

# Outcomes in Adults With Asperger Syndrome

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This article explores the current research literature on adult outcomes of individuals with Asperger syndrome (AS). Specific areas addressed are the characteristics associated with adulthood AS, including employment issues, comorbid mental and physical health conditions, neurological issues, possible problems with the legal system, mortality rates, and treatment. The article interweaves the author's experiences as a parent of an adult son with AS and discusses recommendations and future directions.

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**A**sperger syndrome (AS) is a lifelong developmental disorder that is considered to fall on the higher functioning end of the autism spectrum disorder (ASD) continuum (Frith, 2004; Wing, 1996, 2000). Individuals with AS demonstrate impaired social interaction and restricted, repetitive, or stereotyped patterns of behaviors, interests, and activities. Unlike persons diagnosed with autism, persons with AS have intellectual ability and syntactical speech that is considered to fall within normal limits (American Psychiatric Association, 2000), but they have difficulties with pragmatic language, which may be demonstrated by an inability to provide the right information at the right time, a failure to use social niceties, an inability to read nonverbal cues, or a tendency to interpret information literally.

Although individuals with AS share the same set of core symptoms, these symptoms manifest themselves in various ways in different individuals, making diagnosis challenging. Diagnosis is further complicated, and may be delayed, when the person's strengths, such as strong vocabulary skills and rote memory, obscure problems in early childhood. Thus, teachers and parents may not initially be aware of difficulties because of the child's apparent intellectual ability or large fund of knowledge about a particular area or topic. Children with AS do not have distinct physical characteristics; therefore, their intellectual and physical abilities may be perceived as falling within the normal range. Furthermore, their social skills errors may be perceived as having a deliberate malevolent intent rather than as a true deficit area that needs remediation (Attwood, 2000).

AS can also be hidden in adulthood when an individual's intellectual ability is high and environmental support is good;

however, over time and in unexpected situations, the façade of normality cannot be maintained (Frith, 2004). For example, the individual may display the technical and intellectual skills needed to be successful when beginning a particular job; however, the social skills requirements may be overwhelming, causing him or her to say or do something that is socially inappropriate. Tantom (2000b) reported that consideration of a diagnosis of AS is typically triggered by a person's failure to adapt to a new social challenge, such as leaving school and having to find work.

Given that AS was not recognized by the American Psychiatric Association as a separate pervasive developmental disorder until 1994, when the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)* was published, many individuals with AS were either undiagnosed or misdiagnosed. Many individuals with AS remain undiagnosed well into adulthood (Ehlers & Gillberg, 1993; Gillberg & Ehlers, 1998). Consequently, they do not receive services to assist with their deficit areas. Due to the relatively recent recognition of AS, there is a dearth of longitudinal outcome studies on adults with AS.

## Purpose

This article reviews the current literature on adult outcomes of individuals with AS and makes recommendations for interventions and future research. Specific areas that will be addressed include employment issues, comorbid mental and physical health conditions, neurological issues, possible problems with the legal system, and mortality rates. The author has a strong personal and professional interest in the area of adult outcomes of individuals with AS. Professionally, she has worked with individuals with AS and their families for the past decade. Indeed, it was through this work and research that she realized that her son, Brent, had been misdiagnosed. Brent's social difficulties began surfacing when he was 4 years old, but intense perseverative interests were not apparent until later in elementary school. Tumultuous elementary and middle school years led to a calm adolescence, which was then followed by significant challenges in early adulthood. Brent finally received

a diagnosis of AS in 1997 at the age of 21. He continues to have difficulties, which are further complicated by a more recent additional diagnosis of bipolar disorder.

This author desires to help individuals with AS and their families receive the correct diagnosis and proper interventions. Professionals must educate the public on the issues associated with AS so that we all can develop an awareness and understanding of this socially disabling condition and assist individuals with AS in becoming valued members of society. Because few specialized support systems exist for adults with AS, most of them depend heavily on the support of their families to find jobs and accommodations. We need improved services for all high-functioning individuals on the autism spectrum throughout childhood and adulthood if their long-term outcome is to be significantly improved (Howlin, 2003).

### Problems Concerning Research on Adult Outcomes

A great deal of information is now available on children with ASD, but very little has been published on adults at the higher functioning end of the spectrum (Engstrom, Ekstrom, & Emilsson, 2003; Hurlbutt & Chalmers, 2004). Reviewing the research on adults with AS, Howlin (2000) reported several problems. Many individuals currently being studied as adults were diagnosed with autism as children. Few clinicians were aware of AS prior to 1981, when Wing wrote her seminal article in *Psychological Medicine*, and 1991, when Frith revived interest in Hans Asperger's earlier writings. In addition, the hierarchical system used by the text revision of the *DSM-IV* (*DSM-IV-TR*) according to which a diagnosis of autism rules out a diagnosis of AS, and vice versa, has presented problems for diagnosis, and the diagnostic criteria have been used inconsistently (Tryon, Mayes, Rhodes, & Waldo, 2006). Thus, research studies do not always distinguish consistently between autism and AS (Howlin, 2000).

Nordin and Gillberg (1998) recommended that outcome studies be longitudinal and population based. Few, if any, outcome studies on adults with AS today meet these requirements. Further, many of the existing studies used clinically based samples rather than population studies. A 30-year longitudinal study conducted in Denmark (Larsen & Mouridsen, 1997) followed a cohort of 18 children who were originally diagnosed as psychotic during in-patient psychiatric hospitalization but would meet the ICD-10 criteria (World Health Organization, 1992) for autism ( $n = 9$ ) and AS ( $n = 9$ ). The results demonstrated that in adulthood (mean age at time of study = 38 years) the patients with autism had a poorer outcome than the patients with AS in regard to education, employment, autonomy, marriage, reproduction, and the need for continuing medical and institutional care. According to Larsen and Mouridsen, one of the limitations of their study was that the 18 participants might not have been representative of the total

population of individuals with autism and AS. Their sample comprised less than 2% of the potential number of children with autism and just over 0.2% of the potential children with AS in Denmark.

### Types of Research on Adults With AS

Information on outcomes of individuals with AS can be gleaned from autobiographical and biographical accounts, clinical case reports, small-group studies, and the few existing longitudinal research studies. Several individuals with AS have written personal perspectives of their lives, their victories, and their challenges (e.g., Newport, 2001; Shore, 2003; Willey, 1999). Portway and Johnson's (2003) research on childhood experiences in relation to health outcomes in adulthood, as reported by adults with AS and their parents, indicated that although persons with AS "looked normal" and "talked normal," they never seemed to "quite fit in" (p. 435). Furthermore, many of these individuals described themselves as feeling like "outsiders," often being excluded educationally and socially and knowing they were different without anyone understanding why. All of the participants who were interviewed expressed views that likened their situation to "living on the edge of society" and being vulnerable to mental health problems (p. 435).

### Anecdotal Reports, Case Studies, and Group Studies

Asperger's (1944) clinical case reports indicated highly variable outcomes among his patients. He believed that it was often the special skills or interests, determination, and narrowness and single-mindedness of his most able patients that eventually led to their social integration. Wing (1981) examined and diagnosed 34 individuals with AS ranging in age from 5 to 35 years and reported variations from person to person. No studies investigating the course and prognosis of individuals diagnosed with AS were available in 1981 when Wing introduced the term *Asperger syndrome*. Wing (1981) noted that the prognosis of AS is often affected by the occurrence of superimposed psychiatric illnesses. Furthermore, she suggested that clinically diagnosable anxiety and depression may be found in older adolescents and young adults with AS and that this might be related to the painful awareness that they are "different." The degree of adult adjustment appeared to be related to the individual's level and variety of skills and temperament. Moreover, Wing stated, "Good self-care, a special ability that can be used in paid employment, and a placid nature are needed if a person with Asperger's syndrome is to be socially independent" (p. 119).

Tantam's (1991) description of 46 adults (mean age = 24 years) who met the criteria for AS indicated that all had been diagnosed as having autism when they were children. These individuals were known to psychiatrists who had identified

them as eccentric and socially odd. Only 2 had completed any education after high school, and only 4 were employed. Fifty-three percent were living in residential care, 41% were living with their parents, and only 3% were living independently. Tantam noted that despite AS's being considered a milder form of autism, it is still a highly socially disabling condition. The greatest challenges occur during adolescence and young adulthood, when social relationships are key to almost every achievement. Tantam cited Newson, Dawson, and Everard's (1982) study based at the University of Nottingham, United Kingdom, of 93 individuals (mean age = 23 years) from non-clinical sources who met the criteria for AS. Although the overall outcomes of this group were somewhat better than those of Tantam's clinical group, few of these participants lived independently. Eleven percent had education beyond high school, 22% were employed, 16% lived in residential care, 7% lived independently, and 71% lived with parents.

### **Follow-Up Studies From Childhood to Adulthood**

Based on a review of research on long-term outcomes in adult life of more able individuals with high-functioning autism (HFA) or AS, Howlin (2000, p. 79) concluded that "although high-functioning people with autism or Asperger syndrome *may* succeed well as adults, such achievements rarely come easily." Furthermore, although comparisons of outcomes in mixed-ability groups of adults with autism have demonstrated improvement over the past four decades, due to the relative paucity of studies focusing on these individuals, it is difficult to determine if improvements in individuals on the high-functioning end of the autism spectrum have also occurred.

Because of the problems associated with differential diagnosis, Howlin (2000) combined the results of studies involving people with HFA and AS in her review of the research literature on outcomes in adult life. Howlin closely examined several studies (Goode, Howlin, & Rutter, 1999; Larsen & Mouridsen, 1997; Lord & Venter, 1992; Mawhood & Howlin, 1999; Rumsey, Rapoport, & Sceery, 1985; Szatmari, Bartolucci, Bremner, Bond, & Rich, 1989; Venter, Lord, & Schopler, 1992). The studies ranged in size from 9 to 43 participants, with mean ages ranging from 18 to 38 years. Although the groups were relatively homogenous, the results regarding social functioning were extremely variable. For example, the proportion of participants with a college or university education varied across studies from 7% to 50%; the proportion of those living in semi-independent to dependent living arrangements ranged from 16% to 50%; and the proportion of those engaged in paid work ranged from 5% to 55%. The rates of psychiatric disturbance ranged from 9% to 89%, with most of the diagnoses classified as depression or anxiety. The number of individuals reported being married in each study ranged from 0 to 2.

In a more recent study, Howlin, Goode, Hutton, and Rutter (2004) investigated the adult outcomes of 68 individuals

with autism who had a nonverbal IQ of at least 50. (AS was not identified as a separate diagnosis in this study.) To participate, subjects had to meet the *DSM-IV-TR* and ICD-10 criteria for autism. According to Howlin et al., their study represents one of the largest systematic follow-up studies of autism in adult life. One of the most significant factors in determining adult outcome appeared to be the level of intellectual functioning in childhood. Their findings showed that only individuals with IQ scores greater than 70 were likely to do well. Results also suggested that the ability to function adequately in adult life might depend on the degree of support offered by families, employment, and social services, as well as on basic intelligence. The outcomes in the higher functioning group were also highly variable, and on an individual level neither verbal nor performance IQ proved to be consistent prognostic indicators. The variable adult outcomes revealed in this study were consistent with the outcomes reported in the research studies reviewed by Howlin (2000).

Engstrom et al.'s (2003) study of 42 adults from Sweden with AS and HFA revealed somewhat different outcomes than the studies Howlin (2000) examined. The majority of these adults lived independently; however, very few lived in "normal" psychosocial conditions, and most lived alone (p. 109). Only 1 participant was employed, none was married, and none had children. Most needed a high level of public or private support. Engstrom et al. noted that differences in assessment measures and selection biases probably played a major role in the large differences between studies. Furthermore, differences in geographical areas and interventions used may be part of the reason for the different outcomes. The researchers also suggested that independence might be based more on public strategies for individuals with disabilities than on actual social ability.

### **Research Findings on AS in Adulthood**

Several critical areas of concern for adults with AS are employment, comorbid mental and physical health, neurological challenges, possible involvement with the legal system, and mortality rates. A brief review of the current research in each of these areas follows.

#### **Employment Issues**

Individuals with AS have reported difficulty finding a vocational niche, securing work that is commensurate with their ability levels, maintaining jobs, and negotiating social relationships (Frith, 2004; Hurlbutt & Chalmers, 2004; Tantam, 2000a, 2000b). Mark Romoser (2000), an adult with HFA who graduated cum laude from Yale University, used the term *malemployment* to describe the employment situation for many individuals with ASD (p. 246). Romoser defined *malemployment* as working at a job far below your skill level and at a task for which you are unsuited. Employment difficulties begin

with the skills required for a job interview (Berney, 2004; Romoser). This author suggests that although individuals with AS may possess the technical skills required for a job, they may not be able to engage in reciprocal conversation or think and quickly respond to questions during a job interview. Despite the potential to work, few persons with AS are in regular employment, and those who are employed find their employment levels disappointing and their occupational status low. Many times jobs end prematurely, often leading to low self-esteem and depression (Goode, Rutter, & Howlin, 1994). For example, the author's son made social skills errors that resulted in the immediate loss of employment on two separate occasions after working 11 months steadily and despite having received positive performance reviews just days earlier. Each time he was fired, it took him longer to overcome the pain and embarrassment and to gain the courage to apply for work again. Goode et al. also suggested that the fact that individuals with AS are more able than persons with more severe ASD may mean that they are more distressed by their social incapacities. Inability to maintain employment due to poor social communication between employee and employer or coworkers, social skills deficits, and sensory issues were the biggest problems cited by adults with AS who were interviewed by Hurlbutt and Chalmers. Comorbid mental health and physical conditions and neurological issues, including difficulties with sensory issues, insomnia, and social cognition, had an impact on the adult's daily functioning and employability skills.

### **Comorbid Mental Health Conditions**

ASD usually appears with comorbidity (Tsai, 1996). An increasing number of investigators are arguing for accepting behaviors and symptoms that had been considered additional or associate features of ASD (e.g., hyperactivity, poor attention and concentration, compulsions, preoccupations, sleep problems, anxiety and fears, depressive mood, tics) as features of coexisting neuropsychiatric disorders, such as attention-deficit/hyperactivity disorder (ADHD), affective disorders, obsessive-compulsive disorders, and so on (Tsai, 2001). Bolte and Bosch (2005) reported that despite an increasing number of investigations on outcomes in autism and comorbidity in autism, research has not sufficiently combined the two issues. Possible reasons are that the diagnosis of autism encompasses such a severe and comprehensive label that secondary, tertiary, or subsequently appearing psychiatric problems are not viewed as pivotal. Furthermore, ICD-10 guidelines do not encourage multiple psychiatric classifications.

Ghaziuddin, Weidmer-Mikhail, and Ghaziuddin (1998) found the most common comorbid condition in children with AS was ADHD, whereas depression was the most common comorbid condition in adolescents and adults. They suggested that depression may be linked to difficulty in coping and social stigma, or that it may result from biological or genetic factors linked to the pathogenesis of AS. Although depression appears to be common in adults with AS and autism, it has

been difficult to establish a prevalence rate. The diagnosis of depression may also be obscured by the symptoms of AS, including social withdrawal and disturbances in appetite and sleep. Moreover, many symptoms commonly associated with AS change with mood (Stewart, Barnard, Pearson, Hasan, & O'Brien, 2006). For example, a decrease in self-care is common in depression and is often also accompanied by a significant decrease in adaptive functioning and the capacity for self-care.

Berney (2004), Ghaziuddin et al. (1998), and Tantam (1991, 2000a, 2000b) reported that affective disorders, including bipolar disorder and anxiety disorder, also coexist with AS, and that suicide rates are higher than would be expected for the general population (Wing, 2000). Berney (2004) further stated that the difficulty that individuals with AS have in identifying feelings could lead them to express their feelings in confusing and even unusual ways that might be misinterpreted as psychosis. For example, impassivity or lack of awareness of emotional climate may look like inappropriate or blunted effect, incomplete answers can be misinterpreted as psychotic symptoms, and thoughts expressed concretely and simply can be misinterpreted as hallucinations. Furthermore, individuals with AS often interpret questions literally or entirely from their own unique perspectives, and they often do not realize when they have been misunderstood. For example, in clinical interviews this author asked persons with AS whether they ever hear or see things that others do not, and they responded affirmatively. Such a response could lead to the assumption that they experienced hallucinations. However, upon clarification, the individuals reported that they had been told by others that they had acute hearing or vision and this, not hallucinations, was what they were describing.

Ozonoff, Garcia, Clark, and Lainhart's (2005) research utilizing the *Minnesota Multiphasic Personality Inventory—Second Edition* (MMPI-2) found that individuals with HFA and AS scored higher than control participants in areas that reflected social isolation, interpersonal difficulties, depressed mood, and coping deficits. The researchers suggested that the MMPI-2 accurately captures the ASD phenotypes and may be a valid tool for measuring both personality and psychopathology in this population. Soderstrom, Rastam, and Gillberg (2002) found that individuals with AS are often reluctant to accept changes and may be prone to anxiety and social detachment. The typical temperament patterns observed were obsessional, passive-dependent, and explosive. Wing (2000) also noted that features of ASD could also overlap with catatonia and Parkinsonian features. For example, catatonic slowness and episodes of "freezing" develop in a small minority of individuals with AS during adolescence and young adulthood. Wing stated that the development of catatonia is sometimes related to stress arising from inappropriate methods of care and management.

It is also possible that individuals who have been treated for chronic mental illness and appear to be resistant to treatment may have a primary diagnosis of AS that has gone un-

recognized. Ryan (1992, p. 907) reported that characteristics of AS such as “eccentricities, emotional lability, anxiety, poor social functioning, repetitive behavior, and fixed habits, can mimic other illness, including schizophrenia spectrum illness, bipolar disorder, anxiety disorders and obsessive compulsive disorder.” Ryan further noted that the disorganizing anxiety these individuals may experience in response to stress, which may include oddness of speech, could easily be misdiagnosed as psychosis.

### **Physical Health Conditions and Neurological and Sensory Issues**

Jennes-Coussens, Magill-Evans, and Koning (2006) investigated factors influencing the social and physical quality of life for 12 men with AS ages 18 to 21. These young adults with AS were not very satisfied with their physical health in the following areas: discomfort and pain, dependence on medical treatment, activities of daily living, work capacity, energy, fatigue, mobility, and rest. Problems in these areas lead to challenges with maintaining employability: It is difficult to maintain attendance at work when one is feeling fatigued and experiencing physical discomfort and pain. This author’s son deals with fatigue and physical aches and pains on a daily basis, and these challenges have clearly affected his ability to maintain consistent employment. He also has a difficult time describing the symptoms and origins of his aches and pains, which makes it difficult for doctors to treat him. His allergist has strongly suggested that foods that contain products to which he is sensitive, such as yeast, gluten, and casein, are causing his general malaise.

Many individuals with AS experience sensory challenges that others are not even aware of. For example, Grandin (1995) contended that noise sensitivity, oversensitivity to touch, and difficulties with rhythm cause behavior problems, and Aylott (2000a) stated that these issues are frequently overlooked by support services. Some sounds can actually hurt a person’s ears, and he or she may be fearful of anticipated noises and hum or make other noises to block them out. A firm touch may be calming, but a light touch may cause alarm in the person’s overaroused sensory system. Williams (1998, p. 9) described this heightened sensory awareness as “simply an internal human ‘normality’ with the volume turned up.” She stated that we all experience times when we are hardly aware of our bodies or the world around us and times when we are so overly aware that it is hard to function. As a result, we have all felt hypercritical at times, been eager to escape, have tuned out or wanted to disappear. There are times when we have lost the plot of what we were reading or have been distracted by thoughts and felt jolted out of a daydream. We also have been so aware of stimuli in our environment that we have taken in almost every overwhelming detail. However, Williams contended that it is not just any one of these that in itself is the sensory experience of autism. Rather, the experience of autism

is the frequency and extreme nature of these experiences together with the degree to which they affect how a person expresses himself or herself in relation to his or her inner and outer worlds. Furthermore, Williams suggested that the sensory experiences of individuals with autism may be similar to those that most individuals have at early stages of their development, before they learn to interpret their senses and cope in the world.

Challenges with motor skills are also prevalent in individuals with AS. Asperger (1944) described awkwardness as a characteristic typical of the boys he studied. Further, Wing (1981) reported that 90% of the 34 individuals with AS she studied displayed clumsy and ill-coordinated gross-motor movements and that posture and gait appeared odd for some. Participating in games involving motor skills can be challenging. In addition, Wing (1981) noted that executive problems or challenges with planning sometimes affect their ability to write or draw. The ICD-10 criteria indicate that clumsiness is frequently associated with AS. Little research has specifically investigated whether neurological abnormalities persist into adulthood. However, Tani et al.’s (2006) recent study revealed that this is indeed the case. They found that deficits in the areas of gross- and fine-motor skills appeared to differentiate adults with AS from adults without AS in their study. Their findings are in agreement with the clumsiness that Tantam (1991) observed in his participants with AS. Furthermore, Tani and colleagues reported that soft neurological signs, in particular, represent a nonspecific vulnerability factor for AS.

Several researchers (e.g., Oyane & Bjorvatn, 2005; Tani et al., 2003) have found that sleep disturbance patterns in adolescents and young adults with AS are similar to those described in children with AS; however, it is not clear whether insomnia in this population is due to AS itself, comorbid psychiatric disorders, or a combination of the two. Oyane and Bjorvatn suggested that sleep disturbance may be explained by a higher prevalence of anxiety, fear, or social behavior problems. This author’s son continues to have significant difficulty falling and staying asleep, which has affected his ability to work consistently in paid employment. He frequently tries to find part-time employment that offers afternoon hours so that he does not have to report to work early in the morning, when he may be unable to wake up due to difficulty falling asleep the previous night. He also has done clerical work for a business that allowed him to set his own hours. He told his boss many times that he would be at work the following day, and due to the fatigue and physical discomfort that he frequently experiences, he was unable to work as he had promised. His boss allowed him to reschedule and left filing work available so that he could do it when he was able to come to work. The organization that Brent worked for provided services to individuals with developmental disabilities and, therefore, was very supportive of his unique needs. He was also fortunate that his job did not require that he meet deadlines and that filing was almost always available to be done whenever he could work.

## Social Cognition

One of the hallmarks of AS is impaired social learning and social awareness. Frith (2004, p. 676) described this as “an extreme form of egocentrism with the resulting lack of consideration for others.” However, this self-absorption and disregard of others is not like the behavior a neurotypical self-ish person might exhibit in acting deliberately for his or her own best interest. Egocentrism in AS appears to be nondeliberate and is not determined by what might currently be best for the person. It also appears to cause significant difficulty in forming long-term interpersonal relationships. Individuals with AS often feel baffled by their family members’ or coworkers’ frustration with their egocentrism because they are not able to put themselves in the other persons’ shoes and imagine what their own actions and words feel like from others’ perspectives. Frith also noted that social impairment is more evident in real-life situations than it is in hypothetical laboratory situations because in real life the social cues are frequently ambivalent and responses are required to be fast.

Building social relationships by making friends and establishing intimate partners is a key developmental life stage for young adults. This is another area of significant challenge for many persons with AS. Although they report a desire for relationships, they tend either to approach others in an inappropriate physical or verbal manner or to misread subtle social cues or body language. Furthermore, sometimes their actions are misread as sexual overtures, when that may not have been the intent. Aylott (2000a) reported that many adults with ASD had not received sex education at school because it had only recently been included as a mandatory curriculum. Furthermore, even if they had received sex education, it may not have been provided within “a social skills context” (p. 856) designed to ensure that students understand the social context for sexual expressions and behavior. The lack of education in this area may also confound problems associated with attempting to establish relationships and connections with others. This author’s son has arranged many dates to meet with women he first chatted with online. Often these dates turned out to be single encounters.

Meeting people over the Internet has had both advantages and drawbacks for the author’s son. The benefit has been that the awkward pauses in a face-to-face conversation are not as apparent over the Internet. However, Brent tends to believe most of what people write online, and he frequently meets people who are savvier than him and who have attempted to take advantage of his naiveté. When he has met people in person, he has misread their intentions and at times offended them with his comments without being aware that this was the case. Individuals with AS can find themselves in vulnerable situations and not even realize the predicaments they may become involved in, especially in today’s litigious world, with its concerns with sexual harassment. As stated earlier, Brent has lost jobs because of social interactions with peers; however,

fortunately, he has never been involved with the legal system as a result of his social skills errors. The author is aware of individuals with AS who have been incarcerated because of poor problem solving due to social cognition challenges.

## Problems With the Legal System

According to Howlin (2000), there is little documentation of any excess of crimes among people with HFA and AS, despite media descriptions of occasional lurid events suggesting otherwise. Mawson, Grounds, and Tantam (1985) reported on various violent behaviors of a 44-year-old man who had originally been diagnosed with schizophrenia but later was thought to have AS. He had stabbed a girl in the wrist with a screwdriver because he said he was jealous that she had a car and he did not like women drivers. He also entered a neighbor’s house with a knife because he was upset by the dog’s barking, and on another occasion tried putting his hands over the mouth of a baby crying at a railway station because he could not tolerate the noise. Baron-Cohen (1988) described a 21-year-old man who was frequently violent toward his 71-year-old girlfriend. Baron-Cohen suggested that this young man was unable to appreciate the thoughts and feelings of others. Wing (1981) and Tantam (1991) noted that isolated incidents of offending resulted from an obsession with experimentation. Some of the crimes reported may be unusual because they are associated with the person’s lack of social understanding, rigidity of behavior, or obsessional interests. Ghaziuddin, Tsai, and Ghaziuddin (1991) reported that the incidence of violence or other offenses by people with ASD was very small. In fact, it was suggested that because of the very rigid way many of these individuals tend to keep rules and regulations, they might be more law abiding than the general population. However, it is important to note that given the challenges with reading and interpreting social skills, these individuals may be set up by more savvy individuals to be accomplices to crimes or unlawful activities without being aware of this.

## Mortality Rates

Previous research has suggested that mortality rates among individuals with ASD below the age of 30 are substantially higher (2%) than in the general population (0.6%; Gillberg, 1991). However, Goode et al. (1994) noted that the disparity could be due to an association with severe mental intellectual disability and other complications, such as epilepsy. Isager, Mouridsen, and Rich (1999) found that mortality rate was related to intelligence according to a U-shaped function, with both severe intellectual disability and normal intelligence being associated with a relatively high risk of death. According to these researchers, the U-shaped correlation between intelligence and death may be explained by physical causes and accidents for patients with severe intellectual disability and by the risk of suicide in people of normal intelligence who suffer from

depression and perhaps drug abuse. They cautioned that more research was needed to verify these findings. It is interesting to note that the mortality rate cited by Isager et al. was about double the expected rate. This may be due to the fact that their patients were followed for a longer period of time (mean of 31 years) than had been done in previous research studies.

## Treatment

The behavioral and pharmacological interventions used to treat individuals with AS do not have any effect on the underlying impairments of AS or autism; rather, they treat the symptoms (Blackshaw, Kinderman, Hare, & Hatton, 2001; Ryan, 1992). Interventions such as education-based treatment plans are often adapted from the field of learning disabilities and focus on turning eccentricities into strengths and on direct teaching of information and social skills (Blackshaw et al.). Tantam (2000b) suggested that professionals must accept the fact that their responsibilities to people with AS extend beyond making a diagnosis in childhood. Thus, he strongly recommended that services include medical and functional assessment, psychoeducation, family intervention, medical and psychological treatment for emotional and conduct problems, and—probably most critically—counseling by professionals who understand the subjective experience of AS. According to Frith (2004), Asperger recommended that education be based on a deep understanding of the condition and noted that individuals with AS were of high value to society.

To be effective, treatment and intervention must be a collaborative effort, explained to and agreed upon by the individual with AS and the service providers (Tantam, 2000b). Service providers should not assume that the person with AS understands his or her condition, even if he or she has read extensively about it. Further, explanations should be clear and matter of fact and should avoid euphemisms, colloquialisms, and metaphors. It is also helpful to explain that although AS is frequently complicated by other psychological disorders and may itself not be treatable, treatment of the other disorders may diminish the severity of the AS. Intervention to treat psychological issues involves consideration of the environment, especially the social environment and the individual's reaction to it. Medication may be recommended if there is a clear-cut comorbid condition that is known to be susceptible to medication. Tantam highly recommended that the views of the individual and his or her caretakers in regard to medication be respected when designing treatment plans and that the goals of treatment and the likely effects and side effects should be explained and consent obtained. Furthermore, Tantam argued that the wishes of the person with AS should take precedence over the wishes of the persons caring for him or her. Tantam found that counseling was effective in identifying and sorting out misinterpretations for some individuals with AS who presented with the following issues: psychosis associated with entry into college, financial exploitation by acquaintances, al-

cohol misuse, family criticisms as a result of job and educational failures, and the consequences of sexual abuse by a previous therapist.

## Recommendations

To improve outcomes of adults with AS, it is imperative to increase public awareness of the condition so that diagnoses can be rendered earlier and appropriate supports can be provided. Educational opportunities and assistance in securing and maintaining employment are critical to ensure that these individuals have the opportunity to be successful in adulthood.

### *Increased Public Awareness, Education, and Recognition of AS*

Public awareness of AS and resources available for educational and other services are still limited, despite recent advancements in the field of ASD (Klin & Volkmar, 2000). Although the National Research Council (2001) recommended that children who receive a diagnosis of ASD be eligible for special educational programming under the educational category of "autism" (p. 3), regardless of the specific diagnostic category within the autism spectrum that they were given, this has historically not been the case. Thus, students with AS have not always received the level of support, services, and resources that are available to peers diagnosed with autism, because their challenges and strengths can be quite different. This has resulted in a void of services for more able individuals with social disabilities. Klin and Volkmar described these children and their families as "orphans in a system primarily categorized in terms of autism on the one hand and the more academically based learning disabilities or mainstream education on the other hand" (p. 341). Furthermore, they proposed that education and treatment center on the long-term goals of promoting social opportunities and better capitalizing on each individual's natural talents, vocational satisfaction, living skills, and general emotional well-being.

Awareness efforts need to continue to target medical professionals and educators, teaching them about the characteristics of AS so that diagnosis can be rendered earlier and services can be accessed sooner. Professionals in education and medicine need to be willing to expand their knowledge of ASD and recognize their own biases and attitudes toward individuals who are socially different. Individuals with AS often find themselves in a network guided by disability specialists who have a limited knowledge of the syndrome (Berney, 2004). Aylott (2000a, p. 857) suggested that healthcare professionals reflect on their expectations and the way that they can "disable the people they are seeking to support by not responding appropriately to their needs." She recommended viewing ASD less from the perspective of an impairment model and more from the perspective of a social model so as to better help adults with ASD develop a positive self-identity and challenge the

barriers that continue to exclude them (Aylott, 2000b). Furthermore, she contended that we will only be able to be fully supportive in helping people on the autism spectrum develop a positive identity if we believe in their potential to be able to achieve and make decisions about relationships, sexuality, and personal growth and development (Aylott, 2000a).

In addition, the public needs to know the characteristics and issues associated with AS so that they can better understand how to interact with individuals with ASD who live in their communities. Tantam (2000b) asserted that the social reactions of others leads to distress in persons with AS to a greater degree than had been previously realized. Although individuals with AS may function well intellectually, their appearances of normality can be deceptive and often break down under stress (Frith, 2004). They need to be surrounded by others who recognize their vulnerabilities, do not take their social challenges or sometimes inappropriate behavior personally, and are willing to support or guide them to the appropriate support services.

### ***Education Services and Employment Opportunities Need to Be Available for Adults With AS***

The National Research Council (2001) reported that educational goals for children with ASD should be the same as those for other children, namely, personal independence and social responsibility. Due to the developmental nature of AS, these goals should continue to be addressed during adulthood. Individuals with AS need to learn consciously the skills most of us acquire intuitively (Berney, 2004), including social skills, shopping, laundry, and personal hygiene. Aylott (2000a) also pointed to the need to teach young people and adults with autism about sex and relationships by using an individual rather than a group approach so that the teacher or counselor can check their understanding of what is being taught.

Some research has indicated that some adolescents with AS have a learned-helplessness attributional style that may predispose them to depression or to maintain depressive symptoms and, therefore, cognitive behavioral interventions may be necessary to target these maladaptive attributions (Barnhill & Myles, 2001). The cause or attribution that the individual makes of an event predicts the reoccurrence of the expectation, and the expectation in turn determines the occurrence of the helplessness deficits, according to the reformulated learned helplessness model (Abramson, Seligman, & Teasdale, 1978). Barnhill and Myles found that the greater number of depressive symptoms adolescents reported, the more they explained negative events by internal, stable, and global causes. In other words, they explained negative events such as a poor grade as their responsibility (internal beliefs), considered the event to be long lasting or consistent over time (stable), and believed the event to be pervasive or occur over many situations rather than be specific to the particular situation (global). Seventy percent of the 33 adolescents studied were taking antidepress-

sant medication, and only 9% of them reported having substantially more depressive symptoms than their peers. These findings suggest that the medication may have controlled their depressive symptoms but did not affect their maladaptive attributional style. Teaching these individuals to change to a more adaptive attributional style may be a goal appropriate in counseling. Depressive symptoms were also found to correlate with ability attributions for social failure for adolescents with AS, suggesting that interventions may need to focus on teaching them to attribute social failure to causes other than ability (Barnhill, 2001). Further research is needed to determine if these findings hold true for adults with AS because this could provide valuable information in designing cognitive-behavioral-based interventions for this population.

Ryan (1992) recommended consideration of educational and habilitative plans, rather than medication-based plans, for adults with AS who have sufficient motivation. She gave an example of an individual who was motivated to work for money because he wanted to buy computer equipment. His eccentricities and interests in computers were developed into strengths. The perseverative interest of this author's son has been to spend time on the computer searching for contests to enter, free items to win, and people to meet through Internet chat rooms. He has had considerable success winning contests, and this has positively reinforced him, so he continues to devote more and more time to these endeavors. Earning money through contests and acquiring free items has been even more motivating at times than paid employment for Brent. This makes it difficult for him to see the need to work to earn money to purchase the items he wants, especially when he is feeling very stressed by the anticipation of social demands at the workplace.

One model of supported employment being implemented in the United Kingdom is the National Autistic Society's supported employment service called Prospects. This program was originally designed as an innovative employment pilot program to address the needs of more able individuals with autism in and around London. Research has suggested that support for individuals with ASD was particularly crucial during the first few weeks of employment (Howlin & Mawhood, 1996). Furthermore, this study revealed a need for flexibility within the supports provided as individuals experience changes in work or have problems that may indicate they need a temporary boost in the number of support hours received.

The Prospects program provides support in the workplace to people with ASD through the government's Access to Work structure, and there is no cost to the employer for the following services: orientation of the client to where things and people are in the place of employment; identification of training needed; job analysis, including guidelines or breakdown of each task within the job; structure, including breaking down the day and creating time plans; disability awareness training for colleagues; social training awareness and instruction on the unwritten rules of the workplace; and development of an effective working relationship between the employee and the



line manager. Once the employee is settled and has gained some confidence, the support is gradually reduced (National Autistic Society, 2006).

It is this author's belief that support services must be individualized for each person with AS. Furthermore, flexibility must be built into the employment assistance service model. For instance, a person may be able to work in a competitive employment environment and require no on-site supervision, needing only regularly scheduled meetings with his or her job coach off site. The role of the job coach could be to serve as a liaison between the individual and the employer, and he or she could troubleshoot any situations before they develop into problems. However, at another time in the same person's life, he or she may need more supported employment assistance, such as one-on-one assistance from a job coach at the work site. This one-on-one support may be gradually faded over time.

The author's son did not receive coaching assistance on his job sites because he insisted that he did not need this level of support when he began receiving vocational rehabilitation assistance. His vocational counselor therefore did not assign him a job coach. In hindsight, it might have been wise to have provided Brent with some initial coaching assistance and then faded it away as he became more comfortable with the work environment and the job demands. However, Brent emphatically stated that he did not want to look different by having a job coach on site since he believed that he was able to handle the job duties on his own. Brent's cognitive abilities certainly suggested that he could handle the actual job tasks. Along with Brent's vocational counselor, it was reluctantly agreed that the vocational counselor's role would be to telephone Brent and the employer every few weeks to discuss Brent's work progress but not to provide an on-site job coach. It was encouraging to see Brent advocate for his needs and desire to work independently. However, the author did not want to see him fail again if some temporary assistance could be given that would enable him to maintain successful employment. Unfortunately, the social demands and the noisy and chaotic office environment became too much for him to handle after a few weeks. Brent was not able to express these challenges explicitly and instead, when asked by his vocational counselor, replied that work was going fine. The employer also indicated that there were no major issues. When Brent started feeling more uncomfortable at work but could not specifically describe the issues, he heeded his parents' coaxing to ask the vocational counselor if the psychologist who diagnosed him with AS could talk with the employer and employees about AS to give them a better understanding of his condition and help him at work. The vocational counselor agreed to set up a meeting with the psychologist, who instantly offered his assistance. Unfortunately, Brent was fired before this could be scheduled with the employer.

Brent's next employer told his new vocational counselor after Brent was hired that he did not realize Brent had a dis-

ability and that he would be happy to hire more individuals like Brent if the counselor knew of any. The employer indicated that he liked Brent and that he would talk directly to him about the work requirements, rather than through the vocational counselor, because Brent had the skills to do the warehousing job. The vocational counselor tried to call the employer several times. At first, she was told that Brent was doing well. Later her phone calls to check on Brent's progress were not returned. Eleven months later the employer initiated a call asking her to come to the work site for the first time because he was going to fire Brent that day when he came to work. She immediately called Brent's father, who was able to be there right after Brent received the devastating news. Brent cried inconsolably, became physically ill, and was not able to drive himself home from work that afternoon. It was fortunate that his father was called and could be there at the work site to support him emotionally and drive him home.

Brent's disappointing work experiences continued despite his parents' efforts to educate the professionals who worked with him. Many of the jobs for which he was hired were below his skill level, and it was later realized that they were also not suitable for him. The professionals, Brent's parents, and Brent himself came to learn that he needs a job with some variety, clear expectations, few distractions, and contact with other persons that is not prolonged so that social challenges do not become overwhelming and so that others do not take advantage of his naiveté. It is also crucial that the professionals working with him be proactive in assessing his job situation, work demands, and the social environment and continue to do this on a regular basis, even if it is behind the scenes and not directly at the work site. Brent often cannot describe how he feels, so it is imperative that persons not assume that his one-word answers of "Fine" or "Okay" truly describe how work is progressing.

## Future Directions

Research efforts must continue to address the issues associated with the differential diagnosis of AS. If diagnosis of the condition is not consistent, it will be difficult to determine whether studies of intervention strategies are resulting in interventions that will be effective for individuals with AS. One of the challenges is that AS encompasses a heterogeneous group of individuals, in which no two are alike. It is also imperative to understand each individual's needs so that appropriate educational and vocational supports can be provided. One way to obtain information about the needs of individuals with AS is to ask them directly about their perceptions of their areas of strength and their areas of need. Families may also be able to provide valuable insights. More employment models like Prospects need to be implemented to assist these individuals to be successful in the work world and to find their niche. Research on the key support services required for successful

employment need to be conducted. In addition, different housing options must be explored and developed. Provisions need to be put in place for the time when adults with AS outlive their parents, especially if no other family members are available to provide support to help these people live independently, semi-independently, or in a group home facility. Many of the existing group home living options provide housing for people with significant cognitive delays or significant mental illness, but there are few, if any, supported or partially supported housing options for individuals with AS in the United States.

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