ADOLESCENTS WITH AUTISM SPECTRUM DISORDER

A CLINICAL HANDBOOK

Edited by
NICHOLAS W. GELBAR

OXFORD

Adolescents with Autism Spectrum Disorder

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PREFACE

Autism spectrum disorder (ASD) continues to receive increased public attention, which has led to major legislative actions supporting research (Combating Autism Act of 2006; Combating Autism Act of 2011; Autism Collaboration, Accountability, Research, Education, and Support Act of 2014) as well as efforts to improve rates of early screening and diagnosis (Learn the Signs, Act Early; Daniel, Prue, Taylor, Thomas, & Scales, 2009). The lifelong implications of ASD are becoming a greater focus of research as young adults with ASD are among the least likely of any disability category to attend college, to be competitively employed, or to live independently (Newman et al., 2011; Taylor & Seltzer, 2011). These outcomes have caused the Interagency Autism Coordinating Committee (2009; 2013) to prioritize research on adolescents and young adults with ASD.

This book seeks to synthesize the current state of the research on adolescents and young adults with ASD in order to provide a resource for researchers and clinicians working with this population. Adolescence is a challenging stage for all individuals, but especially those with ASD. Individuals with ASD face a major shift in available services as they exit the K–12 school system while also facing the general challenges of emerging adulthood (Arnett, 2000), including forging an identity, pursuing a career, and living in an increasingly complex social world. These increased demands, coupled with the heterogeneity across individuals with ASD, preclude a one-size-fits-all approach to providing support and services for this population. This requires that multiple disciplines be involved to support individuals as they make this transition.

Therefore, the contributors to this book represent a wide range of disciplines, and each of their chapters provides guidance to individuals in their discipline, while also providing relevant information for current and future professionals from other disciplines as well as for parents/caregivers. The book is organized into three parts. The first part discusses the experiences of adolescents and young adults with ASD from a medical/clinical perspective, while the second part addresses the educational experiences of this group. The third part discusses considerations concerning two special populations of adolescents/young adults with ASD: women with ASD and college students with ASD.

The first part of this book consists of the first five chapters. Gelbar and Volk in Chapter 1 discuss the nature of ASD, its prevalence, and considerations for providing diagnosis in adolescents/young adulthood. They also summarize the current research concerning the outcomes attained by this population. Nowinski, Milot, Gold, and McDougle summarize the pharmacological and non-pharmacological treatments for common psychiatric concerns facing adolescents with ASD, in Chapter 2. Dai and Eigsti in Chapter 3 explore the research concerning the nature of the executive function difficulties faced by this population, which underlie many of the other challenges they face. In Chapter 4, Mazurek discusses the impact of and treatment for anxiety in adolescents with ASD. Conner, DeVries, and Reaven discuss the research on the use of cognitive-behavior therapy with adolescents and young adults with ASD in Chapter 5. Their chapter also addresses how traditional cognitive behavioral therapy (CBT) approaches have been adapted for this population.

The second part of this book focuses on how to support the educational needs of this group, and consists of five chapters. Wehmeyer and Shogren in Chapter 6 provide an overview of the construct of self-determination, its relationship to young adult outcomes such as education and employment, and interventions that can be implemented to increase self-determination. While this chapter provides a framework for the overall goal of the transition to adulthood, in Chapter 7, Carter describes the evidence-based practices for supporting students with ASD more generally, as they participate in the legally mandated transition services as a part of special education. In Chapter 8, Test, Holzberg, Clark, Terrell, and Rusher further this discussion by focusing on evidence-based approaches for providing employment training to young adults with ASD. Molteni in Chapter 9 focuses on how the principles of applied behavior analysis can be utilized to deliver and assess instruction for adolescents with ASD to build skills across domains. Chapter 10, written by Matheis, Estabillo, and Matson, discusses how to use applied behavior analysis to manage challenging behaviors in adolescents with ASD.

The final part of this book focuses on two special populations of adolescents/young adults with ASD. In Chapter 11, Gelbar depicts the unique support needs of college students with ASD. Lai, Ameis, and Szatmari discuss the unique challenges facing young women with ASD in Chapter 12 in terms of receiving both an appropriate diagnosis and services. Finally, Chapter 13 provides a brief summary of the book as well as offering suggestions for future research.

REFERENCES

Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist*, *55*(5), 469.

Autism Collaboration, Accountability, Research, Education, and Support Act of 2014, Pub. L. 113-157, 128 Stat. 1831, codified as amended at 42 USC §§ 201 & 280i.

Combating Autism Act of 2006, Pub. L. 109-416, 120 Stat. 2821, codified as amended at 42 USC §§ 201, 280i, & 283j.

Combating Autism Act of 2011, Pub. L. 112-32, 125 Stat. 361, codified as amended at 42 USC §§ 201 & 280i.

Daniel, K. L., Prue, C., Taylor, M. K., Thomas, J., & Scales, M. (2009). "Learn the signs. Act early": A campaign to help every child reach his or her full potential. *Public Health*, *123*, e11–e16.

Interagency Autism Coordinating Committee (IACC) (2009). *2009 Strategic Plan for Autism Spectrum Disorder (ASD) Research*. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: https://iacc.hhs.gov/publications/strategic-plan/2009/strategic_plan_2009.pdf.

Interagency Autism Coordinating Committee (IACC) (2013). *IACC Strategic Plan for Autism Spectrum Disorder (ASD) Research—2013 Update*. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: http://iacc.hhs.gov/strategic-plan/2013/index.shtml.

Newman, L., Wagner, M., Knokey, A. M., Marder, C., Nagle, K., Shaver, D., & Wei, X. (2011). The post-high school outcomes of young adults with disabilities up to 8 years after high school: A report from the National Longitudinal Transition Study-2 (NLTS2). NCSER 2011-3005. Washington, DC: National Center for Special Education Research.

Taylor, J. L., & Seltzer, M. M. (2011). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism and Developmental Disorders*, *41*(5), 566–574.

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PART I

Diagnosis and Treatment of Adolescents with Autism Spectrum Disorder

1

The Challenge of Entering Adulthood for Individuals with Autism Spectrum Disorder

NICHOLAS W. GELBAR AND DANIEL T. VOLK ■

- There is a tremendous amount of variation (heterogeneity) in terms of both symptom presentation and functional ability in individuals with autism spectrum disorder.
- The challenges faced by adolescents and young adults with autism spectrum disorder can be better understood by considering the unique sociocultural changes that most individuals experience within these stages.
- In general, adolescents and young adults with ASD have poor social employment, post–secondary, and independent living outcomes, and these are impacted by factors such as psychiatric comorbidity, social economic status, and the presence and degree of symptoms.
- Additional research efforts, particularly large-scale studies, are needed to better understanding the experiences and outcomes of adolescents and young adults.

Adolescence has become a distinct and important stage of development for all individuals. From the emergence of a "teen culture" during the immediate post–World War II years, the length of this phase of life has increased steadily as the developed world's economy has shifted from industrial to post-industrial. One researcher noted, "The social and institutional structures that once both supported

and restricted people in the course of coming of age have weakened, leaving people with greater freedom, but less support as they make their way into adulthood" (Arnett, 2006, p. 4).

Arnett (2000) notes that the concurrent trends of increased post–secondary education attendance, increased age of marriage and age of bearing children, and increased age to acquire financial independence have created a context in which two phases predate adulthood: (1) adolescence (~ages 12–18) and (2) emerging adulthood (~ages 18–25). Age markers within these phases serve as approximate guides, as these periods are experienced differently by individuals, who progress through stages at their own pace. Arnett notes that emerging adults "often explore a variety of possible life directions in love, work, and worldviews" (Arnett, 2000, p. 469). A practical implication of experimenting within various careers and roles is that individuals experience a longer period of instability and are more likely to be geographically mobile (Arnett, 2000).

The absence of a synchronous process for traversing these phases can make it difficult for parents, educators, and counselors to advise individuals within each stage. Additionally, these times may be especially difficult, as young people are expected to enter phases that have not previously existed, and they thus have few role models to assist them in the successful transition to adulthood. Throughout this process, young people are challenged to create their own blueprints for their lives. These challenges may explain the use of the term "quarter-life crisis" in books (Robbins & Wilner, 2001) and music (Mayer, 2001), as well as in a famous TED talk that advocates for people to not waste the time spent in their twenties (Jay, 2013).

This sociocultural context is essential for understanding the experiences of adolescents and emerging/young adults with autism spectrum disorder (ASD) as they enter and navigate through these unique phases of life. Difficulties with social communication and executive function, in addition to a propensity for restricted interests and behavioral rigidity/concreteness, make the transition to adulthood particularly challenging for this group. A better understanding of the intersection between the sociocultural context and unique ASD-related difficulties can help explain the poor outcomes that this group experiences in traversing these life phases. Before discussing these outcomes, it is important to understand the nature of autism as a spectrum.

WHAT IS AUTISM SPECTRUM DISORDER?

Kanner and Asperger first discussed variants of what is now described as autism spectrum disorder in the 1940s (Kanner, 1943; Asperger, 1944). Both described unique symptoms that represent a portion of what is now considered the *autism spectrum*. Specifically, Kanner described what is now sometimes referred to as *classic autism*, by focusing on individuals with repetitive behaviors, intense interests, and language difficulties. Asperger and the syndrome that bore his name described individuals who had typical cognitive abilities and intact language, but

had highly restricted interests and milder social/communication challenges (e.g., having a flat affect or a professorial tone). In time, the cases they described were recognized as distinct psychological disorders, and their symptoms were codified and included in the third edition of *The Diagnostic and Statistical Manual of Mental Disorders* (DSM) of the American Psychiatric Association. Though it is beyond the scope of this chapter to discuss the history of ASD-specific diagnostic criteria, it is important to understand how the current diagnostic criteria have developed over time as a reflection of prior iterations specified within previous DSM versions.

In the fourth, revised edition of the DSM (DSM-IV-TR), autism and Asperger's syndrome were categorized as Pervasive Developmental Disorders (PDD; APA, 2000). Related and rarer syndromes such as Rett's and Childhood Disintegration Disorder were also included as PDDs. Additionally, a category (PDD–Not Otherwise Specified) was also added to encompass individuals who did not clearly meet all of the criteria for any of the disorders, but who met most of the criteria and were experiencing significant difficulties.

Within the DSM-IV-TR, the diagnostic criteria for autism involved the presence of deficits in social interaction and communication as well as the presence of repetitive behaviors and/or restricted interests (APA, 2000). Similarly, the Asperger's Syndrome category specified that individuals have difficulties in the areas of social interaction and restricted interests and/or repetitive behaviors (APA, 2000). The primary difference between Autism and Asperger's Syndrome diagnoses centered around the presence (Autism) or absence (Asperger's) of a history of delays in the development of language. At this point, the diagnostic criteria had broadened, and the concept of "high-functioning" Autism had gained acceptance. These changes within the DSM-IV-TR began to recognize a group of individuals who were less affected than those with "classic" Autism, but who still had more difficulties than individuals with Asperger's syndrome.

Despite an attempt to differentiate between individuals with similar characteristics but differing levels of functioning, the overlap in symptom presentation between individuals with high-functioning autism and Asperger's syndrome resulted in the inconsistent use of diagnostic labels by clinicians (Mayes, Calhoun, & Crites, 2001; Ozonoff, South, & Miller, 2000). For this and other reasons, the developers of the DSM-5 did not differentiate subtypes of Autism (APA, 2013). Specifically, the DSM-5 replaced the category of PDD with a single, overarching disorder category called Autism Spectrum Disorder (APA, 2013). In combining social and communication symptoms into one category, the three symptom categories formally present in the DSM-IV (Social, Communication, Repetitive Behaviors/Restricted Interest) were collapsed into two categories (Social Communication/Interaction, Restricted/Repetitive Behavior). The DSM-5's Social Communication and Interaction category specifies the three potential symptoms of deficits in social–emotional reciprocity, nonverbal communication, and understanding relationships. The four symptoms listed under the Repetitive Behaviors and/or Restricted Interests category include repetitive movements or speech patterns, rigidity and/or ritualized behaviors, restricted interests, and

under- or over-reactivity to sensory stimuli. It is important to note that the only new symptom included in the DSM-5 criteria is the sensory stimuli symptom, which had previously been considered an associated characteristic of ASD. Though individuals previously diagnosed using DSM-IV criteria will continue to meet the diagnostic criteria under the DSM-5, researchers are concerned about the potential for the new criteria to lead to increases in the average age of diagnosis (McPartland, Reichow, & Volkmar, 2012). While the diagnostic criteria have changed slightly between DSM-IV and DSM-5, historically, the diagnostic criteria have widened over time. Importantly, emphasis on a functional pattern representing core deficits in social communication and the presence of repetitive behaviors and/or restricted interests has remained consistent over time.

Beyond and across these core symptoms, autism is marked by vast heterogeneity. Individuals with ASD range from those who do not communicate verbally to those who have acquired their PhDs. Hence, autism is conceptualized as a spectrum. Individuals with ASD vary in terms of language, intellectual, academic, executive function (discussed in depth in Chapter 3), and adaptive abilities, just to name a few. The presentation of sensory abnormalities, repetitive behaviors, and intense interests varies widely across individuals with ASD, as do social difficulties. For example, while some individuals with ASD show little to no interest in socializing with other people, many others are socially interested, but lack the skills to initiate or maintain relationships.

An additional area of concern for most individuals with ASD is the development of adaptive skills (Kanne et al., 2011; Klin et al., 2007; Perry, Flanagan, Geier, & Freeman, 2009). As with social skills and many other areas of functioning, the magnitude and scope of these difficulties often vary considerably across individuals. While intellectual ability is often discussed in the context of adaptive skills, several studies of populations of individuals with ASD who do not have an intellectual disability have indicated that there is only a weak relationship between one's intellectual ability and one's adaptive skills (Bölte & Poustka, 2002; Klin et al., 2007; Perry et al., 2009) for this group. In other words, despite not having an intellectual disability, individuals with ASD often have significantly lower adaptive skill scores than would be expected, given their level of intellectual functioning. These findings indicate that individuals with ASD may require greater support than do other individuals who have similar intellectual abilities. This is another example of the vast heterogeneity present across the ASD population. Throughout this book, it will be important to keep an understanding of the variation amongst individuals with ASD in mind, as specific strategies will not necessarily work with all individuals with ASD but rather can be targeted to assist those along a portion of the spectrum.

Finally, it is important to understand the difference between *diagnosis* and *classification*. While medical professionals are engaged in diagnosis (a process described in more depth later in the chapter, based on the criteria detailed in APA, 2000; or *International Classification of Diseases*, 10th ed. [ICD-10]), educational professionals are tasked with determining whether an individual is classified as having a disability who requires special education services or accommodations/

modifications under Section 504 of the Rehabilitation Act of 1973. The exact details of this process are not germane to this chapter, save for the fact that not all children/adolescents with an ASD diagnosis will qualify to receive special education services. In other words, some individuals with ASD will simply be considered not to need specialized instruction or curriculum modification in educational settings. In an attempt to encompass the various situations faced by individuals with ASD in these contexts, the focus of some chapters in this volume will be on the entire spectrum, while others will focus on individuals who qualify to receive special education services.

PREVALENCE OF AUTISM SPECTRUM DISORDERS

After a discussion of the nature and heterogeneity of ASD, the next logical question is, how many individuals are impacted by ASD? In an attempt to answer this question in the most holistic manner possible, major research efforts have focused on accurately estimating the number of current cases within the population at a given point in time. Specifically, this section will focus on studies that aim to assess *prevalence*, calculated as the number of both new and preexisting cases at a specified point in time, divided by the total population at that same point in time, as opposed to *incidence,* which is primarily concerned with the number of new cases during a specified interval (Centers for Disease Control [CDC], 2016). In comparison to epidemiological studies regarding prevalence, few studies have focused on estimating the incidence of ASD, because of difficulties in clearly defining age of onset (Wing & Potter, 2002). Thus the primary question that researchers have posed has been, "How many individuals have ASD right now?" as opposed to, "How many new people acquire ASD each year?" Regardless, in consideration of ASD as a lifelong developmental disorder, it is important to understand that *prevalence* and *incidence* are related terms, such that a higher incidence will ultimately result in an increased overall prevalence estimate.

HISTORICAL PREVALENCE ESTIMATES

In tracking the history of ASD prevalence estimates, virtually all original ASD estimates dating back to the 1960s and 1970s relied on Kanner's original definition of ASD (discussed previously) and thus only accounted for ASD characteristics in individuals who had more severe symptom presentation (Kanner, 1943). While estimates from a 1970s study suggested that between 0.7 and 2.4 children per 10,000 in the United States had an autism spectrum disorder, international samples from England and Denmark around the same time estimated the prevalence to be closer to 4.5 per 10,000 children (Wing & Potter, 2002). By the late 1980s, prevalence estimates within the United States doubled to approximately 4 per 10,000 children, and this coincided with the introduction of the disorder into the DSM-III (1980) and the DSM-III-R (1987). This taxonomy shifted the focus of

ASD (at this time considered a Pervasive Developmental Disorder) from a psychiatric disorder to a developmental disorder, and, with the creation of several ASD subtypes, began to conceptualize ASD characteristics as existing along a continuum or spectrum (Wing & Potter, 2002; Fombonne, 2003). Similarly, a majority of international rates followed a similar pattern overall, increasing throughout the 1980s and continuing to be slightly higher than the US rates.

New inclusions in the 1994 DSM-IV (American Psychiatric Association, 1994), most notably Asperger's Syndrome Disorder, and widening of the age requirements for diagnosis, as well as the development of the ICD-10, helped further expand the ASD spectrum, probably contributing to a steady increase in ASD prevalence estimates throughout the 1990s and early 2000s. While studies during these periods presented a broader range of prevalence estimates, from up to 40 per 10,000 children to as low as 11 per 10,000 in the Unites States, on average, the trend can be characterized as a substantial increase in prevalence rates over decades (Wing & Potter, 2002).

In addition to affecting how ASD is defined, the widening of diagnostic criteria has led to greater publicity in concurrence with increasing prevalence rates. The consequence of this increased attention has been a popular awareness of ASD, which has subsequently led to more individuals' being screened and diagnosed. A closer look at current prevalence rates, how they are calculated, and key influential factors within this process will help inform a better understanding of prevalence trends, thus clarifying why adolescent and young adult populations are increasing.

CURRENT PREVALENCE RATES AND ESTIMATION METHODS

In the United States, the Centers for Disease Control and Prevention (CDC) have sponsored numerous large-scale projects intended to estimate ASD prevalence rates through use of national surveys and other monitoring networks. In particular, the Autism and Developmental Disabilities Monitoring (ADDM) network consists of 14 CDC-funded sites throughout the United States, which work with local school and community health agencies to estimate the number of eight-year-old children with ASD (CDC, 2016). To accomplish this, the ADDM network uses a record-review process to review data from school and community sources. In addition to students with current diagnoses, the ADDM network reviews data for students who present with documented behaviors that are consistent with an ASD diagnosis. For example, in the 2012 process, trained abstractors collected a variety of sources from educational (e.g., developmental evaluations for special education services) and health care outlets (e.g., diagnostic and developmental evaluations) and compared this information to DSM-IV-TR ASD diagnostic criteria to make informed, student-specific diagnosis decisions (for more detailed information on ADDM network methodology, see Christensen et al., 2016).

In 2000 and 2002, the ADDM network estimated the prevalence of ASD amongst eight-year-old children to be 1 in 150 (CDC, 2007a; CDC, 2007b). Based on the 2012 results from the assessment of eight-year-old children across 11 sites, the ADDM network projected ASD prevalence rates to have more than doubled, with current estimates suggesting that 1 in 68 children has ASD (CDC, 2016; Christensen et al., 2016). Despite this tremendous increase in the prevalence estimate since the early 2000s, more recent trends regarding the current prevalence are more difficult to predict, as data collected between the 2010 and 2012 time points did not display significant differences. Additionally, significant variations in regard to the geographic sites assessed within the 2012 data make it difficult to determine if and how ASD rates might be stabilizing (CDC, 2016). For example, while prevalence estimate from the South Carolina site was 1 in 81, the New Jersey site reported a prevalence rate of 1 in 41. Other key findings from the report were that boys are 4.5 times more likely to be identified with ASD than girls, that most children were reported to have been diagnosed with ASD after age four, and that 18% of children met diagnostic criteria for ASD but had yet to be formally diagnosed by a community provider, or had not been receiving special education services under the autism-specific disability category within schools (CDC, 2016; Christensen et al., 2016). Taken together, ADDM's focus on better understanding specific population patterns and common pathways to diagnosis through assessment in strategically positioned centers has helped to further our understanding of ASD prevalence.

In addition to the CDC's use of the ADDM community network, survey and interview efforts have helped supplement understanding of ASD prevalence. Specifically, the National Health Interview Survey (NHIS) and the National Survey of Children's Health (NSCH) are two tools that have been used over the past decade to estimate ASD prevalence for children in the 3–17-year-old age range. In projecting the lifetime prevalence of an ASD diagnosis within this age range, NHIS data have displayed a similar pattern to ADDM data, estimating the prevalence to be 1 in 175 in 2003 and increasing to 1 in 45 in 2014 (Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015). It is important to note that NHIS survey components were altered between these assessment time-points, and that this may have affected results (Zablotsky et al., 2015). As indicated by Zablotsky and colleagues (2015), ASD prevalence rate increases directly coincided with the 2014 rewording and reordering of ASD survey items, which, for the first time, allowed for a standalone question to ask about whether or not a child had ever received a diagnosis of ASD. Relative to results from 2011 to 2013 time points, 2014 data displayed a significant decrease in reported instances of "other developmental disability," but when comparing lifetime prevalence rates regarding a diagnosis of any developmental disability, results across all time points did not significantly differ (Zablotsky et al., 2015). In consideration of results over the past five to six years, these findings suggest that, rather than more individuals' being diagnosed with ASD relative to other disorders, participants may be simply reporting disabilities in a different manner.

Following the trend of overall increases from the early 2000s, results from the parent-reported NSCH telephone survey have displayed a similar pattern. Specifically, the ASD prevalence estimates in children 6–17 were projected to be 1 in 181 in 2003, but jumped to 1 in 50 in the 2011–2012 data set (Zablotsky et al., 2015). Although these large-scale efforts report relatively similar estimates, from the NHIS estimate of 1 in 45 to the ADDM networks 1 in 68, as each tool differs in estimation methodology across projects and, in many cases, assesses data from different years, estimates are not intended to be meaningfully compared. Rather, each assessment is intended to help contribute to a more holistic understanding of the true population prevalence and how estimations are changing over time. Though the relative consistency in findings across differing assessment tools provides increased validity to the assertion that Autism Spectrum Disorder diagnoses have indeed rapidly increased from the early 2000s, these results do not indicate what has influenced this trend or whether this increasing trend will continue into the future. In conceptualizing these figures, additional factors of influence will be further discussed.

ADDITIONAL PREVALENCE CONSIDERATIONS

Researchers have often attributed increasing trends in the prevalence rates of ASD to increased awareness, as discussed earlier; to better resources for identification, which will be discussed in the "Diagnosis" section; and to changes in diagnostic criteria (King & Bearman, 2009; Matson & Kozlowski, 2011). Given changes in all of these factors over time, it is difficult to definitively determine true prevalence rate increases.

As alluded to previously, the diagnostic criteria such as specific symptom presence, number of key symptoms, age of onset, and categorization in relation to other disorders has changed across DSM revisions since ASD was first published as a disorder within the DSM-III (Matson & Kozlowski, 2011). Though research on this topic has been limited, one such study, assessing ASD changes and diagnostic criteria from 1992 to 2005, found that over a quarter of ASD cases were linked directly to changes in diagnosis criteria, and over one-third of diagnoses were a result of diagnostic substitutions or the switching from a previous diagnosis to ASD (King & Bearman, 2009; Matson & Kozlowski, 2011). To this end, some research suggests that, given a rise in ASD awareness and service provision, as well as a more holistic understanding of how ASD presents with other disorders, practitioners may be more likely to diagnose an individual with ASD as opposed to an Intellectual Disability or other disorder than in the past when seeing a patient presenting with similar characteristics (Leonard et al., 2010; Matson & Kozlowski, 2011). In the face of significant ASD classification and diagnostic revisions within the DSM-5, most notably the expansion of the ASD category to encompass what was previously considered Asperger's disorder, there have been concerns regarding the impacts of prevalence estimates. Though some evidence suggests that it may be more difficult to meet diagnostic criteria under DSM-5

criteria than DSM-IV criteria (Maenner et al., 2014), few studies have been conducted comparing these criteria, and more time and research are needed to accurately evaluate the impact of these diagnostic changes on prevalence estimates.

DIAGNOSIS

While the focus in the field has been on early screening and diagnosis (Howlin, 2000; Levy & Perry, 2011), many adolescents and young adults require diagnostic services (Trammell, Wilczynski, Dale, & McIntosh, 2013). Indeed, there are many who argue that there are adults who would have been identified with ASD if the current screening and diagnostic approaches had been available 30–40 years ago (Lai & Baron-Cohen, 2015). As ASD is characterized as a neurodevelopmental disorder, its symptoms have to be present in early childhood, and this makes diagnosis in older individuals more difficult. To understand these difficulties, it is important to consider first how ASD is typically diagnosed in children.

Diagnosis results from the congruence of data from multiple informants and from multiple methods. First, parents/caregivers participate in a developmental interview with a clinician where they discuss the child's behavior and progress towards developmental milestones. In addition, behavior rating scales are often given to the parents/caregivers and other informants and serve to indicate if the child's behavior across settings indicates the presence of symptomology associated with ASD. Finally, the clinician completes a direct observation of the child's behavior over a period of time. This is an overview of typical diagnostic steps, and several resources provide more detailed information about the process and specific instruments. Specifically, the "gold standard" for the diagnosis of ASD is a combination of a structured developmental interview (Autism Diagnostic Interview–Revised [ADI-R]; Rutter, LeCouteur, & Lord, 2003) and a structured observation (Autism Diagnostic Observation Schedule–Second Edition [ADOS-2]; Lord, DiLavore, & Gotham, 2012). This combination has been shown to the most effective approach for ASD diagnosis (Risi et al., 2006).

While these measures can be utilized with adolescents or adults suspected of having ASD, there are various unique challenges in diagnosing these individuals. Lai and Baron-Cohen note: "Making a first diagnosis of autism spectrum conditions in adults can be challenging for practical reasons (e.g., no person to provide a developmental history), developmental reasons (e.g., the acquisition of learnt or camouflaging strategies), and clinical reasons (e.g., high frequency of co-occurring disorders)" (2015, p. 1013). Trammel and colleagues (2013) elaborate further:

> Referral questions are often too general, measures designed to assess adolescents and adults with ASDs are lacking, accurate developmental histories are difficult to obtain, a medical history of multiple treatments and diagnoses abound, and client refusal or incapacity to fully collaborate during the process often complicates assessments. (Trammel et al., 2013, p. 937)

All of these factors make the diagnosis of ASD in adolescents and young adults very challenging. Attempts to gather information from parents/caregivers are crucial to establish a history of the symptoms of ASD. It is also necessary to complete a thorough medical, social, and educational history up to the present, as previous diagnoses and behaviors will inform the process of differential diagnosis. Direct-observation methods will be useful for observing symptomology, but these can be complicated by individuals who may have learned compensation strategies. In short, diagnosis of adolescents and young adults with ASD tends to be more reliant on the presence of a pattern of data across informants and methods. Clinicians must take into account any limitations within the available data and ultimately rely on the diagnostic criteria as their guide when deciding whether individuals meet the criteria.

OUTCOMES

In discussing prevalence estimates and diagnosis, the notion that individuals with ASD function across a broad spectrum, with behaviors that present in various ways and with differing ability levels, has been emphasized as a fact that makes clear-cut estimation and identification difficult. In speaking to this immense heterogeneity across the spectrum, this fact continues to make generalization and prediction of outcomes, particularly on an individual basis, difficult. Additionally, research efforts across outcome areas have been inconsistent, with some research areas such as social outcomes being more comprehensively studied than others, such as educational or vocational outcomes. A shortage of large-scale studies intended to assess substantial samples of individuals with ASD over time may be the most influential reason why we lack a more comprehensive understanding of experiences across outcome areas.

In presenting our current understanding of the outcomes for individuals with ASD, we draw attention to the limits of existing literature bases in key outcome areas, resulting from a reliance on few large-scale studies supplemented by the more numerous smaller-scale studies. To this end, the National Longitudinal Transition Study–2 (NLTS-2), published in 2015, will be a frequently discussed large-scale study, which followed approximately 921 individuals with ASD from high school into young adulthood. Though this study yielded numerous important outcome findings, many of which will subsequently be discussed, it is important to note that the sample of individuals was derived solely from those receiving special education services (Roux, Shattuck, Rast, Rava, & Anderson, 2015). As result, this sample may under-represent a population of adolescents and young adults who are higher functioning and who require less intensive supports than typically provided within a special-education setting (e.g., 504 accommodations). In discussing the pathways for individuals with ASD across a vast spectrum and attempting to conceptualize outcomes, assessing a sample of individuals who have been pre-classified into special-education services and thus who need more substantial reports may have the tendency to negatively skew outcome results.

GENERAL SYMPTOMOLOGY AND YOUNG ADULTHOOD

In regard to symptom severity for individuals diagnosed with ASD, evidence suggests that, in general, symptoms steadily improve from childhood to late adolescence (Levy & Perry, 2011; McGovern & Sigman, 2005; Seltzer et al., 2003; Shattuck et al., 2007). Children who initially present with the least severe symptoms at first diagnosis tend to improve more rapidly than those who present with more severe symptoms, and, in regard to communicative, social, and repetitive behavior outcomes, individuals may follow one of several developmental trajectories (Fountain, Winter, & Bearman, 2012). Despite modest improvement over time from childhood to adulthood, generally speaking, individuals with ASD do not obtain normal levels of functioning and are typically dependent upon various levels of support (Seltzer, Shattuck, Abbeduto, & Greenberg, 2004).

While progress is made most rapidly before age six, functioning may begin to slow around adolescence (Fountain, Winter, & Bearman, 2012). In particular, amongst higher-functioning individuals with ASD, this pattern may reflect struggles to navigate the increasing social relationship, academic, employment, and independent living demands of young adulthood (Howlin, Goode, Hutton, & Rutter, 2004; Kapp, Gantman, & Laugeson, 2011). Disorder comorbidity, socioeconomic status (SES), presence and degree of particular symptoms, and access to transition services have been identified as a few of the most influential factors in predicting outcomes across these domain areas.

Concerning SES, studies suggest that children who come from higher-income households and who are born to white, well-educated mothers are more likely to be higher functioning and to experience more rapid developmental gains than are children who are born to families with lower incomes, who are part of a minority group, and who are born to less-educated mothers (Fountain, Winter, & Bearman, 2012; Roux et al., 2015). Additionally, age of diagnosis has been associated with race in that, compared to children from other ethnicity groups, white children are more likely to be diagnosed at an earlier age (Mandell, Listerud, Levy, & Pinto-Martin, 2002; Mandell et al., 2009). Taken together, these findings are likely to be a reflection of greater and earlier access to diagnostic and support services amongst those in higher SES brackets. In fact, this disparity in access to diagnostic resources has skewed prevalence findings, in that those in higher SES classes have reported higher ASD prevalence rates than those in lower SES classes (CDC, 2016; Durkin et al., 2010; Fountain, King, & Bearman, 2011). These findings are particularly troubling given that proper identification typically proceeds access to support, and there is strong literature base emphasizing the positive impact of early intervention services (Dawson et al., 2010; Howlin, Magiati, & Charman, 2009; Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011). With an understanding that the earlier the services can be provided, the better, clearly families from lower SES brackets, who are likely to reside in areas with more limited resources and less likely to have the skills and resources to access supports, are at a disadvantage. Moving beyond early childhood, these factors and the absence of early intervention may have future implications for the degree of impairment in regard to

specific ASD-related characteristics, and have been shown to subsequently influence multiple outcome areas (Roux et al., 2015).

For example, based on data from NLTS-2, researchers found that individuals with better social and conversational skills were most likely to pursue higher education and/or employment following high school graduation. Additional research aligns with these findings, suggesting that the ability to communicate more effectively predicts success in securing employment, in post–secondary settings, and in social relationships (Eaves & Ho, 2008; Kapp, Gantman, & Laugeson, 2011; Roux et al., 2015). In consideration of how influential this factor is, access to early-intervention services that concentrate on developing language and communication skills would be a valuable asset. In addition to degree of impairment in particular domains, the presence or absence of comorbid disorders has been considered another important factor in predicting outcomes.

PRESENCE OF COMORBID DIAGNOSES

In recent years, researchers have increasingly focused on the co-occurrence of psychological disorders in individuals with ASD to better explain outcome patterns, which will be discussed in more depth in Chapters 2–6 of this volume. Studies consistently suggest that a large percentage of individuals with ASD manifest co-occurring mental health and medical conditions, with data from the NLTS-2 indicating comorbidity in 60% of the sample (Roux et al., 2015).

In comparison to comorbidity rates across other disabilities, sources suggest that co-occurring psychiatric conditions may be twice as likely in individuals with ASD (Joshi et al., 2013, Kohane et al., 2012; Lai & Baron-Cohen, 2015; Simonoff et al., 2008; Roux et al., 2015). Specifically, obsessive compulsive disorders (OCD), anxiety, and depression are the most common comorbid disorders, with estimates that up to or greater than 30% of individuals meet an OCD diagnosis, and 50% or more of individuals meet diagnostic criteria for anxiety or depression (Lai & Baron-Cohen, 2015; Simonoff et al., 2008; Simonoff et al., 2013). Adolescents and adults with high-functioning ASD are more likely to be diagnosed with a comorbid depressive disorder and more likely to report social anxiety symptoms than are lower-functioning peers or individuals who are younger (Lai & Baron-Cohen, 2015; White, Ollendick, & Bray, 2011; White, Oswald, Ollendick, & Schahill, 2009). This may be a reflection of a greater awareness of social differences, a general desire to evade uncomfortable social situations, and a result of learned helplessness and subsequent avoidance following negative experiences (Barnhill, 2001; Ghaziuddin, Ghaziuddin, & Greden, 2002; Humphrey & Symes, 2010; Tantam, 2003). For example, the increasing social emphasis and the ever-present social demands of adolescence are likely to more blatantly expose the characteristic skill deficits of individuals with ASD, thus resulting in negative social experiences. Such experiences may manifest in social anxiety and depressive symptoms, which further undermine future attempts to relate and socialize.

Intellectual ability is an additional frequently studied factor in individuals with ASD, often considered the most influential predictor of outcomes over time. A multitude of studies suggest that individuals with ASD and comorbid Intellectual Disability (ID) display less progress and significantly more impairment over time in comparison to non–intellectually disabled individuals with ASD (Howlin, Goode, Hutton, & Rutter, 2004; Shattuck et al., 2007; Sigman & McGovern, 2005; Smith & Matson, 2010; Taylor & Seltzer, 2011).

Appropriate diagnosis and the consideration of comorbidity is tricky for several reasons, as comorbidity may both reflect and aggravate ASD symptomology, and teasing out characteristics that may be similar across disorders (e.g., ASD and social anxiety) is likely to be complicated (as discussed in more depth in Chapters 4 and 5). Primary differential diagnoses, which share common symptomology characteristics with ASD and are also sometimes classified as "comorbid," include Social Anxiety Disorder, Psychotic Disorder, Personality Disorder, and OCD (APA, 2013; Lai & Baron-Cohen, 2015).

Additionally, communicating symptomology—particularly for internalizing disorders such as anxiety and depression, which often require discussion of abstract, non-concrete terms (e.g., "feelings," "anxious")—may represent a tremendous challenge for individuals with ASD. The complexity of comorbidity is that multi-disorder characteristics blend together to more severely hinder functioning, and the sad reality is that this pattern of functioning is more common than not.

A better understanding of these influential factors is useful, as they are likely to play a role in virtually all outcome domains. The following discussion will serve as a summary of overall outcomes for individuals with ASD in regard to social relationship, employment, post–secondary education, and independent-living domains, all of which are considered to be relevant in young adulthood.

SOCIAL RELATIONSHIPS

As ASD is characterized by persistent deficits in social communication and social interaction, of all outcome areas, it is perhaps least surprising that establishing and maintaining social relationships is extremely challenging for young adults with ASD (APA, 2013). Many individuals with ASD express a desire to have more fulfilling social lives but describe experiencing pervasive loneliness during adolescence and into adulthood (Bauminger, Shulman, & Agam, 2003; Roux, 2015; Whitehouse, Durkin, Jaquet, & Ziatas, 2009). In addition to inhibited social skills, poor social reciprocity, and difficulties in taking others' perspectives, other characteristic ASD symptoms such as rigidity, preference for sameness, high attention to detail, and strict adherence to rules, may undermine successful relationship-building (APA, 2013; Kapp, Gantman, & Laugeson, 2011).

Specifically developing relationships requires initiation, risk-taking, and the ability to adapt to change, all areas where individuals with ASD typically struggle. Numerous studies have sought to better understand the experiences of individuals

with ASD through assessment of their perceptions within social exchanges. For example, in one such study, individuals with high-functioning ASD endorsed reading other people's feelings and responding to other people's feelings as two of the most significant challenges they faced in social situations (Balfe & Tantum, 2010). Though some individuals with ASD have less difficulty with understanding complex emotions, individuals with high-functioning ASD may struggle to appropriately respond to such emotions in social situations, which in turn may result in feelings of isolation and social frustration (Jobe & White, 2007; Montgomery et al., 2008).

In a more global sense, another study found that college students who endorsed more ASD-like characteristics such as social-skill deficits, rigidity, and preference for sameness also reported fewer friendships, shorter duration of friendships, and increased levels of loneliness than did peers with fewer ASD-like characteristics (Jobe & White, 2007). In addition to these factors, individuals with ASD often struggle to appropriately articulate sentence elements; may discuss topics in an out-of-context, repetitive, or overly formal manner; may gaze in unexpected ways; and may struggle to pick up on the conversational cues of others, all of which are important behaviors for successful social exchange (Kapp, Gantman, & Laugeson, 2011; Paul, Orlovski, Marcinko, & Volkmar, 2009; Shriberg et al., 2001).

Taken together, these factors help explain why individuals with ASD consistently report such poor social outcomes. For example, in assessing peer relationships and social activity amongst 235 adolescents and adults with ASD, one study reported prevalence of same-aged peer friendships to be 8%, with roughly 50% of the sample indicating that they had no peer relationships outside of prearranged settings (e.g., school or work) (Orsmond, Krauss, & Seltzer, 2004). Howlin, Goode, Hutton, and Rutter (2004) found similar results in assessing adults with an ASD diagnosis and an IQ of 50 or higher, in that 56% of these adults indicated that they had no friends or acquaintances.

Estimates from the NLTS-2 data set, which assessed young adults' social and community participation over a one-year period, found that 50% of the sample reported never having been invited to a social activity with friends, and that one in four were "socially isolated" in that they never saw friends or spoke with them on the phone (Roux et al., 2015). In struggling to develop friendships, individuals with ASD consequently have difficulties in developing more intimate, romantic relationships. Specifically, individuals with high-functioning ASD often misinterpret disinterest by potential partners and may not engage in appropriate courtship behaviors (Tincani & Bondy, 2015). In addition to inhibiting the development of romantic partnerships, ASD-related symptoms hamper the building of friendships (as discussed previously), which often serve as reference points to gauge what appropriate social and romantic boundaries look like. Thus, in responding to a desire for intimacy, individuals with ASD are disadvantaged both in regard to ASD-related deficits that make interpreting social signs more challenging, and because they have limited opportunities to learn from models about how to appropriately show interest and when to disengage from pursuing a potential partner (Stokes, Newton, & Kaur, 2007).

In building on an understanding of how inherited ASD-related skill deficits impact or inhibit social efforts, other studies have attempted to better understand the experiences of individuals with ASD by examining how (e.g., where and with whom) they typically socialize. Specifically, research suggests that most social encounters reported by young adults with ASD occur within prearranged and structured settings (e.g., school or work) (Orsmond et al., 2004). While adolescents with ASD are more likely to report the presence of friendships than are adults with ASD, this younger group is also more likely to be within a formalized school setting surrounded by same-aged peers and supportive adults, and thus more likely to have increased opportunities to socialize. Within the school setting, research suggests that adolescents with ASD may be more likely to report teachers and other adults as "friends" due to a perception of these individuals as more socially supportive than same-aged peers (Daniel & Billingsley, 2010; Orsmond et al., 2004). Additionally, upon exiting formal schooling, research suggests, adults with ASD are more likely to engage in social and recreational activities that require less social interaction and that are routine-based, such as taking a walk or engaging in an exercise regimen, rather than casually socializing with friends, (Orsmond et al., 2004).

Taken together, these social behaviors and outcomes for adolescents and young adults with ASD are a direct reflection of an inhibited skill set that is increasingly exposed in the face of contexts that value and demand more advanced social interaction. A crucial factor affecting virtually every other outcome domain area, ASD-related social deficits play out in a vicious cycle in which social and communicative deficits undermine relationship formation and result in decreased opportunities for social learning, which ultimately further inhibits the development of successful relationships.

EMPLOYMENT AND POST–SECONDARY EDUCATION

With an estimated 49,000 individuals with ASD graduating from high school in the United States each year, many individuals will seek to either enter the work force or continue education in a post–secondary setting (Wei, Wagner, Hudson, Yu, & Javitz, 2016). In the face of new challenges and limited supports, the majority of these individuals will struggle during this transition. According to results from NLTS-2, 66% of high school graduates with ASD fail to obtain a job or to continue with post–secondary education within the first two years of leaving high school. Influential factors regarding post–secondary and employment outcomes for young adults with ASD will be discussed next, followed by estimates of current outcome statistics.

In contrast to a widespread social-outcome literature base, research regarding predictors of vocational and post–secondary success for young adults with ASD is sparse. In a recent review assessing the literature base to identify ASD-related, evidence-based practices and the most frequently studied outcome variables associated with these practices for individuals across various age groups, Wong et al.

(2015) reported that studies of the 19–22 age group and of vocational outcomes were among the least common. Specifically, while social and communication outcomes were studied most frequently, with over 300 studies assessing one of these variables, a mere 12 studies directly assessed vocational outcomes (Wong et al., 2015).

Post–Secondary Education

Approximately 16,000 high school graduates with autism pursue higher education each year; and, in light of dramatic increases in ASD diagnoses (discussed previously), this number will continue to rise (Wei, Wagner, Hudson, Yu, & Javitz, 2016). According to data from the NLTS-2 project, approximately 36% of young adults with ASD will attend any type of post–secondary education (e.g., two- or four-year colleges; vocational, business, or technical school), while roughly 75% of high school graduates in the general population attend post–secondary school. In comparison to individuals in other disability groups such as those with speech/language impairments, learning disabilities, emotional disturbances, and intellectual disabilities, individuals with ASD report the second-lowest post–secondary attendance rates (Roux et al., 2015). Additionally, individuals with ASD also had among the lowest completion rates, as only 38.8% of those who attended post–secondary education completed their program (Newman et al., 2011).

Unfortunately, research regarding post–secondary participation and predictors of post–secondary success for young adults with ASD is limited. One such study, using data from the NLTS-2, found parental expectations, higher household income, strong academic performance, and having a post–high school goal concentrated on post–secondary involvement, all to be predictive of post–secondary attendance (Chiang, Cheung, Hickson, Xiang, & Tsai, 2012). Past studies support these findings, particularly in regard to high-school academic performance and parental expectations, and suggest that participation in regular high-school academic settings, in vocational education, transition planning, and high school paid employment may positively impact post–secondary attendance (Baer et al., 2003; Chiang et al., 2012; Test et al., 2009). Though these studies may help provide preliminary support for important factors related to post–secondary outcomes for young adults with ASD, more research is needed to identify additional high school predictors and thereby better inform transition planning. In addition to high-school predictors of subsequent college attendance, the situational factors present in the college setting are likely to have an impact on the post–secondary success of individuals with ASD.

As discussed by McGuire (2010), high school settings are more structured and controlled, and have formal and informal checkpoints (e.g., attendance, scheduled in-class assessments) that are embedded in daily routines, allowing student progress to be monitored in a more routine fashion. Students spend more direct instructional time with teachers, and, unlike in college settings, students are not required to maintain a minimum grade point average in order to continue

enrollment. More autonomy within the college setting comes with increased responsibility (as discussed in Chapter 11), as students are challenged to independently allocate time to studying outside of class, to reaching out to professors when necessary, to self-disclosing their disability and advocating for accommodations, and, in general, to solving more complex problems with less guidance (Brinckerhoff, McGuire, & Shaw, 2002; McGuire, 2010). Unlike the high school setting, colleges are not legally required to identify students with disabilities, nor are they required to provide special education or individualized support services for students (see Chapter 11 of this book for more detailed discussion). As no legally prescribed model for post–secondary disability service exists, young adults with ASD and their families are dealt the burden of independently seeking appropriate support services (McGuire, 2010). These factors may help explain why just 40% of young adults within the NLTS-2 sample reported receiving post–secondary support despite self-disclosing their disability (Roux et al., 2015). Substantial context changes requiring more independence and flexibility coupled with fewer supports than ever before help explain why individuals with ASD fall through the cracks and report poor post–secondary outcomes.

Employment

Finding adequate employment after graduating from high school represents a significant challenge for young adults with ASD, as most studies estimate the static employment rate for this population to be between 20% and 30% (Eaves & Ho, 2008; Roux et al., 2015; Taylor & Seltzer, 2011). Individuals who are employed typically work part-time or in sheltered settings and are engaged in unskilled tasks (e.g., delivering papers, dishwashing, etc.) (Eaves & Ho, 2008; Roux et al., 2015; Taylor & Seltzer, 2011). Tracking individuals into adulthood, NLTS-2 data found that 58% of individuals with ASD reported working for pay outside their home at any time between high school graduation and their early 20s. This statistic is particularly troubling when one considers that, according to the Bureau of Labor Statistics, 97% of the total young adult population reported holding a job during this same time period (Bureau of Labor Statistics, 2010; Roux et al., 2015). Research by Eaves and Ho (2008) found similar results, in that, among a sample of individuals with ASD followed into early adulthood (mean age 24), just 56% of individuals had ever been employed.

Despite limited research in this domain, evidence suggests that ASD-related deficits in interacting and clearly communicating may be the most influential factors undermining successful employment experiences (Kapp, Gantman, & Laugeson, 2011; Müller, Schuler, Burton, & Yates, 2003; Schall & Wehman, 2009). Specifically, studies have displayed that individuals who are higher functioning, who have more advanced verbal IQ scores, and who have stronger conversation abilities have better employment outcomes (Eaves & Ho, 2008; Roux et al., 2015; Taylor & Seltzer, 2011; Tincani & Bondy, 2015). To this end, employment opportunities for individuals with lower cognitive abilities and for

those with behavioral issues are likely to be more difficult to secure (Tincani & Bondy, 2015).

Even if young adults with ASD have average cognitive abilities and meet qualification requirements, other ASD-related symptom deficits such as difficulties in matching personal strengths and weaknesses to job-specific tasks, low frustration tolerance, and interference from common comorbid medical conditions such as epilepsy and noise sensitivity, have the potential to negatively impact both the obtaining and maintaining of competitive work opportunities (Eaves & Ho, 2008; Hendricks, 2010; Kapp, Gantman, & Laugeson, 2011). In this sense, it is important to understand how individuals struggle in the face of job-related societal expectations. For example, talking with a potential employer on the phone and participating in a job interview are two common societal practices that, among other things, allow employers to assess one's social skills, relatability, and likelihood of "fit" within a particular work setting. Research suggests that these interactions may be particularly anxiety-provoking and challenging for individuals with ASD and thus may serve as barriers to obtaining employment despite qualification (Müller et al., 2003). Inadequate post–high school support in the form of targeted services to help individuals with ASD research, apply to, and prepare for potential job opportunities may help explain their poor employment outcomes.

While over 50% of individuals with ASD report receiving high school services and participating in transition planning, upon exiting high school, services dramatically decrease (Roux et al., 2015). Research suggests that individuals with ASD in particular suffer from a lack of post–high school supports (Taylor & Seltzer, 2011). For example, in assessing post–high school outcomes amongst individuals with various disabilities, Taylor and Seltzer (2011) found that 85% of individuals with a comorbid disorder of ASD and ID reported receiving employment/vocational services, and that these individuals were three times more likely to be employed than were individuals with a single ASD diagnosis, just 18% of whom received comparable services. These results not only suggest that post–secondary services for individuals with ASD are inadequate, but that programs or services for individuals with other disabilities may be more streamlined into the work environment. Other research comparing individuals with ASD to those with Down syndrome supports these results in that, though young adults with ASD may have more limited functional abilities and exhibit more behavioral problems, thus indicating that they are in need of more significant supports, they continue to receive fewer post–high school services (Esbensen, Bishop, Seltzer, Greenberg, & Taylor, 2010).

In general, research continues to identify a service gap in that individuals with ASD often receive no post–high school vocational or life skill services (Roux et al., 2015), are slow to enter the workforce, and report the poorest employment rates and lowest average salaries in comparison to other disability groups (Howlin, Mawhood, & Rutter, 2000; Roux et al., 2015). Though some research suggests that the use of post–high school employment services can help young adults with ASD obtain jobs at higher rates, research regarding this topic continues to be scarce (Howlin, Alcock, & Burkin, 2005). This gap in research regarding post–high

school employment outcomes and limited post–high school transition services for individuals with ASD is concerning and is likely to become an increasingly important issue for a larger group of high school graduates.

INDEPENDENCE IN LIVING

Similar to post–secondary and employment outcomes, there is limited research base regarding independent-living outcomes for individuals with ASD. Despite some evidence suggesting that cognitive ability, in particular an IQ greater than 70 and better social abilities, are associated with more positive independent-living outcomes, a majority of studies report some degree of continued dependence on others (Billstedt, Gillberg, & Gillberg, 2005; Howlin et al., 2004; Kapp, Gantman, & Laugeson, 2011). For example, Renty and Roeyers (2006) found that, amongst a sample of high-functioning adults with average IQ scores, two-thirds of the sample lived with their parents. Similarly, in assessing young adult outcomes from high school graduation into their early 20s, data from the NLTS-2 reported that just 19% of young adults with ASD had ever lived away from their parents (Roux et al., 2015).

The pervasive nature of ASD in regard to deficits in daily living skills and comorbid mental and physical conditions, as well as a lack of external supports, all adversely affect individuals' ability to live independently, often resulting in dependence upon parents (Balfe & Tantam, 2010; Howlin et al., 2004; Kapp, Gantman, & Laugeson, 2011). As is often the case for typically developing individuals who must make important decisions regarding the future, young adulthood may serve as a particularly stressful time for individuals with ASD and their families, who are presented with numerous additional challenges. Given that a large portion of young adults with ASD report neither obtaining a job nor continuing on to a post–secondary education within the first two years of high school graduation (Roux et al., 2015), these students are likely to be in the home, where they are likely to have fewer structured services, limited daytime activities, and less consistent support. Adapting to the loss of mandated services is likely to present a tremendous challenge to both an adolescent and his/her family.

MAJOR THEMES

In consideration of ASD-related research across age groups, there continues to be a large imbalance, with the vast majority of research involving children, and few studies assessing young adults (Wong et al., 2015). In understanding the experiences of young adults with ASD, the field continues to be plagued by a lack of studies in the post–secondary, employment, and independent-living domains. Though a variety of small-scale studies have helped to further understanding of post–high school experiences of individuals with ASD, the NLTS-2 represents the only recent large-scale effort in assessing a special-education population of