

# Transition to Adulthood for High-Functioning Individuals with Autism Spectrum Disorders

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## 1. Introduction

Adolescence and young adulthood appear to form the most difficult period in the lives of high-functioning individuals with autism spectrum disorders (ASD; Tantam, 2003). The challenges often faced by those without intellectual disabilities appear to result from the demands of social relationships, academics, employment, and independent living in those with ASD, which may exacerbate core ASD deficits or co-occurring conditions (Barnhill, 2007; Howlin, 2000). The features of these developmental periods, combined with the general challenges with transitions in this population, may explain why the reduction in ASD symptoms that individuals experience throughout life (Seltzer et al., 2003) tend to slow in the transition to adulthood (Taylor & Lounds, 2010). This population appears to be growing despite a shortfall in services and knowledge about these individuals, posing the need for more attention to this area (Barnard et al., 2001; Gerhardt & Lainer, 2011; Shattuck et al., 2011). Adulthood marks a transfer of legal responsibility for individuals with ASD from parental support to self-advocacy. Young adults are often faced with needs to make decisions about their lives, yet they may not fully understand their own unique profile of strengths and weaknesses, or how to advocate for services to meet their needs (Geller & Greenberg, 2010; Townson et al., 2007). In addition, these young adults often feel socially alienated during this period of transition, as though they do not belong or fit in with their peer group (Portway & Johnson, 2003; Ryan & Raisanen, 2008; Simmeborn Fleischer, in press), while sensing others' may be underestimating their competences (Ashby & Causton-Theoharis, 2009). These struggles may not only relate to social deficits, but may also be associated with cognitive, emotional, and sensory information processing deficits (Chamak et al., 2008). For example, sensory overload may compromise the cognitive performance of individuals with ASD or lead to withdrawal or absence of participation from various social situations (Madriaga, 2010). Yet for adults with ASD, quality of life or subjective wellbeing appears positively related to perceived informal support and inversely related to unmet formal support needs. Disability characteristics such as ASD symptoms and IQ appear to be unrelated to subjective wellbeing (Renty & Roeyers, 2006). These findings have implications for the provision of accommodations and formal support for relationships and daytime activities for adults with ASD. Yet services tend to decline for individuals with ASD after they leave high school, which appears related to reduced abatement of ASD symptoms, the frequent absence of daytime activities such as higher education or work, and strains on the mother-child

relationship (Shattuck et al., 2011; Taylor & Seltzer, 2011, in press). This gap in services suggests the need for strong coping skills, yet the strategies adults with ASD employ in their daily lives vary widely in types and degrees of success (Simmeborn Fleischer, in press; Müller et al., 2008; Sperry & Mesibov, 2005). Given the importance of quality of life during transition to adulthood and beyond, this chapter focuses on areas that encompass environmental components related to wellbeing, such as: social relationships, mental health, education, employment, and independent living.

## **2. Outcomes in adolescence and adulthood**

The core symptoms found in ASD include deficits in communication, impaired social interaction, and restricted interests and repetitive behavior (American Psychiatric Association [APA], 2000). These core deficits are further highlighted by poor social cognition or lack of theory of mind, a hallmark feature in ASD. For example, those with ASD often demonstrate deficits in the ability to understand another person's perspective, the demonstration and expression of empathy, or the understanding of emotions, all of which may be related to deficits in imagination and ability to engage in meaningful social interactions (Baron-Cohen & Wheelwright, 2004; APA, 2000). Such impairments in adults with ASD may include deficits in inferring point of view from language, explaining thoughts or feelings, or relating them to behavior and events, especially when provided with less apparent social cues (Colle et al., 2008).

Adults with ASD also have a tendency for selective attention that allows them to take in a high amount of information, but also display difficulties in integrating information or applying it in context (Bogte et al., 2009; Remington et al., 2009), resulting in a trend toward systematic, exhaustive decision making despite the ability to process information at a typical speed (Johnson et al., 2010). This type of idiosyncratic information processing (Minshew et al., 1997) can prove challenging in a variety of social contexts. While the tendency toward restricted, repetitive behaviors can be enhanced through selective attention and may even prove useful for scientific or professional endeavors (Yechiam et al., 2010), idiosyncratic information processing may actually impede reciprocity and spontaneity in social conversations and interactions (APA, 2000). Similarly, lack of cognitive flexibility and executive function deficits in individuals with ASD (Kleinhans et al., 2005) may relate to the greater unpredictability of social norms and contexts (Geurts, et al., 2009; Kenworthy, et al., 2008), making social interactions even more challenging.

Social deficits and low cognitive flexibility lie at the root of many challenges faced by individuals with ASD, particularly with regard to social relationships, education, mental health, education, employment, and independent living (Barnhill, 2007; Farley, 2009; Howlin et al., 2004). The following chapter will highlight the challenges experienced by transitional youth and young adults with ASD in these five key areas, all of which encompass transition into adulthood (Geller & Greenberg, 2010; Hendricks & Wehman, 2009; Lawrence et al., 2010).

### **2.1 Social relationships**

Not surprisingly, autism spectrum disorders (ASD) are characterized by impairments in the ability to develop peer relationships like friendships (American Psychological Association, 2000). Adolescents with ASD, relative to their neurotypical peers, tend to have low

friendship quality, if they have any friends, and to be on the periphery of social networks at their school, if not isolated (Locke et al., 2010). Although adolescents with ASD sometimes describe friendships in terms suggesting social and emotional reciprocity, such as mutual caring, responsiveness, and forgiveness, they often focus on concrete areas like common interests (Daniel & Billingsley, 2010; Howard et al., 2006; Carrington et al., 2003). This tendency does not appear to reflect lack of caring or poor emotional empathy, but rather deficits in understanding others' perspective (Blair, 2005; Dziobek et al., 2008; Jones et al., 2010; Poutska et al., 2010; Rogers et al., 2007). Individuals with ASD may identify making friends as their greatest social challenge, which may relate not only to knowing how to make appropriate choices regarding compatible social status groups or personalities, but also failing to initiate social interactions, and passively waiting for others to approach in order to avoid social rejection (Daniel & Billingsley, 2010).

One critical challenge in forming and maintaining relationships lies in conversational skills. Many, if not most, adolescents and adults with ASD have a pedantic speaking style (Ghaziddin & Gerstein, 1996). They also often have difficulty with articulation in areas such as phrasing, stress, and tone when speaking (Shriberg et al., 2001). Other difficulties include inappropriately formal, irrelevant or inappropriate detail, out-of-sync content and unannounced topic shifts, topic perseveration, unresponsiveness to others' cues, little reciprocal exchange, and absent or inappropriate intonation or gaze (Paul et al., 2009). Children with ASD may show deficits in resolving ambiguity, understanding inferential language, and using linguistic flexibility to produce speech acts limited by the communicative context. Adults with ASD may demonstrate difficulties in interpreting figurative language and producing relevant speech acts (Lewis et al., 2007). Moreover, linguistic impairments appear mostly related to specific pragmatic deficits rather than general linguistic abilities, as individuals with ASD may not demonstrate impairments in general narrative abilities like story length and syntactic complexity, but may not use the gist well to organize the story cohesively (Colle et al., 2008).

Perhaps due to deficits in conversational skills and difficulty relating to peers, many adolescents with ASD identify adults and school staff as their friends (Daniel & Billingsley, 2010; Humphrey & Symes, 2010b), even though they enjoy or desire friendships with peers (Daneil & Billingsley, 2010; Howard, Cohen, & Orsmond, 2006; Carrington, Templeton, & Papinczak, 2003). In turn, these adolescents often report comparable social support from teachers relative to typical peers, but low social support from classmates and friends (Humphrey & Symes, 2010b; Lasgaard et al., 2010). These adolescents may also view peers as unpredictable (Humphrey & Symes, 2010b) or disagree with the services for which their parents are advocating (Humphrey & Lewis, 2008), but think of teachers as reliable, helpful resources and sometimes as confidantes or "friends" (Humphrey & Symes, 2010b). For instance, in response to ridicule, adolescents with ASD will usually tell a teacher or another trusted adult (Connor, 2000), even though this strategy has limited effectiveness (Humphrey & Symes, 2010a).

Similarly, many adolescents and young adults with ASD have no friends, or only one or two casual friends, and rarely participate in social and recreational activities like making phone calls, having get-togethers, and attending clubs or social activities (Liptak et al., 2011; Orsmond et al., 2004). Friendships in both adolescents and adults with ASD often lack rich quality regarding intimacy, empathy, and supportiveness (Baron-Cohen & Wheelwright, 2003). Already challenged by poor social skills in such basic areas as using social cues and

entering, engaging in, and exiting two-way conversations, many young adults with ASD further limit their opportunities for social success by making few social initiations or withdrawing from social interactions or settings altogether (Shatyer, 2007). Yet adults with ASD do not necessarily prefer to be alone and may spend as much time in social company as their neurotypical peers, but tend to do so with people more familiar to them (Hintzen et al., 2010). Not surprisingly, many parents play an active role in social coaching or facilitating friendships for their adolescents and young adults with ASD (Howard et al., 2006; Orsmond et al., 2004), and parental advocacy tends to improve social participation (Liptak et al., 2011). For example, parents may encourage get-togethers and help their adolescent or young adult identify potential sources of friends in part by suggesting clubs that emphasize their child's interests and strengths (Gantman et al., in press; Geller & Greenberg, 2010; Laugeson & Frankel, 2010; Laugeson et al., 2009; Laugeson et al., in press). Many adolescents and adults with ASD describe their social challenges or deficits as barriers to their goal of fitting in (Humphrey & Lewis, 2008; Jones & Meldal, 2001) and often view their differences related to ASD as an underlying problem or obstacle to social acceptance (Humphrey & Lewis, 2008). For example, adolescents and young adults with ASD may rigidly adhere to moral or social rules or norms (e.g., "lying is bad") even at the expense of self-presentation gains, which suggests a need for tact and flexibility (Scheeren et al., 2010). Restricted styles of information processing may explain why adolescents and young adults with ASD may refuse to deceive even when they show understanding of how to make a good impression (Scheeren et al., 2010). Moreover, they may make a similar degree of positive self-statements when they want a peer to like them, but also make more references to honesty or truth than neurotypical peers that can interfere with the goal of a positive social impression. For instance, they may appear less strategic in adjusting to audience preferences and demands, in part because of a choice to not lie (such as pretending that one shares an interest in a neighbor's new pet; Scheeren et al., 2010). By adulthood, some individuals with ASD adopt diverse strategies in how they present themselves in public, with some trying to "pass" or apply additional effort to manage impairments related to ASD, and others openly self-disclosing their diagnosis for educational and advocacy purposes (Davidson & Henderson, 2010). Adults may also tend to be more open and less strategic around loved ones and friends, who tend to be more understanding.

Not surprisingly, the presence of poor social skills also appears to impact the development of romantic relationships and further affect the social independence of adolescents and young adults with ASD. Most neurotypical individuals develop close friendships and romantic relationships by young adulthood (Collins & Madsen, 2006), during which time romantic relationships are associated with achieving norms of adulthood like independence from parents, identity development, and commitment to long-term social relationships (Barry et al., 2009). The social and romantic functioning of individuals with ASD compares unfavorably to neurotypical peers, with social skills predicting the ability to form romantic relationships (Stokes et al., 2007). Even though both groups report sharing similar interests in forming intimate relationships, those with ASD often lack the social skills knowledge to appropriately pursue and engage in romantic relationships (Hellemans et al., 2007; Ousley & Mesibov, 1991). For example, they may not understand norms of social boundaries and naively behave in an intrusive manner with potential romantic partners, which may even be perceived as stalking behavior (Stokes et al., 2007). Other behavior possibly perceived as abusive includes inappropriate violent or sexual comments to peers of either sex, touching

peers without invitation, and pursuing younger children because of their greater compliance (Ray et al., 2004).

While many adults with ASD recognize that they need more education regarding romantic relationships and would benefit from receiving it a younger age (Mehzabin & Stokes, 2011; Müller et al., 2008), parents of youth with ASD often have concerns about their adolescent's sexuality or dating that surpass his or her social deficits and may not feel ready to have their child address this topic (Stokes & Kaur, 2005). Perhaps for all these reasons, romantic relationships appear to be infrequent (Stokes et al., 2007) and marriages are even rarer (Barnhill, 2007) for adults with ASD.

Nevertheless, while individuals with ASD may encounter great challenges establishing romantic relationships, some of those who do marry may enjoy successful relationships in part because of ASD-related qualities. Some men with ASD have happy, decades-old marriages in which informal support from family and friends, but not necessarily formal support or other coping styles, predict individual and marital well-being for both spouses (Renty & Roeyers, 2007). Marriage may provide more satisfaction to women than men with ASD; in marriages in which one spouse has high ASD traits, having high ASD traits may lower marital satisfaction for husbands but not wives. In both cases, the spouse's high ASD traits do not appear to affect the marital satisfaction of the spouse without high ASD traits (Pollmann et al., 2010). Strengths and weaknesses among the marital relationships between ASD husbands and neurotypical wives do exist. For example, young adult men with high ASD traits in romantic relationships show less interest in sex and less extravagant courtship than men with low ASD traits, but higher commitment to specific partners and long-term romantic relationships and greater investment of the allocation of resources toward a career and potential marriage (Del Giudice et al., 2010). Suggesting further complexity of romantic relationships, college students with high ASD traits may experience more romantic loneliness compared to their counterparts with low ASD traits, but ultimately may experience longer relationships (Jobe & Williams White, 2007). The ASD traits of attention to detail and difficulties with attention switching or need for sameness seem to instill a hyperfocus on loyalty to a specific partner that can lead to a committed relationship (Del Giudice et al., 2010; Jobe & Williams White, 2007).

Likely related to low self-awareness of social impairment, adolescents and young adults with ASD rate themselves more positively on measures of social functioning than do their parents, teachers, and clinicians, regardless of IQ (Cederlund et al., 2010; Green et al., 2000; Johnson et al., 2009; Koning & Magill-Evans, 2001). For example, many adolescents with ASD have poor self-awareness and report no differences between themselves and neurotypical peers (Green et al., 2000). Furthermore, many adolescents and young adults with ASD go through life never imagining that they have a disability until their parents disclose their ASD diagnosis to them, which often does not happen until at least adolescence (Huws & Jones, 2008). Even if their diagnosis had been shared at an earlier age, many adolescents seem unaware or unaccepting of their ASD diagnosis by not talking about their disability despite being asked about it (Camarena & Sarigiani, 2010). Perhaps earlier disclosure about ASD in a developmentally and socially sensitive manner, that takes into account the whole person and both the strengths and weaknesses associated with ASD, would help many individuals with ASD have a better understanding of themselves and their differences. In this way, these individuals might have a greater self-knowledge and self-awareness on which to build their social skills so that they may develop stronger and more meaningful friendships and romantic relationships.

## 2.2 Mental Health

The social deficits just described often co-occur and interact with psychiatric conditions such as anxiety and, perhaps especially, depression (Ghaziuddin et al., 2002). Adolescents who feel different from their peers are more likely to endorse depressive symptoms (Hedley & Young, 2006). A complicating factor may be that the depressed adolescent with ASD may not fully understand the role their ASD diagnosis or social deficits play in their challenges, consider themselves misunderstood and mistreated, and consequently feel depressed. Similarly, adolescents with ASD may develop a passive, failure-prone attributional style consistent with learned helplessness and depression (Abramson et al., 1978). Perceiving themselves as having made many great efforts at friendship in various settings, many make low ability attributions for social failure, thereby causing depression (Barnhill, 2001). They may generalize this social attribution, explaining negative events with internal, stable, and global causes and attributing external, unstable, and specific causes to negative events. This low-ability attribution to pervasive, outside forces beyond their control suggests a poor coping style, rather than more adaptively attributing failure to lack of effort or chance and task difficulty factors (Barnhill & Myles, 2001). Self-doubt, low self-esteem, and other depressive symptoms may intensify during the transition to adulthood, sometimes externalized as oppositional, irritable, or aggressive behaviors, or internalized as isolation and profound sadness (Ghaziuddin et al., 2002).

In adulthood, depression co-occurs more commonly in those who are older, have higher IQ, and less severe ASD symptoms, possibly reflecting greater self-awareness and harsher attitudes by others who have higher expectations (Sterling et al., 2008). For example, adolescents and young adults with less severe ASD symptoms are more likely to be victimized by peers, perhaps because they appear odd, rather than impaired by disability, making them more vulnerable to anxiety, depression, suicidal ideation, and avoidant behavior (Shtayermman, 2007). Adolescents and young adults with ASD often suffer from social stigma (Shtayermann, 2009). This social stigma relates not so much to disclosure of a label like Asperger's Disorder, but more to the presentation of atypical behaviors associated with ASD (Butler & Gillis, 2011).

Having a good friend or even physical companionship can form a strong shield against peer victimization (Hodges et al., 1999), and ultimately depression or anxiety. Perhaps due to the social naïveté and social isolation experienced by many with ASD, these adolescents and young adults may be seen as easy targets for teasing and bullying (Humphrey & Symes, 2010). Loneliness, low-quality best friendships (Whitehouse et al., 2009) and social withdrawal (White & Roberson-Nay, 2009) contribute to depression in adolescents and likely adults with ASD. Furthermore, social disability, poor social motivation, and negative affect have negative social impacts for adolescents with ASD (Schwartz et al., 2009; White & Roberson-Nay, 2009; Whitehouse et al., 2009). Furthermore, social rejection such as bullying may lead to a cycle of more bullying, because for most victims with ASD, the experience of bullying weakens social relationships and creates or exacerbates mental health problems like anxiety, low self-esteem, and loneliness, resulting in more asocial behavior like withdrawal (Humphrey & Symes, 2010).

Feelings of loneliness about relationships with peers often contribute to depression and social withdrawal in adolescents and adults with ASD. Usually in inclusive settings, adolescents with ASD interact mainly with and make regular social initiations toward neurotypical peers, but their social difficulties often result in social neglect and thus

loneliness (Bauminger et al., 2003). Indeed, low perceived social support from classmates and friends contributes to the experience of loneliness in this population (Lasgaard et al., 2010; Whitehouse et al., 2009) and possibly relates to low centrality and connectedness in social networks with peers (Locke et al., 2010). Adults with ASD describe experiencing a profound sense of isolation and related depression, with low-quality social relationships because of not knowing how to initiate and sustain conversations and relationships (Müller et al., 2008). For many adults with ASD, the highest level as existing friendships are “acquaintanceships” (Müller et al., 2008). Similarly, writings and interviews with people with ASD commonly include intense descriptions of loneliness and alienation related to social difficulties (Causton-Theoharis et al., 2009; Jones et al., 2001). Furthermore, because many individuals with ASD lack the social skills to appropriately engage in romantic relationships (despite having similar interests in these relationships compared to neurotypical peers), adolescents and adults with ASD often experience romantic loneliness (Mehzabin & Stokes, 2011; Ousley & Mesibov, 1991). Young adults with ASD report high concerns that they may never find a life partner (Mehzabin & Stokes, 2011) and adults with ASD in romantic relationships report longing for greater intimacy (Müller et al., 2008).

Like depression, anxiety appears to increase over time in people with ASD. Specifically, social anxiety and withdrawal increase throughout adolescence in this population, even though these symptoms tend to decrease during this period of development for neurotypical peers (Kuusikko et al., 2008). Anxiety appears to reflect concerns about peer relationships for adolescents and young adults with ASD, but may have a deeper root, as ASD symptoms may overlap with generalized anxiety and social anxiety (Cath et al., 2008). Restricted interests and general rigidity may cause anxiety about unfamiliar or unstructured experiences, as individuals with ASD often display obsessive behavior but are much less likely to seek out or feel rewarded by new stimuli (Anckarsäter et al., 2006; Ozonoff et al., 2005; Soderstrom et al., 2002). Although many want to establish and maintain social relationships, transitional youth with ASD may feel so anxious about the possibility of rejection that they feel compelled to avoid social situations and the possible risk of rejection or social failure. This avoidance may be so severe that these individuals do not even exhibit the initiative and self-directedness to give themselves the necessary exposure to peers or a significant chance to succeed (Anckarsäter et al., 2006; Ozonoff et al., 2005; Soderstrom et al., 2002).

Low social functioning and anxiety in social relationships tends to carry over to romantic relationships in adolescents and adults with ASD (Stokes et al., 2007). Romantic relationships appear more challenging and infrequent for young adults with ASD than other social relationships (Jennes-Coussens et al., 2006). Reports indicate significant concern and worry that others may misinterpret their behavior as sexual, possibly related to a lack of understanding about privacy and social boundaries, and sometimes a lack of understanding about their own sexual physical responses such as arousal (Mehzabin & Stokes, 2011). Having had less sex education and fewer sexual experiences than neurotypical peers, adolescents and young adults with ASD learn from themselves, peers, or friends, even though the information gleaned may be less accurate than that coming from an authoritative source.

Related to comorbid depression and anxiety, the low ability to self-regulate emotions at a physiological level may also render individuals with ASD especially vulnerable to stress in their social interactions (Bellini, 2006). Instead of trying to adaptively manage intense

emotions, adolescents and adults may try to avoid them and associated interactions (Corden et al., 2008). The high prevalence of a cognitive form of alexithymia in adults with ASD (Berthoz & Hill, 2005), a personality trait that poses barriers for the recognition, description, and interpretation of one's own emotional states (Silani et al., 2008), presents further obstacles for the ability of adolescents and adults with ASD to understand and regulate difficult emotions that impair psychosocial functioning (Hill et al., 2004). Alexithymia positively correlates with depression in adults with ASD (Hill et al., 2004), in part because it limits their ability to dissociate the emotions of others from their own. It may occur in at least 85 percent of the ASD population, but only 15 percent of the general population, suggesting that an inability to recognize and interpret emotional states may be a core feature of ASD (Hill et al., 2004). Alexithymia may also significantly reduce empathy in both the ASD (Bird et al., 2010) and general (Grynberg et al., 2010) population.

Poor emotion regulation abilities appear related to anxiety, possibly not only linking to emotional reactivity but also playing a role in the etiology of anxiety disorders (Cisler et al., 2010). While generalized anxiety relates more closely to poor emotion regulation strategies and intensity of emotions, social anxiety relates to poor emotional understanding (Mennin et al., 2009), all of which appear significant in ASD. Furthermore, many people with ASD refer to impairments in emotion regulation as sources of distress, fear, and anxiety and caused by sensory and information overload (Chamak et al., 2008). Indeed, sensory processing difficulties can cause anxiety for those with ASD across the lifespan, but they manifest heterogeneously within the population (Crane et al., 2009; Lane et al., 2010). Hypersensitivity to sensory input, such as sensitivity to noise and touch, can also impact physical health through discomfort and behavioral dysregulation, affecting energy, sleep, and exercise (Jennes-Coussens et al., 2006).

Co-occurring conditions may exacerbate core ASD social deficits (Barnhill, 2007), yet comorbid symptoms often go overlooked or lack treatment priority because they fall outside the hallmark aspects of ASD (Sterling et al., 2008). Accordingly, psychiatric disabilities like psychosis, schizophrenia, and bipolar disorder often viewed as less related to ASD than anxiety and depression may not receive sufficient clinical attention, even though adults with ASD present with all these conditions in higher proportions than the general population (Spek & Wouters, 2010; Stahlberg et al., 2004). While adolescents and adults with ASD often experience clinically significant distress, the extent to which it relates to self-evaluations or the social environment compared to biology remains unclear. Therefore, threats to mental health abound in adolescents and young adults with ASD and may occur more pervasively and at a more basic level than largely recognized.

### **2.3 Education**

While adolescents and adults with ASD who have average to high intelligence have the potential to perform well academically, many still underachieve. Many individuals with ASD lack the motivation to succeed academically, perhaps in part because of the wide range of subjects covered outside of restricted interests (Koegel et al., 2010). Others argue that adolescents with ASD regard school as an overstimulating and stressful environment for social and sensory reasons (Humphrey & Lewis, 2008), making it difficult to achieve academically. Thus, many individuals with ASD underachieve relative to their intellectual abilities (Estes et al., in press), a problem that intensifies with age, as primary grade children with ASD usually fare as well as their neurotypical peers, but fall behind in secondary

school (Goldstein et al., 1994). Moreover, many individuals with ASD drop out of college or never pursue post-secondary education despite their intelligence and focused interests (Cederlund et al., 2008).

Accordingly, while many with ASD can and aspire to succeed in college, they often require continued accommodations and services to do so (Van Bergeijk et al., 2008). The less structured nature and increasing independence of academics and life in college, and the exposure to peers in new environments, pose significant challenges for transitioning to and performing well in higher education (Adreon & Durocher, 2007). Large colleges and universities tend to have larger classes and a more impersonal nature than secondary schools, while smaller colleges usually lack the opportunities for students with ASD to find programs that match their interests and strengths (Van Bergeijk et al., 2008). Moreover, students with disabilities can no longer receive accommodations modifying academic content, but must personally navigate the service delivery system because at age 18, students with ASD and other disabilities become legal self-advocates who must self-disclose and identify their needs (Adreon, & Durocher, 2007). Unfortunately, campus disability offices, historically designed for veterans and still more suitable for students with physical and learning disabilities, usually lack the resources to meet the needs of students with ASD (Van Bergeijk et al., 2008). Sadly, many college students with ASD may lack the initiative or self-advocacy skills needed to seek these resources because of social deficits, anxiety, immaturity, and sometimes passive-dependent temperament (Anckarsäter et al., 2006; Soderstrom et al., 2002).

Although a growing number of colleges offer support programs for students with ASD (Zager & Alpern, 2010), some students may view supports as stigmatizing or unhelpful and prefer not to enroll in special programs despite their parents' wishes (Camarena & Sarigiani, 2009). Conflicting priorities arise from the trend that parents often consider their child's skill deficits most salient in college planning considerations, such as availability of social support and mentoring, while transitional youth with ASD may place greater value on environmental concerns such as the coursework and campus disability awareness (Camarena & Sarigiani, 2010).

The academic difficulties adolescents with ASD often exhibit may relate to Minshew and colleagues' (1997) description of ASD as a disorder of complex information processing that features uneven, idiosyncratic profiles of intelligence that show deficits in social contexts (Goldstein et al., 2008). A review of academic achievement among individuals with ASD found that upper grades require higher-order thinking that may place high demands on the cognitive styles of those with ASD, who struggle with organizational skills, switching attention, problem solving, and comprehension of complex operations (Whitby & Mancil, 2009). Adolescents and adults with ASD show deficits in judging the passage of time (Martin et al., 2010) and in cognitive flexibility (Bogte et al., 2009).

Although deficits which may impede academic success do exist, research also suggests that individuals with ASD may also possess several cognitive strengths. According to empathizing-systemizing theory (Baron-Cohen, 2009), individuals with ASD have deficits in empathizing, but selective advantages in systemizing, a personality characteristic concerned with the understanding of rules, the inner workings of objects, and the organization of systems. Systemizing involves a preference for systems that change in predictable, rule-based ways, and high "systemizers" attempt to find lawful patterns in data and discover the "truth" (Baron-Cohen, 2008). As an example, scientists as a group have high autistic traits

and are better “systemizers” (Baron-Cohen et al., 2001). In addition, people with ASD tend to have a meticulous decision-making style regardless of IQ that appears related to a heightened capacity for information load. However, operating on this higher level to filter out distracting, irrelevant stimuli may be required in order to be productive (Remington et al., 2009). Therefore, while ASD may relate to focused abilities that can produce talent (Asperger, 1944/Frith 1991; Baron-Cohen et al., 2009; Happe´ & Vital, 2009), sustained effort toward quality work may require great motivation and a conducive environment.

Despite the high potential of the more intellectually able students with ASD, many possible obstacles may hinder success and make the prospect of higher education a stressful experience (Glennon, 2001). The increasingly complex nature of assignments and course expectations in secondary school and then post-secondary higher education is just the beginning of these challenges. The transfer of responsibility from parents to individuals for disability-related needs and general independence imposes demands on decision-making and daily adaptive functioning that can become burdensome. Even those students who make wise choices that resiliently accentuate their strengths and compensate as much as possible for their deficits may struggle in group projects or otherwise with the attitudes of peers in classes and on campus, who often do not respond positively to ASD-like behavior (Campbell, 2007; Nevill & White, in press). Nevertheless, colleges and universities offer many social opportunities such as with student organizations and campus events; involvement in college life often complements academic success and may provide a buffer against risks to mental health (Wolf-Wendel et al., 2009). In addition, individuals with ASD may consider taking a “gap year” before starting college to work on social, academic, or independent living skills and to become more certain and motivated about their plans for college (Martin, 2010).

## 2.4 Employment

Perhaps more so than in education, individuals with ASD tend to fare much worse in employment settings than the potential suggested by their abilities (Geller & Greenberg, 2010). This is particularly true for those with at least average intelligence. While restricted interests may lead to hyperfocus and exceptional talent in a specialized area that can offer a foundation for a successful career (Grandin & Duffy, 2004), unfortunately, deficits in social skills often lead to employment failures despite task-related qualifications or performance. Core deficits in social interaction, communication, and sensory regulation; poor self-understanding of matching a personal profile of strengths, weaknesses, and interests to the work environment; and misperceptions by coworkers or supervisors have meant that many technically able people with ASD have failed to maintain appropriate employment or any employment whatsoever (Müller et al., 2003; Simone, 2010).

Adolescents with ASD already begin to fall behind their neurotypical peers in work experience, when ideally one would want them to get an early start to prepare for the intense challenges likely to come (Geller & Greenberg, 2010). Many neurotypical adolescents obtain summer or part-time jobs as a fast food worker, movie ushers, or camp counselors, but these jobs require social skills adolescents with ASD may lack. Many adolescents with ASD spend summers unoccupied, mostly staying home to play video games or keep to themselves, often lacking work experiences of even visiting their parent’s work for a day or equivalent exposure (Bashe & Kirby, 2001). Moreover, high schools often no longer offer vocational classes like auto shop, woodworking, or drafting, which could offer useful

experience for students with ASD, who often have creative or mechanical talents. To compensate for this gap in teaching, students could instead take classes in community college, technical school, or online; however, they may not have the time and energy amid their other secondary school activities (Grandin & Duffy, 2004). Other opportunities may include extracurricular school activities related to career interests, internships, service learning, or occupational mentoring to learn and practice work behaviors and gain awareness of a potential professional niche. Additional support on the job during the first few weeks of employment may help adults with ASD, as a mentor or job coach may provide advice about office politics or assist with the facilitation of flexible schedules or job sharing (Hurlbutt & Chalmers, 2004; Nesbitt, 2000; Portway & Johnson, 2005). Such support more easily takes place through the provision of supported employment, but few high-functioning academically included students with ASD receive such services (Higgins et al., 2008).

Indeed, employment needs often far exceed supports available for adolescents and adults with ASD (Gerhardt & Lainer, 2011). This phenomenon especially applies to those without intellectual disability or more severe symptoms of ASD (Liptak et al., 2011). Young adults with ASD and at least average intelligence are several times more likely to not have a daytime activity outside the home, such as higher education or work, than young adults with ASD and intellectual disability, who sometimes attend sheltered workshops or day activity centers (Taylor & Seltzer, 2011). Although adults with ASD without intellectual disability served by vocational rehabilitation centers incur lower costs to the system, these individuals are actually employed at lower percentages and for shorter periods of time than those with ASD and intellectual disabilities (Cimera & Cowan, 2009). Usually lacking formal support and various skills generally necessary for the workplace, even highly intelligent individuals with ASD at any one time are generally, if not unemployed, underemployed throughout adulthood (Howlin et al., 2004; Jennes-Cousens et al., 2006; Simone, 2010).

Several hypotheses have been offered to explain difficulties in employment for those with ASD. An initial challenge is the interview. Prospective employers expect a reciprocal conversation that requires quick thinking and responses to questions, posing a large hurdle for many adolescents and adults with ASD (Berney, 2004). Without knowledge of the ASD diagnosis, the interviewer may quickly conclude that the person with ASD has difficulty communicating and may erroneously think of him or her as intellectually incompetent or mentally unsuitable for the task (Portway & Johnson, 2005; Lawrence et al., 2010). However, disclosing one's diagnosis of ASD at an interview also poses risks to the hiring process (Meyerding, 2006). Individuals with ASD may need to have much higher skills and quality work than other applicants to get the job, and need to sell their portfolio, resume, or talents rather than their personality (Grandin & Duffy, 2004). For these reasons, some adults with ASD never get a job in their field of study (Hurlbutt & Chalmers, 2004).

As difficult as the hiring process may be, perhaps the greatest challenge individuals with ASD experience lies in maintaining employment. Related to the core deficits of ASD, these individuals may dominate conversations, persevere on topics of personal interest, talk about inappropriate topics or make other social blunders, be misunderstood or feel disrespected, become exhausted by social demands, or think of small talk as phony (Grandin & Duffy, 2004; Simone, 2010). They may not know how to engage in office politics or refrain from doing so for ethical reasons so as not to compromise their integrity. They

may get bullied, scapegoated, or deceived by coworkers, which can be a humiliating experience that weakens mental health or even physical health, and can be difficult to move past because of difficulty regulating emotions (Simone, 2010). They may try to react to victimization by being polite, but if seen as naïve and defenseless, co-workers' victimizing behavior may escalate (Hurlbutt & Chalmers, 2004). They may unknowingly violate other workers' personal space, causing discomfort, or cause stigma for other odd behaviors that do not demonstrate empathy or good listening skills, such as a pedantic speaking style coupled with poor reading of nonverbal cues that can cause them to be perceived as arrogant (Higgins et al., 2008). Or they may lack social tact and sound blunt in sensitive situations (Hurlbutt & Chalmers, 2004; Simone, 2010). As a method to combat these difficulties, coworkers who act as mentors or coaches may provide great help for these individuals in handling the challenges of the workplace (Hurlbutt & Chalmers, 2004; Simone, 2010). This informal support could reduce the need to disclose the ASD diagnosis on the job for accommodations or adjusted expectations, which, while possibly not as risky as doing so during the application or interview process, involves complicated considerations because of poor understanding or information about ASD in the workplace (Meyerling, 2000; Nesbitt, 2000).

Cognitive and sensory characteristics associated with ASD can also make completing work itself difficult. Employees with ASD may want to stress the need for explicit expectations with clear, written instructions, such as an outline (Hurlbutt & Chalmers, 2004; Simone, 2004). These individuals often struggle with multitasking, but perform well when they can focus on one task at a time (Higgins et al., 2008; Simone, 2010). As perfectionists without good perspective taking abilities, they may offer unsolicited advice or constructive feedback, or become immersed in a task or project of interest beyond the needs of the assignment (Simone, 2010). They may need autonomy to work at their own pace or flexible arrangements like working from home (Simone, 2010), but may have trouble asking for help or advocating for their needs (Hurlbutt & Chalmers, 2004; Simone, 2010). Moreover, sensory issues like sensitivity to noise, odor, sound, and lights may cause workers with ASD to become irritable or withdraw (Grandin & Duffy, 2004; Higgins et al., 2008; Simone, 2010). Some employees with ASD require total silence to concentrate and may even experience loud noises as traumatizing. They may be especially physically uncomfortable with the dress code or air conditioning and need to take frequent breaks to get natural lighting from overstimulation by fluorescent lights (Simone, 2010).

Despite the desire and ability of intellectually capable adolescents and adults with ASD, they tend to have poor job experiences. They typically have many positive characteristics related to ASD that can be assets at work, such as attention to detail, honesty, integrity, focus, diligence, taking pride in their work, a desire to please, independent and creative thinking, perseverance, and the ability to handle high amounts of data (Grandin & Duffy, 2004; Meyerling, 2006; Simone, 2010). Yet most do not disclose their ASD diagnosis at work, and those who do usually only tell a few supportive coworkers, for fear they will be suspicious, hostile, or patronizing from misunderstanding (Meyerling, 2006; Simone, 2010). This creates a higher need for workers with ASD to try to compensate by learning their field and building skills exceptionally well beyond the social challenges of marketing themselves and networking. If they do so, and find a field that values their strengths and tolerates their eccentricities and weaknesses, they have a much better opportunity of maintaining a suitable career (Grandin & Duffy, 2004).

## 2.5 Independent living

As a pervasive developmental disability, ASD typically affects the ability to live independently. While individuals with ASD and intellectual disability generally do not achieve typical outcomes such as independent living in adulthood, the performance varies widely in those with ASD and at least average intelligence (Howlin et al., 2004). Instead, daily living skills – perhaps more so than other types of adaptive behaviors – play a significant role in having friendships, employment or education typical of one's cognitive abilities, and general independence (Farley et al., 2009). Many adolescents and adults with ASD have difficulties with life skills such as cleaning, cooking, and hygiene (Balfe & Tantam, 2010) or other aspects of daily living such as sleeping (Limoges et al., 2005; Oyane & Bjorvatn, 2005), healthy or flexible eating, managing money, shopping, and driving or taking public transportation (Geller & Greenberg, 2010). Poor physical quality of life appears common and may contribute to this phenomenon beyond social naïveté or lack of motivation, as many report dependence on medical treatment or pain and discomfort that can limit energy, work capacity, and other activities of daily living (Jennes-Coussens et al., 2006). Poor mental health can also reduce independence, as young adults with ASD who live with their parents endorse more depressive symptoms than those who live independently (Cederlund et al., 2010).

Individuals with ASD vary in their ability to live independently from an almost typical level of functioning in general to requiring constant supervision (Frith, 2004). It remains unclear how many adults with ASD live independently. In countries like Sweden, where more formal support is provided, it appears that the majority lives independently but still may depend on services (Cederlund et al., 2008; Engström et al., 2003). Yet independent living involves taking responsibility for one's day-to-day affairs such as managing personal finances, gainful employment, and buying clothes for oneself, and in these respects a large minority, if not majority, of adults with ASD in Britain (Howlin, 2000; Howlin et al., 2004) and the United States (Farley et al., 2009) attain at least a moderate degree of independence. Generally, adults with ASD achieve adulthood milestones such as steady employment and living by oneself or with a partner or children later than neurotypical adults, and are unlikely to achieve independence during the traditional college-going years (Marriage et al., 2009).

This high dependence of individuals with ASD on their parents during young adulthood appears to place additional stress on the family during this period. For young adults with ASD, the parent-child relationship is generally positive and may protect against distress from poor peer relationships or the demands of daily living across the autism spectrum; parents tend to display positive affect and lack significant emotional expressivity or criticism toward their child (Greenberg et al., 2006; Wasserman et al., 2010). Yet, while the relationship generally improves as the child progresses through high school, and may continue to maintain or improve during the transition to adulthood for those with intellectual disability (Lounds et al., 2007), gains in the relationships (such as maternal warmth) may slow or reverse during the transition to young adulthood for those with at least average IQ (Taylor & Seltzer, in press). Since those without intellectual disabilities tend to experience a greater loss in services and are more likely to not have a daytime activity, increasing caregiving burdens and unmet needs for services or high expectations for development may strain parents (Taylor & Seltzer, 2011; Taylor & Seltzer, in press).

Adults with ASD tend to exert little responsibility for themselves relative to their peers. Individuals with ASD generally feel more comfortable with rigid routines and restricted

interests, and may resist change (Frith, 2004; Ozonoff et al., 2005). From childhood and throughout adulthood they may remain averse to seeking new experiences and, unlike neurotypical peers, become more motivated by fear of failure or other dangers than approaching the possibility of success or another reward (Anckarsäter et al., 2006; Schwartz et al., 2009; Soderstrom et al., 2002; South et al., 2011). By adolescence they may blame themselves for social or other disappointments and develop learned helplessness (Barnhill, 2001; Barnhill & Myles, 2001). Alternatively, they may become perfectionists (Greenaway & Howlin, 2010), such that those who are more intelligent or self-aware may continue to work on tasks that have a greater chance of failure despite having greater anxiety than others with ASD or neurotypical peers (South et al., 2011). These patterns reflect poor coping that can manifest in passive, avoidant behavior or obsessive, explosive behavior rather than flexibility and balanced risk-taking (Anckarsäter et al., 2006; Soderstrom et al., 2002).

Part of the challenge may lie in poor understanding of the self and others. People with ASD experience deficits in inferring others' emotional or mental states from social cues, sometimes referred to as *theory of mind* or *mindreading*, especially when they are subtler or numerous (Koning & Magill-Evans, 2001). They may sometimes compensate in understanding others' perspective through the use of logic and conscious effort (Beeger et al., 2010; Ponnet et al., 2004, 2005), but their judgments may still show impaired accuracy in more dynamic or unfamiliar, less structured contexts (Ponnet et al., 2008; Roeyers & Demurie, 2010). This ASD hallmark of poor social cognition may stem from introspective deficits about one's own thoughts and emotions (Lombardo & Baron-Cohen, 2011), although adults with ASD appear to have an intact sense of agency, or understanding themselves as the generators of their actions (David et al., 2008; Zwickel et al., in press). Therefore, individuals with ASD may have poor awareness of their various challenges in general, which may affect strategies of working toward goals of independent living.

Moreover, adolescents and adults with ASD may have subtle difficulties or deficits in executive functions like planning and making decisions, other goal-directed thinking, and self-regulation (Hill, 2004), which would make independent living challenging at best. Although these abilities show improvement into young adulthood (Berger et al., 2003; Luna et al., 2007), nevertheless, adults with ASD continue to fare best with predictability and may not know how to apply exceptions to rules (Pijnacker et al., 2009) during independent living. They tend to experience difficulties making valid inferences from prior knowledge (McKenzie et al., 2010; Bowler, et al., 2008), and thinking flexibly. They also may not understand the gist of things and instead attend to details, or when they have the opportunity, take longer to gather and choose between information before making confident decisions (Johnson et al., 2010; Yechiam et al., 2010).

The difficulties adolescents and adults with ASD may have making decisions for themselves suggests the pervasive nature of potential obstacles to independence that transcend difficulties with peer relationships (Channon et al., 2001). Transition planning teams during high school need to prepare adolescents with ASD for life and work skills toward independent living, but often fail to include age-appropriate goals (Kurth & Mastergeorge, 2010). Even so, more services are needed in adulthood. Meanwhile, parents need to strike a balance between providing support and facilitating a transition to social and general independence so that their children learn to advocate for themselves, whether through formal systems or informally.

### 3. Conclusion

This chapter suggests that individuals with ASD usually experience significant challenges in typical milestones or expectations in adulthood (Geller & Greenberg, 2010). While they tend to desire them, adolescents and adults with ASD usually lack or struggle to establish a peer support network, friendships, or romantic relationships. Social disappointments or failures often harm self-esteem and contribute to mental health problems that reduce motivation for growth opportunities like constructive risk-taking. Despite the prevailing focus in transition planning on academic achievement, even adults with advanced degrees in relevant fields often fail to secure suitable employment. Difficulties with creating self-disciplined structure and routines, and communicating personal needs, create challenges in higher education and work beyond following instructions from professors or employers and cooperating with classmates or coworkers. Adults with ASD often remain highly dependent on their family of origin, sometimes limited in the development and expression of separate values, preferences, and goals. While well-meaning parents sometimes become overly protective, the lack of sufficient professional support through transition planning and social, job, or life coaches means that strategic use of support from parents can help individuals with ASD acquire the skills to become more independent. Transitioning youth and adults with ASD must learn to exert control over their lives and undertake as much responsibility as possible. Clearly much work lies ahead in helping individuals with ASD become more socially connected, emotionally secure, educated, productive, and independent into adulthood. The descriptions in this chapter suggest continuity as well as change in the ASD phenotype; and more investigation into the development of ASD across the lifespan, which has traditionally focused on early and middle childhood (Matson & Neal, 2009). With more and better research and provision of services for adolescents and adults with ASD, perhaps supports can help to strike an appropriate balance between adaptation and accommodation (Barnhill, 2007). This may be especially true for employment, as the same restricted interests and attention to detail that can become disabling in social contexts can produce talent in the workforce (Happé & Vital, 2009). Indeed, Hans Asperger noted this phenomenon in the original paper on the disability named after him that the special interests and abilities of individuals with ASD can lead to success in professions such as the scientific or artistic fields (Asperger, 1944/Frith, 1991). With the right support, more adults with ASD can achieve success like Temple Grandin (2006), whose interests in science and animals led her to develop many of the humane livestock facilities in the world, and Tim Page (2009), whose early interests in music and media pointed him to a Pulitzer Prize-winning career as a music critic.

To maximize outcomes, the identification of and provision of services for adults with ASD need significant expansion. Most adults who meet criteria for ASD in the general population lack a clinical diagnosis, and among them, most lack personal awareness of ASD (Brugha et al., 2011, 2007; White et al., 2011). The amount of adults who meet diagnostic criteria for ASD appears comparable to the current diagnosed prevalence of ASD in children, or about one percent (Brugha et al., 2011, 2007).

Evidence suggests that the prevalence of ASD in the general population does not vary by age within adulthood, suggesting a long history of neglect for the clinical and support needs of many individuals in this population (Brugha et al., 2011). Undiagnosed individuals with ASD tend to lack intellectual disability, but the absence of a diagnosis does not reflect achievement of potential or lack of need for services. Compared with the general

population, these individuals have less likelihood of marriage or owning property, lower educational qualifications and income, and higher dependence on government support (Brugha et al., 2011). Lack of a diagnosis may exacerbate distress and make accessing appropriate mental health services, among other forms of help, more difficult. For example, symptoms in undiagnosed ASD in adults often relate to social anxiety, depression, and aggression, yet such adults do not appear to have greater use of the mental health system than the general population (Brugha et al., 2011; White et al., in press).

Providing appropriate support to adults with ASD will not only help them achieve a higher quality of life, but the increased productivity that may result from this investment can also ultimately save social economic costs. While adults with ASD tend to be unemployed or underemployed, they often do not receive supported employment programs to help integrate them into the workforce. When provided, they tend to help adults with ASD move toward competitive employment that reduces or eliminates their need for welfare and also contribute more to the economy and society (Howlin et al., 2005; Ja'rbrink et al., 2007). Beyond social services, clinical interventions also have the potential to significantly help adults with ASD. Not only must research on interventions for adults continue, but also the ASD field would benefit from longitudinal research on early intervention to understand long-term implications for commonly used and evidence-based programs for children with ASD.

Continuing to gain and disseminate knowledge about the ASD population may help individuals with ASD, their families, and professionals better understand their challenges and help them accomplish a high quality of life. As attention to the range of practical issues facing individuals with ASD and public understanding of ASD increases, tolerance for ASD may grow and current misperceptions of behaviors associated with ASD as character flaws may decline (Geller & Greenberg, 2010). Such progress, along with more understanding of how to legally accommodate individuals with ASD in higher education and especially the workplace, may encourage more adults with ASD to self-disclose to become more comfortable and proactive toward advocating for their needs and achieving greater success.

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