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Adults with Asperger Syndrome: A Childhood Disorder Grows Up

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Abstract

Asperger syndrome is a chronic developmental disorder characterized by problems in social relatedness, empathic communication and understanding, and circumscribed interests. The inclusion of Asperger's Disorder (Asperger syndrome) in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV; American Psychiatric Association, 1994), has produced a marked interest in the identification and treatment of this autism-related condition. Although there has been a dramatic increase in the research and clinical studies related to children, there is a paucity of information regarding Asperger syndrome in adults. The purpose of this article is to provide an overview of the assessment and practice issues for adults with this lifelong disorder.

## Adults with Asperger Syndrome: A Childhood Disorder Grows Up

### Introduction

Asperger syndrome is a neurodevelopmental disorder first described by Hans Asperger (1944), a Viennese physician, over a half-century ago (Asperger, 1991). Few clinicians were aware of this autism-related condition prior to 1980, when Lorna Wing first popularized Asperger's work and brought it to the attention of the clinical community (Wing, 1981). The essential diagnostic features of Asperger syndrome are severe and sustained impairments in social relatedness and restricted, repetitive patterns of behavior, interests, or activities in the presence of generally age-appropriate language acquisition and cognitive functioning (Volkmar & Klin, 2000). As a continuous and lifelong pervasive developmental disorder, Asperger syndrome has significant clinical implications for personal, social, occupational and other important areas of functioning. Often referred to as a "hidden disability," individuals with this condition have no clearly visible or obvious disabilities and are not easily distinguished from other members of their peer group (Prior, 2003). In many respects, it is this "mildness" that makes the psychological and social consequences of Asperger syndrome so debilitating (Grandin & Baron, 2005; Tantum, 2000).

### Adults with Asperger Syndrome

Since the inclusion of Asperger's Disorder as a clinical entity in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV; American Psychiatric Association, 1994) and the *International Classification of Diseases* (ICD-10; World Health Organization, 1993), there has been a marked increase in the volume of research and

clinical studies relating to children and adolescents. Although the prevalence in the general population is unknown, estimates of Asperger syndrome in the school age population are as high 1 to 5 per 1,000 children (Ehlers & Gillberg; Kadesjo, Gillberg, & Nagberg, 1999). Yet, we may be identifying only one-half of the children and youth affected with this condition (Attwood, 2006; Barnhill, 2001). Thus, it should come as no surprise that many adults have not been diagnosed during childhood and remain an underserved population (Gillberg & Ehlers, 1998; Woodbury-Smith, Robinson, Wheelwright, & Baron-Cohen, 2005).

We have only recently begun to appreciate the complex challenges faced by adults with Asperger syndrome (Attwood, 1998; Hurlbutt & Chalmers, 2004; Howlin, 2000; Tantam, 2000). Because they grow up experiencing the world in a very different way than most neurotypical peers, problems often become more apparent over time as greater demands are made on social skills and adaptive behavior. (Attwood, 2006). Accurate differential diagnosis and a greater appreciation of the social difficulties associated with Asperger syndrome are critical because the high proportion of individuals who may be overlooked, misdiagnosed with another psychiatric condition, or present with comorbid psychiatric disorders such as depression and anxiety (Barnhill & Myles, 2001; Ghaziuddin, 2002; Myles & Simpson, 2002; Perlman, 2000; Wing, 1981). The aim of this article is to provide the practitioner with a knowledge base on which to build his or her understanding of this condition in adults.

### Nosology and Diagnostic Challenges

Although there is a wealth of information regarding children with autism spectrum disorders (e.g., Ozonoff, Dawson, & McPartland, 2002; Myles & Simpson, 2003; Wilkinson, 2005), little is known about the identification of adults on the higher end of the autism spectrum. Much of this nosological difficulty is due to the fact that Asperger syndrome is difficult to diagnose utilizing DSM-IV and ICD-10 criteria. There is no single set of clinical criteria for adults. The diagnostic criteria were principally developed to identify the disorder in children, with no adjustments to the criteria for the diagnosis of adults. This presents a problem in that the DSM classification criterion fails to account for the dimensional nature of characteristics and variations in the manifestation of the disorder through adolescence and adulthood (Prior, 2003; Wing, 2005). Although further nosologic discussion is beyond the scope of the present article, Asperger syndrome is widely believed to be an early-onset social disability situated on the high-functioning end of the autism spectrum (Attwood, 2006; Barnhill, 2001; Mayes & Calhoun, 2003; Prior, 2003; Wing, 2005). Despite a lack of consensual definition of the condition, there is agreement that Asperger syndrome can have deleterious effect on the “growing up” process and impair the demands of everyday living (Attwood, 2006; Grandin & Baron, 2005; Howland, 2000; Klin, McPartland, & Volkmar, 2005; Prior, 2003).

### The Core Syndrome

Even though there is considerable clinical heterogeneity in the profiles of adults with Asperger syndrome, there are discernible core deficits associated with the broader

phenotype (Myles & Simpson, 2002; Tantum, 2000; Wing, 2005). They include impairment in social relationships and pragmatic language, and a restricted range of interests or lack of flexibility in thought (Barnhill, 2001; Myles & Simpson, 2002). Of these domains, it is the social disability or impairment that is the most prominent and defining feature of the condition (Attwood, 2006; Klin, et al., 2005). Research suggests that individuals with Asperger syndrome demonstrate a range of theory-of-mind deficits which lead to difficulty in understanding the perspectives of others, inferring the intentions of others, evaluating other peoples' interests and beliefs, and problems predicting and understanding the intentions of other people (Barnhill, 2001; Baron-Cohen, 1995; Klin et al., 2005). These individuals not only have difficulty conceptualizing the thoughts and feelings of others, but conceptualizing their own thoughts and feelings as well. It is this "mindblindness" or deficit in perspective taking that appears to explain the difficulties in social reasoning and adaptive behavior experienced by persons with Asperger syndrome (Baron-Cohen & Wheelwright, 2004; Klin et al., 2005).

#### Implications for Practice

A number of autism professionals posit that Asperger syndrome falls on a continuum and that there is no clear distinction between "mild autism" and the boundaries of neurotypicality (Attwood, 2006; Klin et al., 2005; Wing, 2005). It is the larger view of the autism phenotype that provides an opportunity for clinicians to deliver services to a greater number of individuals who have received no treatment or were misdiagnosed. This includes the groups of more successful individuals in the general

population who present with sub-clinical features of autism spectrum disorders but whose social problems and subtle theory of mind challenges impact their personal and social lives (Klin et al., 2005). While these individuals may succeed as adults, they continue to have social “vulnerabilities” which often necessitate clinical services (Attwood, 2006; Howlin, 2000; Myles & Simpson, 2002).

The core impairments of Asperger syndrome are not always salient in adults with the condition. It is generally the secondary problems that bring the individual to the clinician for treatment. Clinical impairment may take the form of increased social isolation, rejection, and high levels of anxiety and withdrawal. Chronically frustrated by their social failures and difficulty establishing and maintaining friendships, many individuals with Asperger syndrome develop secondary symptoms of a mood disorder that requires treatment (Klin et al., 2005). Although epidemiological data is sparse, depression and anxiety are widely reported in individuals with Asperger syndrome and are one of the most comorbid psychiatric conditions of this group (Barnhill & Myles, 2001; Ghaziuddin, 2002; Howlin, 2000; Wing, 1981).

#### Screening and Diagnostic Assessment

The assessment and identification of Asperger syndrome presents a significant clinical challenge to the practitioner. While there are several third-party ratings scales for children (Campbell, 2005; Lord & Corsello, 2005), there are few instruments available to assist the clinician in the identification of adults who present with the core characteristics of the autistic phenotype on the high end of the spectrum. Developing standardized assessment instruments for Asperger syndrome tends to be especially difficult because

there is little consensus on how to define the disorder, and little consistency in which the DSM-IV and ICD-10 criteria are applied (Lord & Corsello, 2005). While there is no single set of criteria or “gold standard” for diagnosing Asperger syndrome in adults, there are a limited number of instruments that can be used for screening and assessment. Clinicians will find the following phenotypic and standard clinical measures useful in their diagnostic activities.

### *Screening Instruments*

The *Autism Spectrum Disorder in Adults Screening Questionnaire* (ASDASQ; Nylander & Gillberg, 2001) has shown utility as a screening instrument for autism spectrum disorders in adult psychiatric populations. This brief 10-item questionnaire is based on the operationalized diagnostic criteria for Asperger syndrome and can be completed by members of various mental health professions. Clients who score high on these symptom/impairment-oriented items measure might then be referred for a more comprehensive assessment.

The *Asperger Syndrome (and high-functioning autism) Diagnostic Interview* (ASDI; Gillberg, Gillberg, Restam, & Wentz, 2001) is a structured interview based on Gillberg’s diagnostic criteria for Asperger’s Disorder. It includes 20 items intended for informants (parents and siblings) who know the individual well and who knew them well when they were children. Although the interview was not designed for use in accordance with the Asperger’s Disorder criteria in the DSM-IV or ICD-10, the ASDI can be used for making “preliminary” diagnostic decisions in clinical settings for individual’s who are suspected of having a high-functioning autism spectrum disorder (Gillberg et al., 2001).

The *Autism-Spectrum Quotient* (AQ; Baron-Cohen, Wheelwright, Skinner, Martin, and Clubley, 2001) is a brief, self-report measure designed to quantify where an individual with normal cognitive functioning is situated on the autism continuum. The questionnaire is comprised of a series of 50 questions associated with the characteristics of the broader autism phenotype. The early research indicates that the AQ has good discriminative validity and is a useful screening instrument in clinical practice (Woodbury-Smith et al., 2005).

The *Empathy Quotient* (EQ; Baron-Cohen & Wheelwright, 2004) is a self-report questionnaire comprising 40 items that refer to everyday situations involving the understanding of empathic behavior. It has reasonable construct and external validity and can be used to measure empathy deficits in social functioning. Early research suggests that the EQ might be helpful in identifying theory of mind deficits (judging, explaining, anticipating, and interpreting another's behavior) in adults with normal intelligence.

#### *Diagnostic Assessment*

The *Adult Asperger Assessment* (AAA; Baron-Cohen, Wheelwright, Robinson, & Woodbury-Smith, 2005) is a relatively new diagnostic instrument specifically developed for assessing adults with Asperger syndrome. It links the above referenced AQ and EQ screening instruments, and uses more stringent diagnostic criteria specifically related to adults. These criteria include all the symptoms from the DSM-IV as well as several other criteria based on the characteristics of Asperger syndrome in adults. The AAA employs a template in which the individual is asked to endorse items from the AQ and EQ to provide examples of symptoms. During the clinical interview, the clinician validates

these symptom examples by gathering information from both the individual and his or her relative or other informant. Following the interview, the clinician then formulates a diagnostic impression based on confirmation of the symptoms and prerequisites of the Asperger syndrome criteria.

#### *Standard Clinical Instruments*

Standard tests of personality and clinical instruments such as the Minnesota Multiphasic Personality Inventory (MMPI) hold promise for assessing personality and psychopathology in adults with Asperger syndrome. A recent empirical study by Ozonoff and her colleagues found that a group of adults with Asperger syndrome had higher scores than normal controls on several MMPI-2 scales, reflecting social isolation, interpersonal difficulties, depressed mood, and coping deficits consistent with the DSM-IV description of Asperger syndrome (Ozonoff, Garcia, Clark, & Lainhart, 2005). Their research suggests that the MMPI-2 might accurately capture the phenotype of Asperger syndrome and high-functioning autism in adulthood and may be a useful tool for the measurement of personality and psychotherapy in adults with mild autism spectrum symptoms (Ozonoff et al., 2005).

#### *Behavior Checklists*

The assessment of adult psychopathology is enhanced by systematically obtaining multi-informant reports, especially with parallel instruments (Achenbach, Krukowski, Dumenci, & Ivanova, 2005). The *Achenbach System of Empirically Based Assessment* (ASEBA; Achenbach & Rescorla, 2003) includes a recently developed Adult Behavior Checklist (ABCL) and Adult Self-Report (ASR). Although not specifically designed to

assess high functioning autism in adults, these forms are helpful for assessing adaptive functioning and problems in a variety of settings. The ABCL is completed by another adult who knows the individual well (e.g., spouse, partner, family member or friend) while the ASR is completed directly by the individual. Both tools include cross-informant scales (Anxious/Depressed, Withdrawn, Somatic Complaints, Thought Problems, Attention Problems, Aggressive Behavior, Rule-Breaking Behavior, and Intrusive) and DSM-IV oriented scales (Depressive Problems, Anxiety Problems, Somatic Problems, Avoidant Personality Problems, Attention Deficit/Hyperactivity Problems, and Antisocial Personality Problems). Clinicians may find the ABCL and ASR helpful in identifying the symptoms and comorbidities of the broader phenotype symptoms of Asperger syndrome.

#### *Adaptive Behavior Assessment*

Given the complexity of Asperger syndrome, the diagnostic procedure should include an adaptive behavior assessment and a careful review of the individual's medical, developmental, and family history. Particular emphasis should be placed on social development, including past and present problems in social interaction, development of friendships, pattern of attachments to family members and mood presentation (Klin et al., 2005; Tantum, 2000). Previous school reports are especially useful in identifying problems with peer-relationships and behavior that may have been present in the school context. A detailed educational and psychosocial history is critically important, especially with reference to the presence of circumscribed interests and social functioning (Attwood, 2006).

A significant finding in the literature is that adaptive behavior is usually significantly lower than general cognitive ability (Klin, Sparrow, Marans, Carter, & Volkmar, 2000). Although there are a limited number of adaptive behavior instruments available for use with adults, the *Vineland Behavior Rating Scale – Second Edition* (VABS-II: Sparrow, Cicchetti, & Balla, 2005) can be used to determine whether individuals are able to translate their cognitive assets into “real-world” adaptive skills such as personal and social self-sufficiency (Klin et al., 2000). The VABS-II covers the full spectrum of adaptive behavior (daily living skills, communication, and social domains) and can assist the clinician in the diagnosis of disorders such as high-functioning autism and Asperger syndrome.

#### Treatment and Prognosis

Although there is no single treatment or intervention that can dramatically enhance long-term outcome, individual psychotherapy and counseling may be beneficial, especially when combined with direct practical guidance on how to deal effectively with various social situations (Attwood, 2006; Howlin, 2005). Clinicians must base their treatment on an understanding of the nature of Asperger syndrome, particularly theory-of-mind research. Therapy should focus on perspective taking, social difficulties, depressive symptoms, and a more direct problem-solving paradigm (Klin et al., 2005.) Cognitive-behavioral therapy (CBT) appears to have direct applicability to adults with impaired or delayed theory-of-mind abilities who have difficulty understanding, managing, and expressing emotions (Attwood, 2006; Hare, 1997; Prior, 2003; Sofronoff, Attwood, & Hinton, 2005). CBT addresses the rigid, demanding, and absolute beliefs

frequently seen in individuals with Asperger syndrome, and may be effective in ameliorating comorbid mood disorders. In addition, activities can include cognitive restructuring, self-appraisal exercises, and stress management (Prior, 2003). Social support networks and social skills training groups for adults should also be considered an important component of the individual's treatment plan. This includes a focus on basic social and communication skills, adaptive functioning, and academic or employability skills (Hurlbutt & Chalmers, 2004). Although psychopharmacology cannot yet target the core symptomatology of Asperger syndrome, a medication regimen might be useful for treating coexisting anxiety and depression (Grandin, 2005; Klin et al., 2005; Tantum, 2000).

Little is known about the prognosis and outcomes in adults with Asperger syndrome in that there are relatively few long-term follow-up studies available (Tantum, 2000). However, it does seem clear that outcome can depend greatly on the degree of support provided in adulthood (Howlin, 2005). Although early adulthood may bring about symptom reduction and improved functioning, individuals with Asperger syndrome continue to have a need for services (Attwood, 2006; Tantum, 2000). As the knowledge and awareness of Asperger syndrome increases, many adults are expected to recognize their symptomatology, even though they may have not experienced major social difficulties and clinical impairment earlier in life. This late recognition and disclosure will result in a greater need for services as individuals seek treatment to address the secondary problems associated with the condition (Prior, 2003). A diagnosis in adulthood can also lead to greater self-understanding, self-advocacy, and better decision-making in

life span activities such as employment and personal relationships (Attwood, 2006; Howlin, 2005; Tantum, 2000).

### Conclusion

It seems quite clear that children with Asperger syndrome grow up to be adults with Asperger syndrome. However, it is not uncommon for adults to elude formal diagnosis until they come to the attention of psychologists and other mental health professionals. This under-identification and treatment of adults with the symptoms of Asperger syndrome argues for a more intense focus on education and research to improve outcomes for this group. The failure to identify individuals until late teens and adulthood and provide the necessary support early on, can lead to significant emotional and psychiatric problems later in life (Howlin, 2000). Clinical expertise needs to be enhanced to ensure not only early diagnosis, but to address the recognition and treatment of secondary psychiatric issues in adulthood. In order to make informed decisions about the assessment and treatment for individuals with Asperger syndrome, clinicians must maintain an awareness of the state of science in the field, particularly to emerging empirical studies demonstrating the effectiveness of the assessment and treatment of this “childhood” disorder (Barnhill, 2001).

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Appendix

Suggested Reading and Resources

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Autism Research Centre

(<http://www.autismresearchcentre.com/arc/default.asp>)

Autism Society of America

(<http://www.autismsociety.org/>)

More advanced individuals with Autism, Asperger's syndrome, and Pervasive developmental disorder (PDD) (MAAP Services)

(<http://www.maapservices.org>)

National Autistic Society

(<http://www.nas.org.uk/>)

National Institute of Mental Health (NIMH)

(<http://www.nimh.nih.gov/healthinformation/autismmenu.cfm>)

Online Asperger Syndrome Information and Support (OASIS)

([www.aspergersyndrome.org](http://www.aspergersyndrome.org))

Stanford Child and Adolescent Psychiatry: Autism and Asperger Research Reports

(<http://aarr.stanford.edu/>)

Treatment and Education of Autistic and Related Communication Handicapped Children

(TEACCH)

([www.teacch.com](http://www.teacch.com))

Yale Child Study Center

(<http://www.med.yale.edu/chldstdy/autism/>)

