors. The small sample size and bias in ascertainment do limit the extent to which these data can be truly extrapolated to the wider community ASD population. Nonetheless, these data do suggest that small numbers of adults with ASD may be predisposed to violent unlawful behavior. The evidence to date is summarized succinctly by Maughan, who commented nearly 20 years ago that "Asperger individuals do not

appear to show a seriously increased likelihood of violent or aggressive acts in adulthood, and will make up only a very small proportion of adjudicated violent offenders. But they are of concern because of the unusual, unpredictable, and distressing pattern of their aggressivity, and, in the context of assessment of dangerousness, their apparent inability to consider the effects of their actions on others" (Maughan, 1993, p. 121).

The Nature of Unlawful Behavior

Whether or not the prevalence is high, what is clear is that some adults with ASD engage in unlawful behavior. The case reports and case series along with the Special Hospital studies all describe a range of unlawful activity, including behaviors at the mild end of the criminal spectrum such as theft, and the most severe behaviors including sexual assault and murder. There is some emerging evidence that fire-setting may be more common among offenders with AS than the non-AS offending population (Hare et al., 1999; Mouridsen, Rich, Isager, & Nedergaard, 2008; Siponmaa, Kristiansson, Jonson, Nyden, & Gillberg, 2001). Moreover, whilst there is some evidence that people with ASD may commit sexual offences, this is a rare occurrence if all the literature is considered together. In conclusion, a range of problematic behaviors have been described, with no specific observable pattern. As will become apparent in subsequent paragraphs, however, relatively minor transgressions that occur as a direct result of social misunderstanding, or as a result of the pursuit of circumscribed interests, are perhaps those that are seen most frequently in clinical practice, and are not reflected well in the literature which has focused on the rarer and more serious crimes.

Causes of Unlawful Behavior

Factors that may mediate unlawful behavior can crudely be classified into those factors related to (1) the socio-communicative phenotype, (2) the neuropsychological phenotype, and (3) the circumscribed patterns of behavior and interest, including rigidity and resistance to change. Of course, it is also likely that factors associated with criminal behavior in the population at large are also relevant among those with ASD. These include family factors (large family size, poor housing, poor or inconsistent parenting, and a parent with a history of convictions), peer factors (i.e., having friends who are delinquent), and individual factors (low IQ and poor school achievement, truancy, aggressive behavior, and hyperactivity-impulsivity-inattention, summarized in Farrington, 2001). However, the focus of these subsequent sections will be the evidence for an association between core autism phenotypic features and risk of unlawful behavior.

The socio-communicative phenotype and unlawful behavior: The subtle intricacies of social interaction can be challenging for people with ASD. For example, knowing how to initiate, sustain, and end conversational exchanges as well as "parapragmatic" abilities such as knowing how close to stand to their interlocutor, when to give and withhold eye contact, and the use and interpretation of body posture and other nonverbal signals can all be challenging. In many situations this may result in social isolation, rejection, or even the derision of others. However, in other situations these impairments can result in others becoming uncomfortable and perhaps making a complaint. Staring behavior, standing too close, and asking (or offering) personal information of strangers may be interpreted as purposeful and result in complaint. Stalking and harassment describe situations whereby an individual follows or otherwise repeatedly makes attempts to engage within another person, within explicit protest and no encouragement on the part of the victim. There have been cases of stalking behavior described in the literature perpetrated by individuals with ASD (Stokes & Newton, 2004). This may be particularly true of young adults with ASD who are socially isolated but who wish to have relationships with others. Their attempts to do so may be clumsy and inappropriate, and this may be compounded by their inability to interpret the nonverbal displeasure expressed by the other person. Critically, none of the transgressions described here are purposeful or carried out with any knowledge of their inappropriateness. This issue is crucial when considering the criminal justice response and the subsequent rehabilitation needs.

Circumscribed interests: Among higher functioning individuals, the third domain of "ritualistic and repetitive patterns of behavior" is generally characterized by engagement in circumscribed patterns of interest. These interests can take many different forms, most often collecting objects or a predilection for factual-based information. These are often pursued in a solitary manner, but their *nature* (i.e., their focus) can, on occasion, be inappropriate. Tantam (1988), for example, described a young man with an interest in Nazi paraphernalia, who would dress up in this and then go out into the community. An "obsession" with notorious historical figures, such as Hitler, or firearms and knives, has also been described. Whilst not illegal in themselves, such preoccupations can be misconstrued as reflecting more darker and harmful intentions, which is often not the case. In such instances the psychiatrist may be called upon to assess "risk." Indeed, in Woodbury-Smith et al.'s study (2010) of circumscribed interests among offenders with ASD, of the four (19 %) with "violent" interests, in only one instance could the interest be related to violent behavior, in a man with an obsession with fire-setting and a conviction for arson. Other case studies have described similar "interests" and later convictions for arson.

Even if the focus is not in itself harmful, the *pursuit* of the interest can result in contact with the CJS. In one case report (Chen et al., 2003) an individual is described who on several occasions stole in order to expand his collection of paper cups, boxes, and plastic bags. Similarly, in the study of circumscribed interests by Woodbury-Smith et al. (2010) a young man with ASD is described whose interest in electronics, and in particular taking items apart to work out how they worked, resulted in several episodes of acquiring electronic items without paying for them.

Taken together, these data do indicate the need to pay close attention to circumscribed interests, whether violent or not, although this may involve nothing more than simply close supervision and observation. Indeed, there are no evidence-based guidelines available on which more specific rehabilitation recommendations can be made.

Empathy and theory of mind: Underlying the clinical features of ASD are a number of consistently identified neuropsychological vulnerabilities. Much literature has focused on impairments of "theory of mind," "executive function," and "emotional processing" or empathy among individuals with ASD across the spectrum of intellectual abilities. Whilst executive dysfunction may arguably be one factor that reduces the propensity to criminal behavior, or at least criminal behavior that requires planning and organizing in its execution, the other impairments, which interfere with an understanding of others, may theoretically predispose to unlawful behavior. One study has attempted to look at this issue in a case–control design (Woodbury-Smith et al., 2005), comparing the degree of these neuropsychological impairments between offenders and non-offenders with ASD and a non-ASD comparison group. This study found that the offenders were generally very similar to non-offending counterparts across the range of psychological domains measured. However, two significant differences emerged. First, the offenders displayed reasonably intact theory of mind skills, comparable to the non-ASD comparison group. And secondly, compared to their non-offending ASD counterparts, the offenders were significantly impaired on their ability to recognize the expression of fear in face stimuli. The study was small, and cross-sectional in nature, but does suggest that there may be a subgroup among those with ASD who have a particular cognitive phenotype and who are predisposed to unlawful behavior.

Asperger first used the term "malice" to describe some of the problematic behaviors observed among the young boys seen in his clinic. Tantam (1988) later described a series of people who have engaged in apparently purposefully hurtful behavior towards others, and described such behaviors as "autistic acts of malice." For example, a young man is described who "[phoned] his grandmother to tell her…that her husband had been killed in a car accident….Her husband…had not been involved in any accident, which became apparent as soon as he arrived home a few hours later" (Tantam, 2000, p. 390). Tantam hypothesized that some people with ASD, rather than being motivated by evil intent, are instead motivated by a sense of powerlessness that they attempt to circumvent by using their power to shock or disrupt. At the same time, whilst attempting to shock, it is also likely that such behavior is the consequence of a lack of understanding of the emotional impact of the "joke" on the other person. People with ASD have also been described as having a somewhat concrete sense of humor, which might also explain why they would find such a statement funny.

Wing has attempted to summarize, through her clinical experience, some of the factors deemed important to the development of offending by people with ASD as follows (Wing, 1997):

- Pursuit of "special" interests
- Revenge

- Hostility towards family
- Hyperarousal
- Vulnerability
- Cry for help
- Lack of awareness of wrongdoing
- Assumption that own needs supersede all other considerations
- Intellectual interest

Meeting the Needs of Offenders with ASD

The management of alleged offenders in the CJS requires consideration of both the criminal justice process as well as disposition, and, in particular, the rehabilitation needs, of such individuals. Unfortunately, there has been little in the way of government policy to inform the development of services, and the research literature has not addressed this important issue very well. Consideration needs to be given to a number of different factors, which include vulnerability during interview, fitness to plead and stand trial, and their criminal responsibility. Moreover, for those who are convicted, disposition needs to be considered, and, in particular, whether their rehabilitation needs can be met in generic mental health facilities or whether specialist programs are required (Royal College of Psychiatrists, 2006).

Assessment: Diagnosis of older adolescents and adults is discussed elsewhere in this volume. Moreover, there are no specific investigations that are routinely suggested in the forensic assessment of ASD. Nevertheless, as part of an assessment to determine criminal intent and/or the rehabilitation needs, assessments of theory of mind, executive function, and emotional understanding/empathy may be deemed appropriate. There are a number of experimental paradigms that have been designed to be used primarily in the research environment rather than clinically, and they do raise the problem of "ecological" validity, but in certain situations they can be useful in making sense of the difficulties of a person with an ASD (Clare & Woodbury-Smith, 2009). As discussed previously, attention to more general forensic risk factors also needs to be included in any assessment, as well as consideration of comorbidity, which will need management in its own right.

During the interview, persons with an ASD may be vulnerable for a number of reasons. It is likely that their developmental vulnerability will not be immediately apparent to those charged with interviewing them. Indeed, instead they may be considered to be disinterested, emotionally detached, and purposefully uncooperative as a result of their impairments of communicative pragmatics. Furthermore, they may be acquiescent or suggestive, particularly in response to leading or closed questions. The Gudjonnson Suggestibility Scale (GSS; Gudjonsson, 1997) is a widely used valid and reliable measure of an individual's acquiescence and suggestibility in the interview setting. It measures two aspects of suggestibility: first, the tendency to give in to leading questions, and secondly, the tendency to shift responses under conditions of interrogative pressure.

Consideration also needs to be given to fitness to enter a plea. There are a set of well-accepted criteria on which fitness can be based. An assessment of fitness to plead should address the following questions, and the reader is referred to a more specialized forensic text for a more detailed discussion:

- Do you know what the police say you have done?
- Do you know the difference between saying "guilty" and "not guilty"?
- What is your lawyer for?
- Can you tell your lawyer your side of things?
- Do you know what it means to say you can object to people on your jury?
- What happens in court?

Responsibility for offences in criminal law rests on the defendant having committed the act itself ("*actus reus*") and having a guilty mind, or criminal intent ("*mens rea*"). It may be argued that persons with an ASD did not have the necessary criminal intent, even if they knew that what they did was wrong in a legal sense. In relation to *mens rea*, i.e., the ability to form criminal intent, it might be argued that some people with ASD may have an inadequate understanding of the consequences to be morally (or criminally) responsible for their offending (Barry-Walsh & Mullen, 2004; Schwartz-Watts, 2005). In most cases, however, people with ASD will not deny their actions and will be fully cognizant of the fact that what they were doing was at least legally wrong, even if they fail to understand their *actus reus* from the point of the victim (and therefore fully understand their transgression from a moral standpoint). For example, one 18-year-old boy with ASD involved in the brutal torture of one of his peers described recognizing at the time that if he got caught he would be in serious trouble, but was unable to articulate the distress of his victim. There is no case law to guide practitioners further on this issue, although the interested reader is referred to several case studies that raise this very issue (Barry-Walsh & Mullen, 2004; Schwartz-Watts, 2005).

Clearly, attention to all of the issues that may arise during transition through the CJS requires that criminal justice practitioners are alert to the possibility of ASD among those who present as vulnerable. Only in this way will specialists (or "experts") be called upon to address these various issues. Unfortunately, despite these vulnerabilities, those with higher functioning ASD are not as immediately recognizable phenotypically as their vulnerable counterparts with, say, intellectual disability (mental retardation) or mental illness. There are no physically identifiable signs, and language is on the whole fully developed. Moreover, previous research has identified the difficulties the Police and others in the justice system have in recognizing those with developmental vulnerabilities (Petersilia, 2001). Indeed, even in clinical settings, there is often not an awareness of the diagnosis among health professionals (Siponmaa et al., 2001). There is therefore an urgent need to provide criminal justice practitioners with education about ASD. The consequences of not recognizing the diagnosis are clearly very serious, as wrongful conviction may result if a police interview is not conducted correctly, or a person may end up in jail when diversion to mental health care or alternative special care would have been more appropriate.

Treatment and rehabilitation: Individuals with ASD, who are convicted, may end up in a variety of different locations, including jail, psychiatric hospitals with varying degrees of security, or in the community with supervision or treatment as a requirement as part of their sentence. In the UK there are also a number of specialist secure facilities for individuals with ASD, primarily in the private sector. This disparity of outcomes reflects the lack of clear guidelines regarding the best services to meet the needs of this population. Moreover, the outcome can simply reflect whether the individual is previously known to services rather than his/her true treatment needs. This is particularly pertinent for those with higher functioning ASD, a significant proportion of whom will still not be diagnosed during their childhood years, and for whom contact with the CJS may be the first indication that something is not quite right.

In general terms jail is not an appropriate environment for someone with an ASD. Despite being characterized by structure, routine, and little social pressure, there are no therapeutic programs suitable for people with ASD, or, indeed, developmental disabilities more generally. The environment encourages social withdrawal, removes the person from his/her established routines and predictable environment, and perhaps most importantly, people with any form of disability are vulnerable to bullying, abuse, and exploitation by more dominant and antisocial types. Psychiatric facilities are certainly preferable, as they are staffed by health professionals and focussed primarily on treatment and rehabilitation rather than punishment and public protection (although public protection is certainly integral to the level of security of different psychiatric facilities). However, the needs of individuals with ASD may be different from those with mental illnesses or personality disorders, and so they may benefit little from the treatments on offer. Moreover, people with ASD may end up being detained for far longer than their peers (Butwell, Jamieson, Leese, & Taylor, 2000) as a result of their lack of progress and thereby a perceived lack of reduction in their risk to others. The lack of resources for adults with higher functioning ASD in the community makes community treatment and supervision orders not an option. Finally, although specialist hospitals for ASD do exist, the lack of evidence base regarding treatments does not encourage the CJS to make recommendations of transfer to such facilities that have significant cost implications for the government. There is clearly, therefore, an urgent need to both identify the needs of adults with ASD who have engaged in unlawful behavior and develop services to meet these needs. In the meantime, such individuals will continue to be managed across a variety of different services.

As indicated above, there are many different reasons why a person with an ASD may have engaged in unlawful behavior, and therefore there may be a number of different treatment approaches that are relevant. In general terms, this may involve addressing comorbid mental illness through specific treatments, and attending to the individual's social circumstances through supervised employment and living. However, as in many cases there may be a direct link between the core ASD impairments and the unlawful behavior; these too may need specific interventions.

Social skills training is now widely used among children with ASD, particularly those who are higher functioning. Social skills can be taught in an explicit 1:1 setting, or through a social skills group, where rules for engaging others, such as how to initiate and end social contact, how far to stand from a person, and "do's and

don'ts" can be taught in a rote fashion and then practiced to improve spontaneity. Alternatively, these skills can be learnt in a more naturalistic way by facilitating social engagement with others through social groups where the focus is on social activities (such as going to a restaurant or to the movies). There is an emerging literature that supports the effectiveness of such groups (Reichow & Volkmar, 2010).

Alternatively, strategies that focus on teaching empathy may be appropriate, particularly where there is evidence for a failure on the part of the person to appreciate the moral wrongdoing of his/her actions. Most "empathy training" uses a group therapy approach, where role playing takes a central part. This may be particularly difficult for someone with an ASD, and so modification of these generic strategies may be necessary. For example, empathy can be taught in a more "concrete" way. At a basic level, a software package has been developed, using lessons, quizzes, and games, to help develop individuals' understanding of emotions (University of Cambridge, 2002). This was found to significantly improve the ability of adults with AS to recognize a variety of complex emotions and mental states over a period of 10–15 weeks (Golan, Baron-Cohen, & Hill, 2006).

Some individuals may offend in the context of their circumscribed interest, and examples of this have been previously described in this chapter. As described, it is not as simple as identifying those with interests of a violent nature, as many will not act out their interests in any harmful or intimidating way. Conversely, just because an interest is not violent in its focus does not preclude its pursuit ultimately resulting in unlawful behaviors. It is also important to point out that for many with ASD their interests are an important part of their lives and, as such, play an important role in facilitating their self-esteem and in some instances their social inclusion and employment. Therefore, sensitivity and attentiveness are both required.

There is very little known about the best way to modify a person's interest. "Reward" contingencies may "mould" an interest into something that is more acceptable, and simple rules ("do's and don'ts") with respect to when and where they can carry out their interest may also be helpful. Cognitive-Behavioral Therapy (CBT) may also have a place in reducing preoccupation with violent and sexual themes (Barry-Walsh & Mullen, 2004). Although interests are certainly "obsessive" in nature, there is no evidence that any of the treatments used to manage Obsessive Compulsive Disorder (OCD) are useful in any of the repetitive or ritualistic behaviors seen in ASD and, therefore, on the whole, their use is not warranted in such circumstances.

Conclusions

In summary, a small yet significant number of primarily higher functioning people with ASD will engage in unlawful behavior. The etiology of their behavior may be understood as arising from a combination of generic forensic risk factors along with factors more specific to the autism phenotype. To most appropriately inform rehabilitation, a comprehensive assessment will consider all of these factors, augmenting clinical interview with additional neuropsychological measures if appropriate. It

is also important to recognize their vulnerability in the interview setting. Those individuals who are convicted are generally rehabilitated in generic forensic services, although the treatment approaches offered in such facilities may not be best suited to the specific needs of this population. The availability of specialist services is rather limited, however, and there is a lack of literature that would guide services. In the future, therefore, it is vital that more research is conducted to identify not so much the prevalence, but, rather, the treatment needs. With the availability of such evidence, the process of commissioning services to more appropriately meet their needs can begin.

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Chapter 14
Assessment and Treatment Planning in Adults with Autism Spectrum Disorders

Julie M. Wolf and Pamela Ventola

Adults with autism spectrum disorders (ASD) may present quite differently than children with ASD due to developmental maturation, effects of years of intervention, and differing environmental demands and expectations placed upon them in adulthood as compared to childhood. Support services for adults are much less widely available than for children, and after the age of 21, adults are no longer entitled to a free and appropriate education under the Individuals with Disabilities Education Act (IDEA). With this reduction in supports and services, young adults may struggle to successfully meet the new demands they face. A comprehensive assessment of an individual's strengths and weaknesses can aid in treatment planning and in identifying areas of support and accommodation that would be beneficial to the adult.

Behavioral and Neuropsychological Outcomes in Adults

Research suggests that some of the core symptoms of autism abate to some extent in adolescence and young adulthood (Seltzer, Shattuck, Abbeduto, & Greenberg, 2004). Improvements in communication were most common, with social deficits tending to persist. In some cases, these social deficits are the result of a lack of social motivation, while in other cases, individuals have a high degree of social motivation but lack the social skills to form meaningful and satisfying social relationships. Some individuals continue to demonstrate restricted interests and repetitive behaviors into adulthood, while for others, these symptoms may attenuate in adulthood. It is important to note that while many individuals show a reduction in symptoms in adulthood, this is not the case for all individuals, and it is rarely the

J.M. Wolf (✉) • P. Ventola
Yale Child Study Center, Yale School of Medicine, New Haven, CT, USA
e-mail: julie.wolf@yale.edu; pamela.ventola@yale.edu

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case that symptoms abate to the extent that an individual no longer meets diagnostic criteria for the disorder in adulthood.

While intellectual ability (IQ) tends to remain stable over time, some individuals show significant increases or decreases in IQ over time (Howlin, Goode, Hutton, & Rutter, 2004). The most common pattern of change seems to be small declines in Performance (nonverbal) IQ and small increases in Verbal IQ from childhood to adulthood, although some individuals demonstrate striking increases in Verbal IQ. Brereton and Tonge (2002) investigated neuropsychological profiles in adults and found persistent impairments in "subtle social cognition" marked by decreased attention to eyes and voices, as well as impairments in memory, executive functioning, attention, cognitive flexibility, psychomotor processing speed, and motor coordination.

Early communication skills and level of cognitive functioning are the strongest predictors of outcome, with those individuals having strong early language skills or higher IQ faring better in adulthood (Eaves & Ho, 2008; Howlin, 2000; Seltzer et al., 2004). Those with an IQ above 70 have the best chance for success at living independently. However, even then, outcome is variable, as some individuals with very high IQ face significant challenges in adulthood.

Comorbidities in Adults with ASD

Identified rates of psychiatric comorbidities in adults with ASD vary greatly across studies. This is likely in part due to differing samples. Additionally, it is challenging to assess comorbid psychopathology in individuals with ASD and intellectual disability, as most traditional measures for assessing psychiatric disorders rely on self-report, interviews, and behavioral observations that are inappropriate for individuals with more severe levels of intellectual disability (Myrbakk & von Tetzchner, 2008). Howlin (2000) found rates of psychiatric comorbidities ranging from 11 to 67 %. Engström, Ekström, and Emilsson (2003) similarly found rates that ranged from 9 to 89 %. Mood disorders and anxiety are the most common diagnoses in adults with ASD, and in many cases, depression and anxiety co-occur.

Estimated rates of depression in ASD have ranged from 20 (Shtayermman, 2007) to 33 % (Howlin, 2000). Bipolar disorder, or mania, is the next most common mood disorder in adults with ASD and was found in 21 % of the sample in one study (Howlin, 2000). Depressed mood may be particularly common in high functioning adults, who have insight into their social and adaptive difficulties, and who may desire to make changes but have limited success in doing so; however, depression is also seen in individuals with comorbid autism and intellectual disability (Smith & Matson, 2010).

Anxiety disorders are also common, as for example, Shtayermman (2007) found that 30 % of individuals with ASD also met criteria for generalized anxiety disorder. Smith and Matson (2010) and Gillott and Standen (2007) compared groups of adults with autism and intellectual disability to a group of adults with intellectual

disability only, and both found that the groups with autism and intellectual disability had significantly higher levels of anxiety than the groups with intellectual disability alone. The most commonly occurring types of anxiety in adults with ASD and intellectual disability were panic/agoraphobia, separation anxiety, obsessive–compulsive disorder (OCD), and generalized anxiety disorder (Gillott & Standen, 2007). The authors attributed the increased occurrence of anxiety in the ASD group to fears of change, anticipation of future events, and sensitivity to sensory stimuli. In addition, participants were found to have higher stress from all of these sources than did controls. The authors further noted that the increased anxiety in the ASD group may be secondary to social deficits, in that individuals with ASD may have less social support to help them cope with their anxiety. In the absence of appropriate coping strategies, individuals may turn to aggression and self-injury.

Differential Diagnosis

In addition to certain disorders commonly co-occurring with ASD, a number of other disorders are easily mistaken for ASD in adults. Oftentimes, a comprehensive evaluation by professionals with expertise in ASD is essential in making a differential diagnosis. Without this expertise as to the nature of the ASD presentation, many individuals may seem to fit the DSM diagnostic criteria for ASD when in fact their difficulties may be attributable to another diagnosis. Thus, extensive clinician training, as well as a thorough exploration of possible alternative explanations for a patient's symptoms, is critical for making an accurate diagnosis, especially in complex cases with multiple co-occurring symptoms.

Although anxiety disorders commonly co-occur with ASD, it is also possible that an anxiety disorder could be mistaken for an ASD when in fact the anxiety alone accounts for the individual's presentation. Many forms of anxiety (e.g., social phobia, generalized anxiety, agoraphobia) can impact social functioning, and thus careful consideration must be given to whether the individual's social difficulties can be accounted for by the anxiety or whether a primary social deficit more indicative of an ASD is present. OCD also shares some features with ASD, particularly with regard to rigid and repetitive behaviors; a determination as to whether an impairment in social cognition is also present can aid in differentiating between these conditions. Furthermore, in OCD, the repetitive behaviors represent a compulsion that is often tied directly to a particular obsessive or anxious thought, and occurs as a means of countering that anxiety (e.g., repeated hand washing tied to a fear of germs; compulsive checking tied to an anxiety that a door was left unlocked or a stove left turned on). In ASD, the repetitive behaviors are not typically tied to a specific obsessive thought in this way, and circumscribed interests, although impairing in their intensity, are not tied to anxiety as are obsessive thoughts.

Depression may also contribute to social difficulties that can be misidentified as an ASD. The lack of energy and lethargy characteristic of depression can contribute to a failure to take initiative, and this can include the social realm (e.g., staying

home, not having the motivation or energy to socialize). As a result, individuals with depression can become socially isolated, which may lead to a referral for a possible ASD. Evaluation of an individual's social cognition and social skill, along with a psychiatric evaluation for depression, can help to determine whether the individual's social presentation is secondary to depressed mood.

Intellectual disability has a high rate of co-occurrence with ASD, and in some individuals with intellectual disability, it can be difficult to determine whether an ASD is also present. Although this differential has typically been made prior to adulthood, at times a patient may present with a history of a diagnosis of intellectual disability when it becomes apparent that an ASD is also present; or with a diagnosis of an ASD when in fact the impairments are attributable solely to the intellectual disability. In these cases, a comprehensive evaluation can help to clarify the diagnosis. Individuals with intellectual disability (without ASD) may exhibit repetitive behaviors and motor mannerisms similar to those seen in ASD. Intellectual disability can also impact language and communication skills. Thus, assessment of social functioning is the most critical factor in differentiating these two conditions. While individuals with autism often exhibit reduced eye contact, joint attention, and seeking to share enjoyment, these skills are typically intact in individuals with intellectual disability. While not diagnostic in itself, the individuals' cognitive profile may provide supportive information, in that individuals with ASD tend to have a high degree of scatter in their profile (i.e., significant areas of strength and weakness) whereas individuals with intellectual disability tend to have a more uniform profile. Additionally, individuals with ASD and comorbid intellectual disability and those with intellectual disability alone have deficits in adaptive skills development, but in individuals with intellectual disability alone, their adaptive skills tend to be equally impaired and generally on par, or even slightly above, their cognitive abilities. In ASD, individuals' adaptive skills tend to be well below their cognitive skills with particular deficits in adaptive socialization.

Nonverbal learning disability (NLD) is another common differential diagnosis, particularly in higher functioning school-aged children and adults. NLD is a learning disability characterized by a specific pattern of neuropsychological strengths and weaknesses. The NLD profile is commonly seen in individuals with Asperger's syndrome (Rourke, 1989). The assessment of NLD requires a comprehensive neuropsychological evaluation. Individuals with NLD have strengths in some neuropsychological processes, including simple motor tasks, auditory perception, verbal attention and memory, and phonological processing, and marked weaknesses in others, such as visual and tactile perception, complex motor tasks, visual attention and memory, problem solving, and social aspects of language. Although individuals with NLD have deficits in social interaction skills, and some individuals with a social disability also evidence an NLD profile based on neuropsychological assessment, not all individuals with NLD have ASD. Instead, their social deficits are a function of their learning profile. For example, they may have difficulty reading nonverbal cues in social interactions due to their impairments in nonverbal information processing. Another feature distinguishing ASD from NLD is the presence of unusual or repetitive behaviors and circumscribed interests. These behaviors are

seen in ASD but not NLD. Given the overlap between ASD and NLD and the complexity of an NLD profile, a comprehensive neuropsychological and diagnostic evaluation is essential when the diagnosis of NLD is in question.

Individuals with attention deficit hyperactivity disorder (ADHD) often have impairments in executive functioning that may cause them to underperform in post-secondary education thus leading to a referral for an evaluation. In addition, ADHD often leads to secondary social impairments that can be mistaken for an ASD, leading to a referral for a differential diagnosis. For example, the impulsivity associated with ADHD can lead to socially inappropriate behaviors, which can, in turn, contribute to individuals feeling socially ostracized. Furthermore, impairments in executive function associated with ADHD can impact the ability to see the "big picture," which may lead the individual to miss important information in social interactions. A careful evaluation of executive functioning and social presentation will help to differentiate between ADHD and ASD. Furthermore, individuals with ADHD would not be expected to display the communication deficits or restricted interests and repetitive behaviors common in ASD.

Individuals with schizophrenia or other psychotic disorders may share some characteristics seen in ASD as well. For example, psychosis can lead to socially inappropriate behaviors as well as a lack of personal and social insight and awareness. In addition, individuals with thought disorders may use nonsensical or atypical language. In making the differential between a psychotic condition and an ASD, it is critical to obtain a detailed history in order to determine onset. While ASD must be present in early development (before age 3), the onset of psychotic disorders typically occurs in late adolescence or early adulthood. (Of note, childhood forms of schizophrenia do exist, although they are rare, and individuals with an adolescent- or adult-onset psychosis may show some prodromal signs during childhood.) In addition, the presence of positive symptoms such as hallucinations and delusions would be suggestive of a psychotic condition rather than an ASD. The evaluation should also carefully assess the individual's grounding in reality. With regard to speech patterns, it is easy to mistake scripted language for non-reality-based language if the evaluator is not familiar with the source from which the individual is scripting. For example, an individual with ASD may make an off-topic, tangential, or fantastical comment that may appear disconnected from reality, when in fact the comment was a quoted line from a favorite movie or television program. It is helpful to transcribe samples of the individual's language, and then investigate whether it may have been scripted. Speaking with parents or siblings can be helpful, as they are often familiar with the individual's favorite television programs and movies and can identify scripted phrases that the individual frequently uses. In some cases, an internet search with the phrasing in quotations may also identify the source from which the individual was repeating lines. If the individual seems to be making frequent nonsensical comments that cannot be tied to an identifiable source, then this may be more suggestive of a thought disorder. Some speech patterns (e.g., tangential or circumstantial speech, neologisms) may be common in both conditions. However, some patterns of speech (e.g., "word salad" in which the individual jumbles words together with no apparent meaning) are more specific to schizophrenia.

A number of personality disorders share features with ASD, as described below. In differentiating between ASD and personality disorders, a detailed history to determine onset is critical, as ASD must be present in early development, whereas personality disorders have an onset in late adolescence or adulthood.

Individuals with avoidant personality disorder may have reduced participation in social activities or lack friendships. However, this is attributable to an active avoidance of social situations due to anxiety (e.g., about being evaluated), rather than to limited social skill, as would be more characteristic of ASD. In addition, individuals with avoidant personality disorder would not be expected to exhibit communication impairments or stereotyped behaviors.

Individuals with schizoid personality disorder show a pervasive pattern of detachment from social relationships, a lack of friendships, and flattened affect. The defining feature of schizoid personality disorder is a *disinterest* in social relationships. While some individuals with ASD express a disinterest in social relationships, the majority express a strong desire to form relationships, but lack the knowledge or skills to do so. Thus, an assessment of social motivation is critical in differentiating these two conditions. In addition, individuals with schizoid personality disorder would not demonstrate stereotyped and repetitive behaviors like those observed in ASD.

One of the more difficult personality disorders to differentiate from adult ASD is schizotypal personality disorder. This disorder shares preoccupations, odd patterns of thinking or speech, atypical patterns of behavior, flattened affect, and a lack of peer relationships with ASD. However, individuals with ASD tend to show a greater degree of social impairment than is typically observed in schizotypal personality disorder, as well as stereotyped patterns of behavior that would not be observed in schizotypal personality disorder. Furthermore, individuals with schizotypal personality disorder may show behaviors that are more related to the psychotic spectrum (e.g., ideas of reference, magical thinking, unusual perceptual experiences, and paranoid ideation) than to the autism spectrum.

Obsessive–compulsive personality disorder (OCPD) shares some features with ASD, particularly with regard to the stereotyped and repetitive behavior domain of ASD. Like many individuals with ASD, those with OCPD may exhibit preoccupation with details, a need for predictability, inflexibility about rules and moral standards, and rigidity of thought and behavior. However, in individuals with OCPD, these behaviors occur in the absence of any core social or language impairments. If social difficulties are present, they are likely to be secondary to anxiety or to the individual's maladaptively rigid and inflexible behaviors.

Diagnostic Evaluation of Adults

When an adult presents with a referral question of a possible ASD, these cases are often more complicated than child referrals. The diagnosis is often less clear; if it was a straightforward case, the individual would likely have been identified previously.

In addition, adults often present with many comorbid concerns, as discussed above. As a result, common referral questions include social isolation, depression, anxiety, and lack of motivation. A multidisciplinary evaluation is often critical to explore the individual's functioning across multiple domains. Specific components of the evaluation should be driven by the referral question and presenting problems, as well as selected to aid in differential diagnosis.

Psychiatric Assessment

A multidisciplinary evaluation will typically begin with a detailed history of the individual's developmental, medical, family, social, and educational functioning. The information may be obtained through unstructured questionnaires and standardized rating scales, but should also involve an interview with the individual's primary caregiver, who can speak to both present concerns and early development. A psychiatric interview should also be conducted with the patient, in order to obtain his or her perspective on current functioning and areas of difficulty. The psychiatric assessment is critical in identifying areas of consideration for differential diagnosis and for identifying comorbid conditions.

Psychological/Neuropsychological Assessment

A psychological or neuropsychological assessment is a critical component of the multidisciplinary evaluation. Common components of the evaluation include the following: (1) cognitive testing to determine an individual's level of functioning and identify areas of strength and weakness to inform treatment planning; (2) an assessment of social functioning (such as the Autism Diagnostic Observation Schedule [ADOS]; Lord, Rutter, DiLavore, & Risi, 2001), to aid in diagnostic determination and identify social strengths and weaknesses; (3) an assessment of adaptive functioning (e.g., the Vineland Adaptive Behavior Scales—Second Edition (Vineland II); Sparrow, Cicchetti, & Balla, 2005), to determine how well the individual is translating his or her cognitive abilities into functional, daily, independent living skills; (4) achievement testing, to assess academic ability if the individual is still in school and is experiencing academic difficulties; (5) neuropsychological testing, to evaluate the individual's functioning across a number of domains, including attention, visual perception, motor functioning, language, nonverbal and visual-spatial ability, memory, and executive functioning (planning, organization, working memory, self-monitoring, and inhibition); and possibly, if indicated, (6) projective testing, to provide a perspective on the individual's psychiatric functioning and thought processes.

In order to determine the presence of an ASD, the psychological evaluation should include a comprehensive assessment of the individual's social functioning

through direct assessment with the individual as well as interviews with parents or caregivers. The "gold-standard" measures for diagnosis are the Autism Diagnostic Interview, Revised (ADI-R; Rutter, LeCouteur, & Lord, 2003) and ADOS (Lord et al., 2001). Ideally, both measures would be administered for the most comprehensive picture of the individual's symptoms related to an autism spectrum diagnosis. However, the ADI-R is quite lengthy to administer, requires extensive training, and is not always feasible in a clinical setting. In addition, the ADI-R focuses heavily on the period between ages 4 and 5, which may be less relevant in understanding an adult, and also relies on the memory of the informant going back many years. Thus, many clinicians opt to informally interview parents regarding the patient's presentation in the areas of social functioning, communication, and restricted interests and repetitive behaviors in lieu of the ADI-R.

In addition to the parent interview, direct assessment of the individual is necessary to assess social and communication functioning. For higher functioning individuals referred for possible ASD, the clinician's job is to assess the nuances and subtleties of social behavior. This includes the individual's ability to understand higher-level language, such as figures of speech and sarcasm, as well as social skills, including the ability to recognize if he/she is being taken advantage of, understanding of romantic relationships, and so on. The clinician should also assess the individual's level of independence and ability to self-manage, as these skills are imperative to successful outcomes into adulthood.

As described above, the ADOS is the "gold-standard" measure for direct diagnostic assessment. The instrument includes a module (Module 4) specifically geared to verbally fluent adults. This is a semi-structured interview session that contains a number of creative activities and questions about emotions, social relationships, daily living, and personal responsibility. The ADOS provides standardized procedures that include social probes, yet there is flexibility in allowing the individual to respond naturally. The clinician then codes the interaction on a number of variables relevant to the diagnosis of ASD, such as atypical use of language, reciprocal communication, nonverbal communication, shared enjoyment, understanding of emotions, insight into social relationships, personal responsibility, social reciprocity, sensory interests, motor mannerisms, self-injury, restricted interests, rituals, and repetitive behaviors. Because Module 4 of the ADOS is intended for verbally fluent individuals, an adult who has limited expressive language should instead be administered a lower level module of the ADOS, such as Module 1 or 2. These modules include toys and items geared for much younger children and toddlers; thus, a common critique of the ADOS is that there is not a module that is suitable for an adult with limited verbal skills. Nonetheless, skilled clinicians can adapt the ADOS materials if needed. For example, to assess capacity for abstraction, the clinician can use action figures as opposed to dolls or miniature figurines. Furthermore, it is important to keep in mind that toys and activities that are exciting to very young children can also be enticing to some older individuals whose level of functioning is comparable to that of a much younger child. Nonetheless, the clinician does need to acknowledge the perspectives of the individual as well as the parents who may be observing when choosing the most appropriate materials.

Speech/Language Assessment

Inclusion of a speech and language assessment as a component of the multidisciplinary evaluation is particularly useful for adults with limited language ability. A comprehensive speech and language assessment can provide a determination of the individual's functioning in the areas of both receptive and expressive language. For verbally fluent adults, evaluation of pragmatic language (i.e., the use of language for social communication purposes) and the organizational aspects of language (e.g., narrative formulation) can be especially helpful.

Treatment Planning

Results of a comprehensive multidisciplinary evaluation can be informative in directing treatment planning. It is critical that treatment be tailored to the individuals, not to their diagnosis. In other words, an individual's unique profile of strengths and weaknesses should guide intervention planning, rather than assuming that the same approaches can be applied to all individuals with an ASD. Other chapters within this volume address specific aspects of intervention and transition planning in detail. The goal of this section is to provide an overview of how the results of an evaluation in various domains can inform the direction of intervention.

Cognitive and Academic Abilities

Results of cognitive and academic testing can help to determine whether an individual will be capable of handling the academic demands of college, or whether the transition to adulthood should focus more on developing vocational skills with the goal of entering the workforce upon conclusion of high school. Individuals attending college are typically successful academically and have average-to-above average cognitive abilities. Thus, an individual with a below-average IQ or intellectual disability will likely struggle to keep pace with peers in a college setting and may be better suited to pursuing a vocation. Likewise, an individual with average-to-above average cognitive abilities but relatively weaker academic achievement testing results may also not be the best candidate for college placement or may simply find college less appealing.

For individuals entering the workforce, a cognitive profile can provide one source of data to inform vocational choice. For example, an individual with a relative strength in visual-spatial construction skills may be best suited to a vocation that emphasizes "hands-on" or mechanical skills. An individual with strong analytical and technical skills may be best suited to a career in the technology or computer industry. An individual with significant cognitive impairments across the board may be best suited to a vocation in which a simple skill can be mastered and performed in repetition.

Cognitive testing data can also provide information as to the types of accommodations and supports that will be most effective for an individual in the workplace. For example, someone with a relative strength in the verbal domain may respond well to verbal instructions, whereas someone with a strength in the perceptual domain might best learn through demonstration and visual supports (work schedules, sequence strips, etc.).

Processing Speed

College students with a weakness in processing speed may struggle to complete assignments and examinations within the allotted time frame. They may also have difficulty keeping up with fast-paced lectures, with regard to both understanding information presented and efficiently taking notes on the material. A number of accommodations may be beneficial for individuals with this weakness, including provision of extra time for exams and assignments, use of a computer for exams and note-taking, audio-recording lectures so they can be reviewed at a later time, and receipt of slides and lecture outlines in advance to reduce note-taking demands and to allow the individual to review topics in advance to aid in comprehension.

Processing speed should be a factor in considering choice of vocation as well, as an individual with slow speed of processing would not be well suited to a job that requires fast-paced decision making, or in which speed of output is necessary for job success or a relevant factor in performance evaluation. Accommodations may also be provided, such as visual supports or written instructions for individuals who have difficulty keeping pace with instructions presented orally.

Executive Functioning

Executive functioning impairments may manifest as difficulties with any number of skills, including planning, organizing, synthesizing, initiating, prioritizing, time management, and multitasking—all of which can be critical for success in the college and work settings. Individuals with ASD can be taught to utilize a number of organizational supports and strategies to accommodate these difficulties. Use of a planner that includes daily schedules and task lists can aid the individual in keeping track of responsibilities. Alternatively, an electronic device (smartphone, tablet, personal digital assistant) can be used to store calendars and to-do lists, and can be programmed to set alarms to remind the individual of important appointments, events, and deadlines. Other strategies such as color coding materials and creating file folders for various types of information can assist those with organizational difficulties. Those who struggle with time management may benefit from receiving interim deadlines for projects to ensure that they remain on pace for timely completion.

While these strategies can be beneficial, some individuals on the autism spectrum may require support from others to effectively implement these strategies. For example, college students may benefit from having a college counselor or other professional who functions as a "point person," with whom they can check in periodically to help ensure that they are meeting obligations and implementing organizational strategies effectively. In the workplace, a job coach can function in a similar role and can also educate employers as to how to effectively utilize organizational strategies to ensure the employee's success. Finally, it is often beneficial for the individuals to have a single supervisor giving them directives, rather than having to juggle or prioritize demands from many different supervisors.

Inattention and Distractibility

Difficulties with attention can manifest in multiple ways, including difficulties managing environmental distractions and sensory stimuli and sustaining attention during a long lecture or lengthy vocational task. A number of accommodations can help to improve the individual's ability to attend to task demands. One is to reduce distractions in the environment. College students may opt to sit at the front of the classroom, close to the instructor. The workplace environment can be modified to remove visual distractors such as signage on the walls or bright lights. The person may also be provided a workspace that is situated away from potentially disruptive auditory stimuli such as telephones, copy machines, or talkative co-workers. For those with auditory sensitivities, use of earphones or earplugs may make the workplace more tolerable.

College students who have attentional deficits may be provided accommodations such as taking exams in a quiet, distraction-free environment, away from peers. They may also benefit from audiotaping lectures so that they can review them at a later time in the event they missed any information due to distractibility. Students may also meet individually with their instructors to go over any assignments or instructions that they may have missed. Finally, frequent breaks throughout the day and a course schedule that affords "down time" between classes may help the individual to sustain attention throughout the day. Lastly, individuals may work with a psychiatrist or other physician to determine whether pharmacological intervention may be useful in alleviating distractibility.

Academic Achievement

As noted above, individuals with significant impairments in academic skills may elect not to pursue college; however, milder weaknesses in this area can be accommodated, allowing for college success. Challenging academic subjects for individuals on the autism spectrum tend to be those that require conceptualizing abstract

information, including abstract mathematics, reading comprehension, and written expression. For some individuals, writing difficulty results from impairments in graphomotor skills or writing fluency. In these cases, the accommodations described under section "Processing Speed" above are helpful (e.g., keyboarding, extra time on exams and written assignments, note-taking supports). For many individuals, mathematical reasoning, reading comprehension, and narrative formulation are challenging due to difficulties with organizing ideas, identifying "big picture" themes, and synthesizing information. In these cases, organizational or visually based computer software can be useful in helping the individuals to generate an outline of the main themes and supporting ideas of what they have read or what they plan to write. In addition, working with a tutor can be useful in providing the individual with additional academic support.

Adaptive Functioning

For those individuals with adaptive functioning impairments, the highest priority for intervention is ensuring the individuals' safety. This means explicitly teaching skills such as responding to an emergency situation (fire, etc.), interacting with emergency personnel, avoiding potentially harmful situations, and protecting valuables. Due to their social impairments, many individuals with ASD are at risk for being taken advantage of or becoming involved in legal troubles due to naiveté about the implications of their behaviors (e.g., that repeatedly contacting romantic interests may be perceived as stalking). Again, understanding the behaviors to avoid and their implications requires explicit instruction.

Once safety concerns are addressed, individuals with ASD often will require instruction in adaptive or daily living skills, including cooking, cleaning, laundry, managing money, hygiene, sleep, transportation, and following community rules. Those who are employed may also require explicit instruction regarding workplace rules, such as dress code, norms for interacting with co-workers and employers, and punctuality. Ideally, these skills will be taught prior to college or employment. Generalization should also be taught explicitly, since many individuals with ASD can master a skill in one context and be unable to apply it to other contexts. Role plays can be useful for teaching certain skills (e.g., responding to a fire drill). Visual supports can also be effective. For example, visuals can be provided with instructions for what to do in an emergency. Visuals can also be provided to aid the individual in completing tasks of daily living (e.g., instructions for doing laundry might be posted in the laundry room; food preparation instructions might be posted in the kitchen). Individuals with ASD may initially require support in implementing learned skills. This support can be faded as the individual demonstrates increased mastery and independence. Some individuals may benefit from working with a "Life Coach" who can provide in vivo instruction and support in carrying out life skills.

Socialization

The impairments in socialization skills that are diagnostic of ASD tend to persist into adulthood (Seltzer et al., 2004). For college students, this can contribute to difficulties getting along with roommates, forming friendships, dating, and succeeding in group projects. In the workplace, social skills deficits can impact relations with co-workers and supervisors. In addition, learning appropriate interviewing skills is often a challenge for adults with social deficits.

Utilizing role play can be an effective strategy in teaching socialization skills (e.g., negotiating within group projects, solving a problem with a roommate, interviewing for a job or college admittance). College students can be provided accommodations to increase social success. In considering housing options, it is important to balance the need to reduce peer conflict with the need to reduce social isolation. While a single room may be more tolerable to a young adult with social impairments than a double room, it may also contribute to social isolation. On the other hand, having a roommate may lead to conflict, particularly if the roommates' lifestyles (sleep schedules, study habits, etc.) are quite different. Often an ideal arrangement is a single room within an apartment or suite, so that the individual is not isolated, but also has his or her own space for social reprieve. Many college campuses offer a "quiet" residence, which can be a good option for some students with ASD. Students can also consider options such as living off campus, or living at home with parents, depending on their individual needs.

It may be beneficial for students to have a college counselor who serves as a "go to" person in the face of social difficulty. This counselor can help the student resolve conflict with roommates and peers and develop skills around peer connections and dating. In addition, residence hall advisors can be trained to work with students with ASD, and in turn help to resolve conflict. Finally, social isolation can be reduced by involving the student in structured activities around areas of interest (e.g., chess club, gaming club, martial arts).

With regard to success in the workplace, individuals with social difficulties should avoid choosing an occupation that has high social demands (answering telephones, customer service, receptionist, etc.). A job coach can explicitly teach interviewing skills and conduct mock interviews with the individual in order to improve interview performance. On the job, supervisors can be provided education and training in working with individuals with ASD. Employees may also consider whether it could be beneficial to disclose their disability to co-workers. In some cases, this may provide opportunities for education and training of co-workers to be sensitive to the needs of individuals with ASD.

Anxiety

Comorbid anxiety can lead to secondary impairments in social functioning and can impact academic functioning (e.g., performance anxiety, social anxiety around giving presentations). Furthermore, anxiety can contribute to perfectionism, difficulties

with time management, and cognitive and behavioral rigidity, which in turn can negatively impact performance in either the college or workplace setting.

For students with social anxiety, the strategies described under section "Socialization" above may be helpful to build skills and reduce anxiety. Professors may also consider offering the student alternative means of making class presentations (e.g., presenting only to the professor, or presenting by video or webcast). If anxiety results in perfectionism and associated difficulties with time management, organizational strategies as discussed in section "Executive Functioning" above may be helpful. In the workplace, individuals with ASD may benefit from a designated "safe place," or location where they can go to calm down when feeling stressed or overwhelmed. Individuals can also be taught coping strategies for managing anxiety (e.g., relaxation, breathing, mental imagery). Finally, treatment for anxiety (both pharmacological and psychotherapeutic) should be considered if anxiety is not otherwise managed.

Depression

Individuals with comorbid depression may struggle with motivation in the workplace or academic setting. In addition, depression can lead to irritability and outbursts, particularly in individuals who already have heightened sensitivity (e.g., to sensory stimuli in the environment). This irritability and associated outbursts can cause the individual to become further socially ostracized. Thus, it is critical that individuals with ASD receive appropriate treatment (medication, psychotherapy) for comorbid depression. In addition, increased community involvement (volunteer work, social opportunities) can help to disrupt apathy or lethargy in individuals who struggle with the motivation to seek employment.

Adult Transition Programs

The increase of effective interventions in the school-aged years coupled with improved identification of higher functioning individuals with ASD means many more individuals are seeking college-level educations and/or have the desire to live independently. However, given the magnitude of their social disability, many of these individuals cannot transition from living at home and attending high school to living independently while managing the demands of college or a work environment. These individuals, based on comprehensive assessments, possess the cognitive capacity to complete college-level work and/or have the skills needed to be successful in a career, but they cannot manage the social aspect of college or the independent living skills needed for college and work settings. Therefore, in recent years,

transition programs have been developed to meet the needs of this growing population of individuals with ASD.

The goals of transition programs are to help individuals make the transition from living at home with parents to living independently while also attending college or starting a career. The programs are usually residential so that skills can be taught in naturalistic environments. Curricula often focus on higher-order social communication skills within the context of daily life, such as getting along with a roommate, communicating appropriately with employers or staff/professors at college, and interacting appropriately with members of the community. Adaptive daily living skills are also a focus. For example, students can be taught how to budget their finances, shop for groceries, cook, clean, wash clothes, travel within the community (e.g., bus/train), and maintain appropriate hygiene, as these adaptive skills are often deficient even in very cognitively able individuals on the autism spectrum. As the goals of the programs are to teach the students the necessary social and adaptive skills to be successful in a career or work setting, the programs also often facilitate job placements and, if needed, provide support or coaching at the place of employment. Study skills classes are also common to help the students, not necessarily with the academic content of college classes, but instead to learn how to organize and plan assignments as well as how to self-advocate and seek additional help as needed. More detailed information and specific aspects about transition programs can be found in other chapters within this volume.

Conclusion

Adults with ASD bring unique elements to the assessment and treatment planning process. A variety of complex differential diagnoses need to be considered in diagnostic evaluations with adults, and different skills need to be assessed, often more high-order and nuanced ones. As the increasing numbers of children diagnosed with ASD in recent years are beginning to reach adulthood, the field is now shifting from a focus on early identification and school-aged treatment to also include services and supports for older adolescents and adults. Colleges, vocational settings, and transition programs are being developed to meet this increasing need, and as outlined in this chapter, a comprehensive assessment can serve as a critical starting place for families. The data and clinical impressions gained from assessments can help inform a programmatic course for the individual with ASD and also provide specific recommendations for how to teach skills, which skills to prioritize, and the best ways to adapt the environment for optimal learning.

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Chapter 15
The Epidemiology of Autism Spectrum Disorders in Adulthood

Traolach S. Brugha, Freya Tyrer, Fiona Scott, M. John Bankart, Sally Anna Cooper, and Sally McManus

Introduction

Why does "epidemiology" matter? According to the World Health Organization (WHO: http://www.who.int/topics/epidemiology/en/) epidemiology is "the study of the distribution and determinants of health-related states or events (including disease)." As a series of reports published by the Centers for Disease Control, Atlanta (Centers for Disease Control and Prevention, 2012; Yeargin-Allsopp et al., 2003) over the past decade have shown, many children with autism[1] still go undiagnosed and unrecognized by services. As more children get recognized this number may be falling, which is progress. However, the differences in childhood recognition rates between the lowest and highest estimates are huge when comparing different areas within the USA. And what about adults? Who is working to recognize and diagnose them? All of this shows that there is no room for complacency about the number who remain undiagnosed.

[1] In this chapter the terms "autism" and "autism spectrum disorder" (or ASD) are used interchangeably—no difference in meaning is intended. But these labels do matter to people individually; for example, some prefer the term autism spectrum conditions (ASCs), disliking the word "disorder." In epidemiology very precise definitions of terms are used as we shall see later in this chapter.

T.S. Brugha (✉) • F. Tyrer • M.J. Bankart
University of Leicester, Leicester, UK
e-mail: tsb@leicester.ac.uk; fct2@leicester.ac.uk; m.j.g.bankart@keele.ac.uk

F. Scott
University of Cambridge, Cambridge, UK
e-mail: spectrumconsultancyltd@gmail.com

S.A. Cooper
University of Glasgow, Glasgow, UK
e-mail: sacooper@clinmed.gla.ac.uk

S. McManus
NatCen Social Research, London, UK
e-mail: sally.mcmanus@natcen.ac.uk

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Parents of children with autism wonder what will happen when the children have grown up and there is no one to care for them. It does not help that up to now everything we knew about autism prevalence (and much else about autism) related only to children. Yet most people alive now are no longer children. So what can epidemiologists offer? Epidemiologists are fortunate in that they can go where services and professional practitioners do not: they can "case find." Case finding utilizes techniques for identifying people with physical and mental conditions whether or not they have been recognized or diagnosed by services. Only epidemiological methods can tell us the complete answer to questions such as: how many, who, and what are the characteristics of people with the condition. A complete answer to these questions is required so that the range of service provision needed can be adequately costed and planned for.

Professionals (doctors, teachers, psychologists, etc.), members of support groups (for people with the condition, for carers including family members) will all have their own perspective on these "how many" and "who" questions. And that perspective will depend partly on what we learn through people known to have the condition. But only a thorough collection and analysis of data systematically carried out across a defined population will give us the complete answer that includes those who are known to have autism and those who have autism but nobody knows about it. This chapter, as befits this book, casts light for the first time on that bigger population of adults with autism—both known and unknown. How many are there? What are their lives like? It tells us how many may be recognized or may not be. And therefore it can provide a voice for those who are not recognized. There is no advocacy group or organization primarily speaking for adults with autism who are undiagnosed—so who will speak up for them? What happens to individuals identified with autism in childhood when they grow up? Where do they go? This chapter is dedicated to them.

Previous Work

Before talking about what happened when our research group tried to find out how many adults there are with autism, it is worth reflecting on how little was generally known when we started. Before then no one had tried to find out how many adults have autism! But there are some sources of information that have provided some early clues. Studies following up adults who were diagnosed as children have shown that the condition does not go away (Howlin, Goode, Hutton, & Rutter, 2004). Worryingly, one set of studies suggested that adults with autism and intellectual disability may live shorter lives (Pickett, Paculdo, Shavelle, & Strauss, 2006), but this could be in part because adults with intellectual disability, particularly men and particularly those with epilepsy, have shorter lives.

Adults in Great Britain who have responded to postal and online surveys (National Autistic Society, 2008) stating that they have an autism spectrum disorder (ASD), are more often male (2:1), rarely aged 65 years or older and are rarely in

full-time employment. They tend to be given a diagnosis of high functioning autism or Asperger syndrome, with 1 in 5 in receipt of psychological or psychiatric services. There are also many single case studies and indeed illuminating autobiographical accounts. But what about information on the lives of those undiagnosed? At best we have personal accounts from those diagnosed, looking back to life before their condition was recognized. In other words, quite a lot of hindsight, but little foresight.

Since completing our first study on the number of adults with autism in the population two other studies have been reported that add to our background of knowledge. An important new US study (Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011) provides evidence to underpin the widespread concern that the transition from childhood to adulthood can result in unmet need for help with education and access to employment, even for children with recognized special education needs and autism. They used data collected in 2007–2008, from the National Longitudinal Transition Study 2 (NLTS2), a 10-year prospective study of youth receiving special education services, which included 680 youth in the autism category, 500 of whom were no longer in high school. For youth with an ASD, 35 % had attended college and 55 % had held paid employment during the first 6 years after high school. More than 50 % of youth who had left high school in the past 2 years had no participation in employment or education. Youth with an ASD had the lowest rates of participation in employment and the highest rates of no participation compared with youth in other disability categories. Similarly, a small study (Balfe & Tantam, 2010) described 45 teenage and adult individuals with Asperger syndrome or high-functioning autism who replied to an advertisement. It found that most were still living at home with parents, and had trouble understanding and responding to other people's feelings, coping with life changes, and managing life skills such as cleaning and managing money.

Epidemiology of Autism in the General Population

Up to now, the answer to the question "how many" could only be estimated for children. In three recent large region-wide or national community surveys of children and young people in England (Baird et al., 2006; Baron-Cohen et al., 2009; Green, McGinnity, Meltzer, Ford, & Goodman, 2005) the prevalence of ASDs was approximately 10 per 1,000 children.[2] When a government National Audit Office research group (National Audit Office, 2009) asked all local health and social care

[2] In earlier surveys in children, lower rates were reported, which was interpreted by some to mean that rates were now on the increase: the median rate for surveys published between 1966 and 1991 was 4.4 cases per 10,000 population; and for surveys published between 1992 and 2001 it was 12.7 (Fombonne, 2005). For now we will set aside this controversial question but we will get back to it when we discuss later in this chapter our findings on rates in adults across the full lifespan into old age.

service providers throughout England to say how many adults they knew with any form of autism, the answer seemed to be about 1 out of every 20 cases that should be recognized assuming a prevalence of 10 per 1,000. This would suggest that either most adults with autism were sufficiently well and independent not to need services as adults or it meant that a lot of adults with an autistic condition were "off the radar screen" and getting no help. One of the hopes of our study was to find out which (if either) of these possibilities was true.

There is evidence that individuals with an autistic condition are more likely to be diagnosed if they have another serious problem that brings them to attention such as another mental disorder, or difficulties with adaptation due to low levels of general intelligence (National Audit Office, 2009). In childhood, ASDs are associated with intellectual disability, male sex and an increased risk of epilepsy in older children. Among significantly intellectually disabled adults (less than 0.5 % of the overall adult population), a rate of autism of 75/1,000 was obtained from an intellectual disability population register (Cooper, Smiley, Morrison, Williamson, & Allan, 2007). The cases were identified from direct observation, detailed case records and interviews with carers, so it would be important to include adults with intellectual disability in any work on the number of adults with autism.

So, in summary, before the work described in this chapter began, we really had no idea how many adults were affected, what kinds of lives they were living and what factors were associated with having autism as an adult.

Methods for Establishing Rates of Disorders

Previously, no one had ever done a survey to look at rates of autism among adults so to do this a research team needed to develop an approach. Surveys are going on all the time around us. They seem to be in the news every day—for example, opinion polls on who should be the next leader of the country—so we all know a bit about surveys and lots of us have been a respondent in one. If you are a survey specialist there will probably be no need to read the next few paragraphs and indeed you may prefer to read the technical scientific reports on our work (Brugha et al., 2009, 2011; Brugha, McManus, et al., 2012; McManus, Meltzer, Brugha, Bebbington, & Jenkins, 2009).

Any scientific or technical topic can be daunting and confusing so we are setting out a brief introduction to survey methods here. If you would like to read more, an experienced survey expert colleague and I have put much of what you need together in a recently published chapter in a public health textbook (Brugha & Meltzer, 2008). More knowledgeable readers can skip over much of the next section.

Let's start with the two questions we were trying to answer with our survey. One, how many people have the condition and, two, what are the characteristics of people who have it (e.g., gender difference and likelihood of having been exposed to a possible environmental or genetic cause)? The ideal way to answer these kinds of questions is to ask them of everyone, as is done every 10 years in the UK Census.

However, this is not a feasible solution for many more complex and detailed questions. So we do a survey—which means we select a much smaller group of people from the whole population and just ask our questions of them. But how can we be sure the answers for our group also apply to the whole population? We can't, but the answers are more likely to be *representative* if everyone in the whole population, that means you and me, has a known *chance* of being in that group (we call the group a probability sample, or a purposive sample). We achieve this by taking a random sample: that means drawing up a list of "everyone," for example an electoral roll, and choosing a group of people from that list on the basis of chance (using a computer program to speed things up considerably!). Compared to a convenience sample, such as persons responding to an advertisement, a randomly chosen group like that is far more likely to be representative, with about the same proportion of men and women, old and young, working and not at work, as that found in the population as a whole. (Indeed, in a survey, we compare the characteristics of the sample group with the census and where the two differ we make adjustments for those differences by weighting the responses).

Before saying more about the survey approach, let's not rule out the idea of a census completely. For example, if you want to know how common autism is among children aged 8 years old in a city or a county, you could, with permission, examine all health and educational records on 8-year-old children for information suggesting that a child might have the condition of interest. And then you could ask a qualified health professional to examine those records more closely, or, more expensively, you could actually examine those children to find out which ones have the condition.[3] The CDC studies, referred to at the start of this chapter, do something quite like this. Child records are examined in defined geographical areas, although the children themselves are not re-examined. The problem with this approach is that it is only as good as the records—and indeed only as good as the services are at deciding which children should have a health check or an educational test that is accurately recorded. The fact that the number of children with autism found by the CDC researchers varies so much from one place to the next suggests that the quality of the records, or the services, is very variable between places. This puts some limitations on the value of statistics derived in this way, as the CDC authors have spelt out carefully and in detail.

So, returning to the survey sampling method and how to choose a group at random from the population—what are the advantages and drawbacks there? The big advantage is that the survey goes directly to representatives of the whole population—making no assumption about the quality of existing records (except for the quality of the list [sampling frame] from which the survey sample group is drawn). So when it came to studying adults, where there are known to be very poor records of who is affected by autism (National Audit Office, 2009), it was a "no brainer": we had to choose the survey, with a direct assessment method. Since no one had

[3] In reality you would have to ask the examiner to consider not just records that look positive but some records (chosen at random) that look negative, in order to get a balanced—or an unbiased—sample.

done this before we had to invent specific methods for surveying autism in the adult population. Now that we've done it, lots of people have asked how we did it when no one else had managed to do it before. It's a story worth telling—if only in the hope that others will now do the same in other populations and improve on our approach!

By now you will have realized that there is a survey cost issue. Examining people for a condition is a lot more expensive than checking records or asking people easy to answer questions about themselves. A medical or psychological examination for a complex condition like autism is very expensive so how can it be done at a reasonable cost? The answer is that we conduct the survey in two phases, and examine fewer people in the second phase. The first phase in our survey included screening questions for autism, and was based on interviews conducted face to face in people's own homes. In the first phase we selected a large group of people and an interviewer went in person to their home and asked them many questions the answers to which might indicate that they have autism. But these questions are not enough to establish whether they definitely have autism: that requires a clinical assessment. But it is too expensive to assess everyone in that way as it takes a long time and can only be done by a specially trained interviewer.

By taking the survey sample method to a second phase, we resample from our first phase survey sample. Having taken a sample from a population and asked those willing to answer questions about their health in phase one, we then chose an even smaller subgroup to agree to a more detailed clinical examination, in a second phase, at a later date.[4] And to choose for the second phase a balanced or unbiased sample, we chose for the clinical examination some who look more likely to have the condition and some who do not. A tricky part of this is how to work out how likely someone is to have the condition. If this were the common cold or the flu you could just ask "in the last week have you had a cold or felt like you had the flu?" But most people would struggle with the same question if you replaced the words "cold" and "flu" with "autism" and "Asperger syndrome!" How we tackled this we'll come back to later.

Now that we know roughly when and how to select a sample we need to consider how large the survey needs to be. For this we need a statistician who will turn this question around and ask you what exactly is the question that you are trying to answer? Let's think of another example to illustrate this. In an example "leader of our nation" question a good answer is we want to know which candidate is ahead; but a better question might be to ask is: "is the most popular candidate far enough ahead in the voting population to win the election?" Thus, because it is an opinion poll of about 1,000 adults and not the election itself, we need to know if the front-runner's lead also exists in the population at large or whether it just happens that lots more of his supporters were sampled by chance. A second poll on a different random set of 1,000 electors on the same day might show a 1 % difference *but the other*

[4] Later but soon enough to allow us to combine information from both interviews into one survey time period but with enough delay to give respondents a bit of a break!

way around. 1,000 may not be enough if we are interested in looking at small differences.

So what questions do we want to ask about autism in the adult population? If it is to ask how many adults have autism that could imply an interest in making a comparison with the frequency of this compared with other conditions; or it could be that an estimate is needed that is precise enough to inform the planning of services and to help to decide what they would cost to deliver. Or the question we might want to answer could be: "does autism affect as many older people as younger people?" For example if the true rate of autism is rising, as surveys of children over recent decades seem to suggest, you would expect fewer cases in older than in younger adults. This turned out to be the question that was of the greatest public interest when the results emerged, although we should emphasize that our study was not designed to answer this question specifically. Given the general interest in this question it proved fortunate that the adult survey began with over 7,000 willing respondents which provided some degree of precision to answer the question—"is autism associated with age?" Had our survey been much smaller we could not have done this.

Adult Autism Survey

So now you are probably wondering how we drew up our sampling list, and how we examined adults to decide which ones had autism? And how did we do this for adults of all levels of ability? Starting with the lists, we actually had to draw up two different lists because of the problem of range of abilities. Most adults live in what we call private households, such as an apartment, or just a room with shared bathroom and cooking facilities, or a house. But some adults with very low intellectual ability cannot care for themselves unaided and either live in a household together with a carer or in some kind of institution. We did this survey throughout England. The first of our two lists, covering adults able to manage without a carer, started out with a list of all postal delivery addresses (excluding large ones), known as the "small postcode address file." In Britain, the Post Office has a list of all the addresses in the country to which a letter can be sent. This list is available to survey research organizations for selecting addresses for surveys. Such a list is not available in the USA. In England postal delivery workers are paid the equivalent of about 50 cents each time they update the list with new information—for example with a new house or apartment. Therefore the list is kept very up-to-date.

Addresses from a list of addresses throughout England were selected at random (to save on the time and travel costs of interviewers this was done in randomly chosen postal areas). Trained survey interviewers then visited the addresses and after excluding those that were found to be unoccupied (and overlooked errors in the list) they tried to make contact with an adult resident. If there was more than one adult living in the household, one was chosen at random and asked to take part. So we are

confident that every adult living in a private household[5] in England when the survey was taking place had a known chance of being counted in the survey. About 59 % of those asked agreed to participate (we were able to run checks to compare those who did and did not agree to take part so that we could make adjustments to allow for differences, or "bias," in the sample (Brugha et al., 2011)). For example, we found that younger men were least likely to cooperate when asked so we were able to make adjustments to our final results—the so-called "weighted prevalence."

Fortunately for us, our second list already existed in the form of three population registers for adults with intellectual disability (as explained recently in a report on this second group (Brugha, Cooper, et al., 2012)). These registers cover about 1.5 million adults in three places in England, including rural, urban and large metropolitan areas. Our plan was to choose 500 adults from these three registers and examine them as we had done in the household study. But one potential pitfall from sampling from two lists is that someone could get counted twice, i.e., was in both lists (we also did some elaborate checks for adults who might have been left out of both lists, such as young adults living in college or in military establishments (Brugha, Cooper, et al., 2012)). We completed the study of the household sample in 2007. When we then began in 2010 to examine adults chosen (at random) from the intellectual disability registers we checked each one living in a private household to see if they could have answered the questions we asked in the 2007 sample and excluded those who could because otherwise someone of the same ability could have been included in both parts of the survey.

Autism is a developmental disorder and clinicians rely heavily on information on early development, such as the age at which the child begins to use language. In clinics, like the first author's adult clinic, we try to interview a parent but our older adult patients often no longer have a living parent or one with good enough memory of their early childhood. Child surveys have had it real easy as there is nearly always an adult available but our survey included adults aged 60, 70, 80 and older! So the search was on for a method that could be applied directly to all adults including elderly adults who do not have a living parent or suitable informant. A further issue was how did we clinically examine adults across all ability levels to decide who were autistic in an equivalent way? This was not easy because no one had really developed and tested methods for adult surveys of autism.

We were fortunate in having advice and excellent training in the use of the Autism Diagnostic Observation Schedule (ADOS; (Lord, Rutter, DiLavore, & Risi, 2002)). The ADOS includes modules for all ability levels from the preverbal (child), module 1, to the older adolescent and adult, module 4. In the first part of the survey in private households we used module 4 and in the second part, in the intellectual

[5]This list includes adults in temporary accommodation classed as "homeless" but not the very small number "living rough," which we did study in an earlier survey (Gill, Meltzer, Hinds, Petticrew, & Office for National Statistics Social Survey Division, 1996) that did not include an autism assessment.

disability registers, we mainly used module 1 (adapted for adults). For the more able adult in an institution who understood and could answer questions we used ADOS module 4. Thus we were able to combine the results of both modules to determine which adults met criteria for autism from the least able to the most able. The authors recommend a total score of 10 or more ("10+") on module 4 and of 12 or more ("12+") on module 1 in order to judge that a person meets criteria for autism. We checked these thresholds in our surveys in separate interviews with parents and carers using the Autism Diagnostic Interview-Revised (ADI-R (Lord, Rutter, & Le Couteur, 1994)) and a longer more detailed interview that also checks for other developmental disorders called the Diagnostic Interview for Social and Communication Disorders (DISCO (Wing, Leekam, Libby, Gould, & Larcombe, 2002)). We found that the same thresholds were appropriate for both parts of the survey (Brugha, Cooper, et al., 2012; Brugha, McManus, et al., 2012). For this extra work we purposively sampled individuals with a high risk of autism and a random sample of individuals with a low risk of autism.

Another important difference between the two parts of the survey was that in the intellectual disability sample, where we had originally wanted to examine 500 adults, we were able to use the appropriate ADOS module in all consenting cases. But our adult household survey covered over 7,000 adults across the whole of England. As mentioned earlier we had a two-phase design (a survey of a survey) but we needed some good questions in the first phase to help us decide who is more likely to be autistic and therefore more worthwhile choosing to undergo these more detailed clinical assessments. This is explained in greater detail elsewhere (Brugha et al., 2011) so here we will just concentrate on the headlines. Essentially, we needed a questionnaire an adult could fill out themselves that helps identify who is more likely to have autism. The obvious candidate was a very popular questionnaire that has also been available for anyone to complete online for many years (http://www.wired.com/wired/archive/9.12/aqtest.html) better known in the academic world as the Autism Spectrum Quotient (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001) or "AQ." We worked with the authors of the AQ to shorten this down from 50 to 20 questions and got permission to include them in the third adult mental health household survey of England that was in the field in 2006–2007 (McManus et al., 2009). That survey had a two-phase design: phase one was managed by one of us, SM, at NatCen (http://www.natcen.ac.uk/) and phase two by TB at the University of Leicester (http://www.le.ac.uk/). The phase two, clinical phase, examinations covered psychosis, anti-social and borderline personality disorder and, for the first time, autism. As explained elsewhere (Brugha et al., 2011) the phase two autism estimates from the clinical evaluations were weighted (back to phase one) to provide estimates for the household population. We also got funding to extend the survey to adults identified through the intellectual disability registers in England (Brugha, Cooper, et al., 2012) in order to obtain combined overall rates for adults of all ability levels.

Adult Survey Findings and Interpretation

In this chapter we are going to spare you the finer technicalities (available in our publications referred to already) and start looking at the main results and discussing what they mean. We start with the 2007 household survey because adults living in the community are less likely to be getting help and attention from services (Brugha et al., 2011). In the first phase of the household survey 7,403 adults completed the 20 question AQ and many other questionnaires relating to their health and life circumstances. We selected 849 for a clinical assessment and the ADOS-4 was completed on 618 adults.

It turned out that the AQ was not very good at picking out potential autism cases: at best sensitivity was 74 % (the proportion of true autism cases picked up) and specificity was 62 % (the proportion of people who did not have autism and were correctly identified as not having autism). Therefore we found in the second phase very few people, 19 in fact, who met criteria for autism. In spite of this, we were still able to tell how many had autism overall and to look at factors that might be associated with having the condition (Brugha et al., 2011). We did not expect any of our measures to neatly divide the world into people with and without the condition. When compared with how often they occurred, the AQ scores (ranging from 0 to a maximum of 20) showed that the majority of people had a score somewhere in the middle of the scale—between 3 and 12—and very few had a low score 0–2 or a very high score, 12+. Thus there was no obvious extreme "bump" (peak) at the top or bottom of the AQ scores (for example IQ shows a bump at the lowest scores accounted for by people born with intellectual disability). The scores on the ADOS-4 were similar, with no obvious separation for the group with autism, but the distribution of scores differed from the AQ in that most of those examined scored zero.

Very few, about 1 % of adults, had a score of 10 or more, which is the score recommended for a diagnosis of autism (Lord et al., 2002) on module 4 of the ADOS. But almost 1.5 % of the population scored at a lower threshold of 7 or more; just over half a percent scored at a higher level of 13 or more (Brugha et al., 2011). This is how we concluded that autism affected 1 in 100 adults sufficiently "able" to live independently in private households and answer survey interview questions. All of this suggests that having autism is a question of degree and not an either/or finding. But planners still want a number for how many cases there are, in preference to an average score, and most of us prefer a number so that we can make comparisons between groups of people easy to understand, which is what we did next.

The most obvious comparison was between rates in adult men and women. We know in childhood that boys have been consistently more often affected (or identified) than girls. We found the same result in our general population household study: just under 2 % of men hit the 10+ threshold and only 2 per 1,000 (0.2 %) women, which is ten times fewer than for men. This gender difference is so great that we have to wonder whether the ADOS-4 is less good at picking up autism in women. In fact, there is growing interest in the research community in the possibility that there are many "missed" cases of autism in women because the focus for the last 50

years has been so heavily loaded to the male presentation of symptomatology. If we are to consider the historically presented male:female ratios of autism one sees that in individuals with autism coupled with intellectual impairment the rates are 4:1 males to females. However in individuals with autism who do not have clinical levels of intellectual impairment the rates are around 9:1. Is it really the case that intellect in women is a protective factor against having autism? Or are we missing a significant proportion of more able women with autism for other reasons? Whilst there is a popular theory currently that autism is an extreme form of the male brain, and biological factors explain the gender differences (Baron-Cohen et al., 2011) this does not seem to explain the intellect-based differences. Some authors suggest that women with autism are "masked" by other conditions, such as eating disorders (Rastam, Gillberg, & Wentz, 2003), depression or anxiety disorders, or borderline personality disorder (New, Triebwasser, & Charney, 2008). This may be the case, as adult psychiatry services are more likely on the balance of probability to assume a women presenting for assessment has a mood or personality disorder rather than a "male" condition such as autism. Similarly, as suggested above, existing diagnostic tools are developed to target the "typical" male presentation of symptoms and may therefore miss the female presentation, which research is indicating is different to that of males (Lai et al., 2011). Epidemiological studies in the future may need different tools and approaches to establish whether there is, in fact, a hidden population of women with autism.

The result that attracted most interest was the effect of age—or the apparent lack of an obvious age trend. As a clinician the first author was expecting to find lower rates of autism in older people because it is his impression, talking to affected adults, that increasing age and maturity brings some degree of improvement and because the descriptions given by parents seem to indicate that things were a lot worse in childhood. And of course the theory of an autism epidemic would predict that the proportion born with autism 50–80 years ago is far less than it is now. But we did not find that. In fact what we found when examining the survey data was that there was no obvious association between having autism and age. The likelihood of having autism appeared to go down very slightly as people got older. Expressed in more technical language: the predicted probability of being an autism case suggested a very gradual decrease with increasing years, although the trend was not significant; thus for every extra year of age the odds of being a case would decrease by 1 %.

Current research suggests that the causes of autism are strongly genetic but that there remain some environmental influences. If there were major environmental effects that had begun or increased in recent decades you would expect those to be associated with lower autism rates among older people. Instead it seems more likely now that the possible environmental causes are not actually new causes, which suggests that they are factors that have been in our environment not just in the last 20 or 30 years but actually with us in the last 50–80 years and probably longer. This finding means that scientists need to be broader in their search for environmental causes of autism: it cannot be all down to new factors like the spread of cellular telephones, computer games, use of the internet or the introduction of new medicines and

vaccination programs (although our study cannot rule out small hard to detect effects for any of these factors).

The results of the survey also confirmed two other important factors long thought to be associated with autism, low IQ (Brugha et al., 2011) and epilepsy (Rai et al., 2012). Adults with no educational qualifications were twice as likely as those with a school leaving qualification to have autism. Adults with a university degree only had a five times lower risk compared to those with just a school leaving qualification. Verbal IQ was clearly reduced in our autism cases—indeed none of our cases in the community had a verbal IQ score greater than 100. Most of my clinical colleagues and I know adults with autism who are highly intelligent—and for example, have completed a PhD. But the survey results suggest that they are rare and exceptional. What could make sense is that having a Ph.D. means that you are more likely to stand out if you are autistic and more likely to be encouraged to obtain a clinical assessment (and smart enough to ensure that you make it to an assessment clinic). This finding also made us realize how important it was for us to extend the survey, as we have done since, to include adults at the lowest levels of intellectual ability.

What about the lives of the people we found with autism? We compared the people we found to have autism with the remainder of the population in our sample. Here too there were surprises. We were expecting to find hardly any in a marriage or cohabitating, and most to be unemployed. Neither factor stood out quite as strongly as that. We found that adults with autism were four times more likely than people without autism to be single than in a long term relationship. More surprisingly, there was no association with being unemployed. The important policy message here is that our focus should not just be about getting adults with autism into work but taking a closer look at whether autism places them at a disadvantage in the workplace. We also need to understand how so many have already managed to hold down a job and to look at the quality of their working lives for signs of autism-related vulnerability and exploitation (which we did not ask about in this survey) as well as looking for good news messages about success in the work place.

Housing is also very important in our lives. What stood out was that adults with autism, compared to adults who do not have autism, are far are less likely to be buying their home or renting from a commercial (private) owner of the property they live in and are more likely to be relying on local government support for housing. It also appears that they are somewhat more likely than people without autism to be living in a low income, more deprived neighborhood. Taken together, the social circumstance of adults with autism is relatively poor compared to the rest of the adult population.

And finally, what about the services that adults with autism receive—diagnostic recognition and support services? In England, like in most western European countries, no one has to pay for health care when they go looking for it (in Great Britain they will have already paid for it through their taxes especially if they are in paid employment). The most astonishing finding of all was that none of the cases of autism we found in our community survey had been given an official diagnosis. They were entirely unrecognized; only in one case was a family member thinking of raising with the doctor the possibility that her relative might have a condition

such as Asperger syndrome. Bear in mind that the household survey in 2007 did not include adults with significant intellectual disability (who we have gone on to study since). We also found it quite difficult to work out if adults with autism in the community were using services or had welfare entitlements. What stood out as significant was that they did not know how to answer questions about welfare entitlements (which may not come as a surprise to anyone working with adults with autism because typically they struggle to manage money sensibly and to budget and pay off debts on time). In all our other surveys since 1993, looking at adults with mental disorders, in each case we have found that those with a mental disorder told us they were more likely to be getting health care specifically for mental health reasons either from their family doctor or from community and hospital services than people without that disorder. The autism group is the first and only group that this does not seem to apply to. Being undiagnosed goes with being untreated as well. This is important and needs to be studied further and, of course, acted upon.

Adults with Intellectual Disability

We will now look at the second part of our project. Research on children with ASD suggests that up to a half will also have difficulties in learning. Research on adults who had learning difficulties while growing up shows that most manage to live independent lives as adults without having to rely on someone else to care for them. This also appears to apply to our 2007 adult autism survey findings in the household population where those with autism appear to be managing to live independently, although at a lower than average level of ability. What about adults clearly recognized as having more severe and significant intellectual disability seen in our latest 2010 survey?

At the time of writing, the findings of the more recent work in 2010 on adults with intellectual disability (Brugha, Cooper, et al., 2012) have not yet appeared in a peer refereed scientific journal and we are still studying them, so that these can only be described in summary form here. We assessed 276 adults in this ability range. A high proportion of the adults we found through the intellectual disability registers had not developed any receptive language skills and the assessment required the cooperation of carers (who have a very difficult role and may in part explain why some chose not to take part in the research). But adults in this very low ability range are a very small part of the overall population—less than half of 1 %. We also had to go through quite elaborate consent procedures. Also, as expected, rates of autism were much higher in this very low ability group. And when we added the results of the two surveys together (2007 and 2010) the overall rate of 1.0 % in the 2007 household survey hardly increased, coming close to 1.1 %[6] in the combined populations. As in the household survey the autism rate was higher in males, but that gen-

[6]The range for this estimate, based on a 95 % confidence interval, is between 0.3 and 1.9 % (Brugha, Cooper, et al., 2012).

der difference was not as great. The rate of autism was also highest in those with the very lowest ability levels. The presence of ASD appeared to be unrelated to ethnic grouping. And finally there was also little to suggest an association with age—rates were similar in older as in younger intellectually disabled adults. Taking the two surveys together the clearest association throughout is that between autism and ability level—the less able are clearly more likely to have ASD and more likely to need care.

Lots of people have asked about what "types" of ASD we found in this project: how many cases had Asperger syndrome, autism, high functioning autism, and so forth? We don't know. This is because the adult survey approach does not give us the fine-grained information on early development of the type that can be collected by specialist autism teams in clinics. And in line with the changes expected in DSM-5 (http://www.dsm5.org/ProposedRevisions/Pages/proposedrevision.aspx?rid=94), we agree that those distinctions about subtype do not stand out in the evidence we have about variability in autism. Nor do they seem to help with treatment recommendations. What we think matters most in deciding on care and treatment, taking account of the care the adult already has, is the person's overall ability level and the presence of other conditions like epilepsy, and problems with use of drugs and alcohol, risk of self harm and of suicide, all of which we plan to look at in the coming months and years using our survey data.

Concluding Remarks

The work described in this chapter shows that it is possible to study autism among the adult population using similar methods to those used to study other mental disorders. It is vital that others undertake similar work elsewhere. There is no previous literature with which to compare our findings. For many the most surprising and concerning finding is that there are so many adults with autism in the community without any recognition or diagnosis, even in a country with health care that is free when needed for everyone. Only those adults with significant intellectual disability were known to also have ASD.

Under-recognition of autism in adults poses an enormous public health challenge. Just a few countries are beginning to address this. In England an autism-specific Act of Parliament is being followed up with a national strategy to improve understanding, recognition and support for adults with ASD (Department of Health, 2010). A key component of this is training professionals who are in caring roles to be aware of how autism manifests itself in adults and supporting adults through recognition, where appropriate, with diagnosis and through understanding and adapting to the kinds of disability that affect adults on the autism spectrum. Outside of the United Kingdom there appears to be relatively little evidence of this kind of approach although the authors are aware of positive initiatives in the Netherlands and Sweden, within Europe.

We would argue that there is a need for training, not just research. We know enough to be taking action and not just waiting for answers from research. The finding in our survey of under diagnosis and of lack of treatment needs to be thought of in terms of availability of support and treatment that is seen as effective. At the time of writing, the UK National Institute for Health and Clinical Excellence (NICE) is finalizing a clinical guideline for adults with autism (http://guidance.nice.org.uk/CG/Wave23/1#keydocs). This includes detailed systematic reviews of screening tests, diagnostic methods, medical and psychological approaches to treatment, and information on the kinds of service structures that need to be developed, albeit within the UK National Health Services, for health and social care.

Discovering how many adults in the community have autism should be about more than counting how many. It should be about opening up to providing help and care. The potential benefits are only just becoming apparent.

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Chapter 16
A Systematic Review of Psychosocial Interventions for Adults with Autism Spectrum Disorders

Lauren Bishop-Fitzpatrick, Nancy J. Minshew, and Shaun M. Eack

Introduction

Autism spectrum disorders (ASD) are chronic congenital neurological conditions which are characterized by abnormal or impaired development in social interaction and communication and a restricted repertoire of activity and interests (American Psychiatric Association, 2000). Currently, it is estimated that ASD affect approximately 1 in 88 children (Centers for Disease Control and Prevention, 2012), 70 % of whom are less than 14 years old (Gerhardt & Lainer, 2011), which indicates that the number of adults with ASD will be increasing dramatically in the coming years. However, relatively little work has investigated the best and most effective ways to treat adults with ASD in the community.

Since autism was first described by Kanner (1943), extensive research has documented its presentation, etiology, and treatment. Individuals diagnosed with an ASD typically experience difficulty in three main areas: (1) communication; (2) social interaction; and (3) flexibility of thinking and behavior (Wing & Gould, 1979).

L. Bishop-Fitzpatrick, M.S.W. (✉)
University of Pittsburgh, School of Social Work, 2117 Cathedral of Learning, 4200 Fifth Ave., Pittsburgh, PA 15260, USA
e-mail: lef35@pitt.edu

N.J. Minshew, M.D.
Western Psychiatric Institute and Clinic, University of Pittsburgh, School of Medicine, Webster Hall, Suite 300, 3811 O'Hara Street, Pittsburgh, PA 15213, USA
e-mail: minshewnj@upmc.edu

S.M. Eack, Ph.D.
University of Pittsburgh, School of Social Work, 2117 Cathedral of Learning, 4200 Fifth Ave., Pittsburgh, PA 15260, USA

Western Psychiatric Institute and Clinic, University of Pittsburgh, School of Medicine, Webster Hall, Suite 300, 3811 O'Hara Street, Pittsburgh, PA 15213, USA
e-mail: sme12@pitt.edu

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In order to address these difficulties, families often seek services for pre-school and school-aged children both inside and outside of the United States special education system (Thomas, Morrissey, & McLaurin, 2007). However, federal regulation mandates that individuals are no longer able to receive special education services after age 21 under the Individuals with Disabilities Education Act (Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011). Given that approximately 70 % of people with ASD are currently less than 14 years old (Gerhardt & Lainer, 2011), the number of adults with ASD, and consequently the number of people who do not qualify for special education services, will increase dramatically in coming years. This is particularly concerning given that a recent study reported that the lifetime per capita societal cost of autism is $3.2 million (Ganz, 2007). More importantly, the areas of lifelong condition management that contribute most to the per capita cost of ASD are adult care and lost productivity, two aspects of living with an ASD which relate specifically to the approximately $1.9 million per capita spent after affected individuals age out of the United States special education system. Despite these findings, relatively little is known about effective interventions for adults with autism that might serve to facilitate positive outcomes for this group.

Historically, the prognosis for individuals diagnosed with ASD in childhood has been poor: Levy and Perry (2011) found across studies that prior to 1990, only 25 % of such individuals were classified as having "good" or "fair" outcomes based on an operationalized definition of a "good" or "fair" outcome for an adult with ASD as having achieved some form of formal education, maintaining employment, living independently, and sustaining social relationships. Currently, the state of affairs is not greatly improved. According to Seltzer, Shattuck, Abbeduto, and Greenberg (2004), very few adults with ASD live independently, get married, go to college, work in competitive jobs, or develop large social networks, and most individuals with ASD remain dependent on their families or on professional service providers. Levy and Perry (2011) found across studies that an average of 50–60 % of adults with ASD leave school without educational or vocational credentials, 76 % are unable to find work, and 90–95 % are unable to establish long-term romantic relationships or meaningful friendships. Beyond this, adults with ASD often suffer from comorbid psychiatric conditions, such as depressive and anxiety disorders, at potentially higher rates than both the general population and individuals with other developmental disabilities (Bradley, Summers, Wood, & Bryson, 2004; Brereton, Tonge, & Einfeld, 2006). This body of literature indicates that only a minority of diagnosed individuals are able to transition successfully to adulthood in the traditional sense, while an even smaller minority of the same individuals would be considered successful among those not affected by ASD.

Because many of the problems associated with ASD in childhood persist into and often intensify in adulthood, psychosocial interventions that target communication, social interaction, and flexibility of thinking and behavior, similar to those reported in reviews of the child ASD literature (Matson, Benavidez, Compton, Paclawskyj, & Baglio, 1996; Odom, Boyd, Hall, & Hume, 2010), may prove efficacious in the treatment of adults with ASD. Certainly, companies that cater to families and to agencies that serve adults with autism market a plethora of costly

intervention programs and self-help books that promise to help this group of people in any number of ways. However, empirical evidence supporting their effectiveness is often unavailable.

The investigation of psychosocial interventions for adults with ASD is a relatively new area of research. However, work in this area is moving in a promising direction. For example, researchers in England have recently developed a psychosocial intervention protocol which utilizes a computer-based program to target impairments in social cognition (Golan & Baron-Cohen, 2006), while researchers in Spain have developed a protocol to reduce stress and more broadly improve quality of life (García-Villamisar & Dattilo, 2010). In addition to psychosocial interventions, researchers have also examined the efficacy of pharmacological treatment on adults with ASD, and while only five double-blind, randomized controlled trials (RCTs), have been conducted with modest sample sizes ($M = 30$), they have provided some evidence for the efficacy of risperidone, fluvoxamine, and haloperidol in the treatment of adults with ASD (Broadstock, Doughty, & Eggleston, 2007). Despite a limited but growing evidence base, a recent study reported that the percentage of adolescents and adults with ASD who were taking at least one psychotropic medication increased from 70 to 81 % over a four and a half year period (Esbensen, Greenberg, Seltzer, & Aman, 2009).

While evidence is accumulating regarding the benefits of psychosocial interventions for adults with ASD, there have been no systematic reviews or meta-analyses conducted to summarize the cumulative evidence base for these approaches. Therefore, we conducted a systematic review to examine the evidence base of psychosocial interventions for adults with ASD in order to determine common themes in treatment approaches and evaluate the evidence of their efficacy.

Method

Literature Search

An extensive literature search was conducted in order to locate published studies documenting interventions for adults with ASD. In order to conduct this literature search, keyword searches were performed over a 4-month period of abstracts available in the PsycINFO, Medline, and Web of Knowledge databases published between January 1950 to September 2011, using the search terms "autism," "Asperger's," or "pervasive developmental disorder" combined with "adult" or "adolescent" combined with "intervention," "treatment," or "therapy." Additionally, abstracts of articles published online ahead of print between July 2011 and September 2011 were searched to identify recent pre-publication studies in five journals: *The Journal of Autism and Developmental Disabilities, Autism, Research on Autism Spectrum Disorders, Research in Developmental Disabilities,* and *The Journal of Intellectual Disability Research*. These searches revealed 1,217

published reports. Additionally, references of relevant studies were examined for additional studies to be included in this research.

Abstracts retrieved from database searches were then reviewed, and studies were included for further consideration if they reported a psychosocial intervention for adults with ASD. From these abstract searches, studies were then examined and included in this review if they (1) were conducted using a single case study, non-controlled trial, non-randomized controlled trial, or RCT design that reported pre-test and post-test data, (2) reported quantitative findings, (3) included participants ages 18 and older, and (4) included participants with ASD. In total, 13 studies assessing psychosocial interventions for adults with ASD were found. Of the 1,204 studies that did not meet inclusion criteria for this review, only two reported findings from psychosocial intervention studies for adults with ASD. Of these two studies, one was excluded because the sample of participants also included children as young as 9 years old (Herbrecht et al., 2009) and the other was excluded because it did not report quantitative findings (McClannahan, MacDuff, & Krantz, 2002). Overall, the largest category of excluded studies were those that described or classified the symptoms and challenges faced by individuals with ASD ($k = 574$). There were also a substantial number of studies that sought to expand upon knowledge of the genetics and neurobiology of ASD ($k = 184$). Other categories of excluded studies included non-empirical studies, including book reviews ($k = 138$), followed by empirical studies of adults only ($k = 97$), measurement studies ($k = 80$), studies of psychosocial interventions for children and adolescents ($k = 73$), review articles ($k = 41$), pharmacological studies ($k = 35$), prevalence studies ($k = 23$), studies of the effect of autism on families ($k = 22$), studies of services available for people with ASD ($k = 16$), studies of adult outcomes for children diagnosed with ASD ($k = 8$), and unrelated studies ($k = 10$).

Study Coding Procedures

After assembling the studies included in this review, theoretically and/or methodically relevant characteristics and variables were recorded. These included the demographic characteristics and IQ of participants. For studies which examined other populations, only demographic and IQ information for the ASD sample was obtained. Finally, the design of each study (i.e., single case study, non-randomized controlled trial, non-controlled trial, or RCT) was recorded.

Study Analysis

After coding the different characteristics of each study, the main outcomes were recorded. In order to ascertain the relative effectiveness of the psychosocial interventions described in the studies, Cohen's d was calculated using mean change

divided by pooled standard deviation. For longitudinal controlled studies, aggregate Cohen's *d* of differential efficacy for the experimental versus control group for the study was calculated using within group standardized change for each group and subtracting the effect sizes of the control group from the treatment group. For uncontrolled pre–post studies, Cohen's *d* was calculated using within-group standardized change for the treatment group. For studies for which only *Z* scores were reported, Cohen's *d* was computed by converting *Z* to *r* and *r* to *d* (Hedges & Olkin, 1984). Cohen's *d* was not reported for single case studies. In all cases, Cohen's *d* was computed using methods which align with best practice (Littell, Corcoran, & Pillai, 2008; Rosenthal, 1984).

Results

A total of 13 studies were identified which evaluated psychosocial interventions and met inclusion criteria. A list of studies and their characteristics are detailed in Table 16.1. The included studies were diverse in their methodologies and represented numerous categories of interventions. A total of five were single case studies, four were RCTs, three were non-randomized controlled trials, and one was an uncontrolled pre–post trial. Six studies evaluated the efficacy of social cognition training, five studies evaluated the efficacy of applied behavior analysis (ABA) techniques, and two studies evaluated the efficacy of other types of community-based interventions. We considered numerous ways to organize the presentation of these studies, including around outcome. In the end, we viewed organization around the type of intervention studied as most appropriate, given that some investigations examined outcomes that were not clearly connected to their intervention targets (e.g., examining the cognitive effects of a supported employment program). While such studies are quite valuable, organizing them around the outcomes they report could give readers the false impression that such interventions are specifically designed to target those outcomes, which is not always the case. Consequently, we decided that organizing the review around the nature of the intervention (as opposed to its effects) was the most accurate way to represent this treatment literature.

Social Cognition Training

Unlike what is indicated in systematic reviews of the child ASD literature (Matson et al., 1996; Odom et al., 2010), more included studies focused on social cognition training than on ABA techniques (Baker et al., 2005; Bölte et al. 2002; Faja et al., 2012; Gantman, Kapp, Orenski, & Laugeson, 2012; Golan & Baron-Cohen, 2006; McDonald & Hemmes, 2003; Moore, 2009; Rehfeldt & Chambers, 2003; Shabani & Fisher, 2006; Trepagnier et al., 2011; Turner-Brown et al., 2008). The six social cognition training studies (Bölte et al. 2002; Faja et al., 2012; Gantman et al., 2012;

Table 16.1 Characteristics of psychosocial intervention studies for adults with autism spectrum disorders

Study	*n*	Mean age	% Male	Mean IQ	Method	Type of intervention	Outcome category	Cohen's *d*
Baker, Valenzuela, and Wieseler (2005)	1	–	100	–	Case study	ABA	Repetitive behavior	–
Bölte et al. (2002)	10	27.2	100	104.2[a]	RCT	Social cognition training	Social cognition	3.59
Faja, Webb, Jones, Merkle, Kamara, Bavaro, Aylward, and Dawson (2012)	13	22.4	–	116.3[a]	RCT	Social cognition training	Face and house recognition	0.75
Gantman, Kapp, Orenski, and Laugeson (2012)	17	20.4	70.6	96.7[a]	RCT	Social cognition training	Deficits in social interaction	1.209
García-Villamisar and Dattilo (2010)	71	30.81	57.7	–	RCT	Other	Adaptive behavior	0.83
García-Villamisar and Hughes (2007)	44	25.52	72.7	–	Non-randomized controlled	Other	Cognitive functioning	0.45
Golan and Baron-Cohen (2006), Experiment 1	65	28.72	76.73	109.05[b]	Non-randomized controlled	Social cognition training	Cognitive functioning	0.25
Golan and Baron-Cohen (2006), Experiment 2	39	24.95	84.6	101.1[b]	Non-randomized controlled	Social cognition training	Social cognition	0.14
McDonald and Hemmes (2003)	1	18	100	–	Case study	ABA	Communication	–
Moore	1	18	100	–	Case study	ABA	Repetitive behavior	–
Rehfeldt and Chambers (2003)	1	23	100	–	Case study	ABA	Repetitive behavior	–
Shabani and Fisher (2006)	1	18	100	–	Case study	ABA	Adaptive behavior	–
Trepagnier, Olsen, Boteler, and Bell (2011)	16	19.77	93.8	109.4[a]	Non-controlled	Social cognition training	Communication	0.58
Turner-Brown, Perry, Dichter, Bodfish, and Penn (2008)	11	36.27	90.91	112.07[a]	Non-randomized controlled	Social cognition training	Deficits of social interaction Social cognition	0.27

[a]Full intelligence quotient (IQ)
[b]Verbal intelligence quotient (VIQ)

Golan & Baron-Cohen, 2006; Trepagnier et al., 2011; Turner-Brown et al., 2008) sought to improve participants' ability to grasp social cues and, as a consequence, improve social functioning. Notably, four out of six of the studies in this category utilized computer-based training, indicating a trend toward the utilization of computer software for this specific type intervention (Bölte et al. 2002; Faja et al., 2012; Golan & Baron-Cohen, 2006; Trepagnier et al., 2011). Additionally, three out of six studies concentrated on improving Theory of Mind (Bölte et al. 2002; Golan & Baron-Cohen, 2006; Turner-Brown et al., 2008). With one exception (Trepagnier et al., 2011), which found only a trend toward improvement in social cognition, all social cognition training interventions saw significant improvement in participants' scores on included measures. The overall effect size (*d*) for the social cognition training studies ranged broadly from 0.14 to 3.59 for improving domains of social cognition, communication, and social skills.

Three of the six social cognition training studies utilized interventions based on the theory of mind theory of autism (Baron-Cohen, Leslie, & Frith, 1985). Bölte and colleagues (2002) designed a computer program to test and train participants in the capacity to detect seven facially expressed emotions (happiness, sadness, anger, disgust, fear, surprise, neutral) using either a picture of the whole face or a picture of the eyes. The authors found that participants in this intervention performed better on Baron-Cohen's Reading the Mind in Eyes (Baron-Cohen, Wheelwright, Hill, Raste, & Plumb, 2001) and Reading the Mind in Face (Baron-Cohen et al., 1996) tasks. Golan and Baron-Cohen (2006) designed and tested a computer-based training program designed to teach people with ASD how to correctly recognize facial emotions. They found significant improvement on measures of face and voice recognition. Finally, Turner-Brown et al. (2008) used a group-based cognitive behavioral intervention that was comprised of three phases (emotion training, figuring out situations, and integration) and designed to improve social-cognitive functioning. The authors found that participants who received the intervention showed significant improvement in theory of mind skills and trend-level improvement in social communication skills. Notably, two of these interventions (Bölte et al. 2002; Golan & Baron-Cohen, 2006) utilized a computer-based protocol to improve theory of mind.

The final three social cognition training studies did not explicitly target theory of mind, but instead used other interventions designed to improve functioning in these areas. Faja and colleagues (2012) reported the results of a study in which participants were randomized to a computerized training program involving either faces or houses and the ability to recognize either faces or houses was tested by asking participants to categorize pictures of faces or houses based on set criteria, such as gender (for faces) or house shape (for houses). The authors found that both participants trained in face recognition and participants trained in house recognition showed improvement on measures of memory of faces and houses. Gantman and colleagues (2012) tested the effectiveness of a caregiver-assisted social skills training intervention (*PEERS for Young Adults*). The authors found that participants reported significantly less loneliness and improved social skills knowledge while their caregivers reported significant improvements in participants' overall social

skills, social responsiveness, empathy, and frequency of get-togethers. Finally, Trepagnier et al. (2011) reported on the development of a computer-based conversation simulation program designed to teach conversational skills to adolescents and adults with ASD. While the authors found that participants generally liked the intervention, the authors did not report any significant level of improvement on psychometric or behavioral measures.

Applied Behavior Analysis

This review identified a total of five studies that utilized ABA techniques. All of the included ABA studies were single case studies. All ABA studies sought to reduce the instances of an undesirable behavior or increase the instances of a desirable behavior. All ABA studies reported positive benefits of treatment, although the maintenance of this benefit varied between studies. Effect size was not reported for the ABA studies, as findings were based on a single subject.

Three studies utilized ABA principles to reduce the instance of undesirable behaviors such as coprophagia (Baker et al., 2005), repeated inappropriate gestures (Moore, 2009), or verbal perseverations (Rehfeldt & Chambers, 2003). Baker et al. (2005) reported on an intervention in which highly spiced, flavorful foods were provided with meals and snacks to reduce coprophagia. The authors found that this intervention variably reduced the frequency of coprophagia for the first 6 months following intervention and completely eliminated coprophagia thereafter. Moore (2009) evaluated a self-management treatment package in which a participant administered positive reinforcement (Diet Cola) as a reward if he was able to achieve an increasing interval without exhibiting stereotypic behaviors (e.g., finger tapping, mouth grabbing, genital touching). The author found that this intervention helped to increase the latency to stereotypic behaviors over time. Finally, Rehfeldt and Chambers (2003) used a reversal (BABAB) design to examine the effects of intervening with mild reprimands (e.g., "you shouldn't talk about sirens so much at work") and reciprocal statements (e.g., "you sure don't like those sirens, do you?") when the participant perseverated verbally. The authors found that this intervention was effective in decreasing the number of verbal perseverations.

Two studies used ABA principles to increase the instances of desirable behaviors such as social interaction (McDonald & Hemmes, 2003) and compliance with medical procedures (Shabani & Fisher, 2006). McDonald and Hemmes (2003) reported on an intervention in which token reinforcers were used to increase the instance of verbal initiating with adult staff in a classroom setting. The authors found that spontaneous initiating increased over the course of the intervention. Shabani and Fisher (2006) evaluated an intervention for a person diagnosed with both autism and diabetes that was designed to make glucose monitoring possible. This intervention used stimulus fading, which consisted of gradually increased exposure to a needle, combined with differential reinforcement to increase the percentage of successful blood glucose monitoring trials. The authors found that the percentage of successful blood glucose monitoring trials improved over the course of the intervention.

Community-Based Interventions

Two studies examined community-based intervention programs. These programs included a supported employment program (García-Villamisar & Hughes, 2007) and a leisure program (García-Villamisar & Dattilo, 2010). García-Villamisar and Hughes (2007) examined the effects of a classic, community-based supported employment program on measures of cognitive functioning. They found that participants enrolled in the supported employment program exhibited better executive functioning on cognitive measures than a comparison group of unemployed participants. García-Villamisar and Dattilo (2010) examined the effects of a leisure program (a group recreation program where participants had access to games, crafts, group activities, community events, and socialization) on quality of life and stress. The authors found that participants in the leisure program reported significant decreases in stress and significant increases in quality of life. Effect sizes for these two studies were 0.45 for improving cognitive functioning and 0.83 for improving adaptive behavior, respectively.

Discussion

Current estimates indicate that approximately 1 in every 88 children has ASD (Centers for Disease Control and Prevention, 2012) and that approximately 70 % of identified individuals with ASD are under age 14 (Gerhardt & Lainer, 2011). This cohort of children is rapidly approaching adulthood and will need effective treatment and services once they age out of entitlement services provided within and through the United States special education system. Studies have indicated that individuals with ASD have challenges and difficulties as they transition to adulthood (Howlin, Goode, Hutton, & Rutter, 2004), which are not being sufficiently met by the available treatments and services for adults with ASD (Shattuck et al., 2011). Therefore, it is important for the autism research community to be familiar with the current evidence base for psychosocial interventions for adults with these conditions in order to inform future research and treatment.

We conducted a systematic review to examine the evidence base of psychosocial intervention studies for adults with ASD. Of the 1,217 studies retrieved from a comprehensive literature search, only 13 studies met inclusion criteria (i.e., reported quantitative findings, included participants ages 18 and older, and included participants with ASD). The studies represented three main types of interventions (social cognition training, ABA, and a small heterogeneous group of community-based programs) and a range of methodological approaches. Of these 13 studies reviewed, four were randomized-controlled trials, while five were single case studies. As a whole, the studies identified had modest sample sizes, with the greatest including 71 participants and over three-quarters of studies having less than 20 participants.

These characteristics identify methodological limitations in the current evidence base of psychosocial treatment for ASD, yet despite these limitations, all studies in this review reported favorable outcomes and benefits to participants.

The studies detailed in this review addressed many of the core deficits of ASD (i.e., communication, social interaction, and flexibility of thinking and behavior) with considerable success. Beyond this, the included studies often used creative techniques to help adults with ASD address these deficits. For instance, three intervention protocols taught skills to address deficits in communication and social interaction via computer-based training (Bölte et al. 2002; Golan & Baron-Cohen, 2006; Trepagnier et al., 2011), an intervention technique that has been found to be enjoyable for and agreeable to adults with ASD (Trepagnier et al., 2011). However, it must be noted that while such computer-based approaches seem to represent an increasing trend, no evidence currently exists indicating they are more effective than non-computer-based interventions. While all included studies were effective, the social cognition training studies appear to show the most promise as they included the most rigorous methodologies while maintaining adequate power and effect sizes. This indicates a particularly promising direction for future research on psychosocial interventions for adults with ASD, especially those that employ more comprehensive interventions designed to target core information professing deficits and facilitate the generalization of social-cognitive abilities such as perspective-taking and social context appraisal to unrehearsed social situations.

Despite evidence of the benefits of psychosocial interventions for adults with ASD, there are significant limitations to the current evidence base. While we conducted an extensive search of the literature available on psychosocial interventions for adults with ASD since 1950, only 13 studies were found. Due to the small number of studies, we were unable to conduct a meta-analysis of the adult ASD literature. As a consequence, clear estimates of effect size for different types of psychosocial interventions are not available. Effect sizes should also be interpreted with caution, especially for studies with small sample sizes, which comprised the majority of studies. The incongruent nature of outcome measures used in some of the included studies also indicate that the reader should take caution before generalizing the results of included studies. For instance, García-Villamisar & Hughes (2007) used cognitive functioning outcomes, such as the Stockings of Cambridge and Big Circle/Little Circle tasks, to measure the effectiveness of a supported employment program but did not report outcome data on the number of adults with ASD who were employed as a result of the program. Similarly, Golan & Baron-Cohen (2006) reported significant improvement on the Cambridge Mindreading (CAM) Face-Voice Battery, which tests recall of specific questions, photographs, and voice recordings which are specifically taught in the Mind Reading intervention program but did not report significant improvement on other measures for which participants had not been specifically trained. Clearly, there is a potential benefit of effectively treating adults with ASD, but there is a need for continued investigation in this area.

This review of the evidence base for psychosocial interventions in adults with ASD is informative in guiding future studies. The new research conducted on

psychosocial interventions for adults should use more rigorous and adequately powered methodology and carefully select outcome measures which are congruent with the intervention type and research questions. Because the social cognition training protocols appear to show the most promise, there is a significant need to test novel social cognition training approaches which use creative intervention techniques in rigorous intervention studies with larger sample sizes. This will undoubtedly build upon the work that has been conducted in this area to date. While many of the studies described in this review use protocols that could be easily adapted to community-based settings, it is important to note that none of the studies detailed in this review apply lab-tested psychosocial intervention programs to samples within the community. In the future, when research has identified efficacious intervention studies through careful testing, these evidence-based interventions need to be disseminated to the community and adapted to community-based settings in order to test their effectiveness in the day-to-day treatment of adults with ASD. As such, it will be important for interventionists to develop treatments that can not only be tested in academic research settings, but easily disseminated to the community-based programs that serve the majority of adults with these conditions.

While the number of studies which comprise the evidence base of psychosocial interventions for adults with ASD is small, all of the studies included in this review report a positive benefit to study participants. This indicates that psychosocial interventions for adults with ASD will likely be beneficial for this population. However, because this field is in its infancy, researchers have the opportunity to make a significant contribution to the way that adults with ASD are treated by creating and conducting innovative and methodologically rigorous intervention studies which help adults with autism adjust to and thrive in the world in which they live.

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