

The Evolving Definition of Asperger's Syndrome

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Abstract

Asperger's Syndrome (AS) is currently defined as one of five pervasive developmental disorders (PDD) with impairments in social interaction, verbal and non-verbal communication, and a preference for repetitive, stereotyped behaviors, interests and activities. There is great variation in skills and deficits between individuals. Disagreement in diagnostic criteria has led to a blurring of the boundaries between the different PDD subtypes. A shift away from a categorical towards a dimensional approach is evident in the draft language of the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), scheduled for publication in 2013. The proposed language removes differentiating criteria for AS and all autism spectrum disorder (ASD) subgroups. Experts agree on the importance of a comprehensive assessment to determine a profile of strengths and weaknesses for effective intervention to address the triad of impairments experienced by individuals with AS.

Introduction

The use of the term, Asperger's syndrome (AS) has an interesting history. AS is one of five pervasive developmental disorders (PDD) characterized by impairments in social interaction, verbal and non-verbal communication and a preference for repetitive, stereotyped behaviors, interests and activities (American Psychiatric Association (APA), 2000; Mayes & Calhoun, 2003). It is a life-long condition with a triad of impairments that have personal, social and educational implications.

The Austrian pediatrician Hans Asperger is credited with first describing the condition in 1944. His most famous cases of "autistic psychopathy" had high intellectual ability (Frith, 2004). In 1943, Leo Kanner, another Austrian physician living in the United States, outlined characteristics of "infantile autism" (Attwood, 2007; Wing & Potter, 2002). Although Kanner and Asperger both used the term autism, it is believed that they were unaware of each other's work at the time (Attwood, 2007; Goldstein & Ozonoff, 2009).

In his seminal paper, Kanner (1943) described eleven children with social deficits who demonstrated obsessive and repetitive behaviors and echolalia. He noted a literal-mindedness, an insistence on sameness/routine, and an excellent rote memory, in addition to a marked contrast between relations to people (avoidance) and to objects (obsession) from the beginning of life (Kanner, 1943). For the next 40 years this description and understanding of autism dominated the literature.

It wasn't until after his death in 1980, that Asperger's "autistic psychopathy" received attention. Lorna Wing, a British psychiatrist, first used the term Asperger's syndrome in 1981 when describing clinical features of some of her patients (Wing, 1981). She became aware that Kanner's descriptions did not accurately account for some of the children and adults in her

research experience (Attwood, 2007). Asperger believed his syndrome to be different from Kanner's early infantile autism even though he acknowledged many similarities between them (Wing, 1981). Wing (1981) hypothesized that the variations could be explained on the basis of the severity of the impairments. She was the first to suggest a spectrum of autistic disorders (Frith, 2004). Today, the use of the term autism spectrum disorder (ASD) is typically used by experts when referring to the three most common PDD categorical groups: autistic disorder, Asperger's disorder (AS) and Pervasive Developmental Disorder Not Otherwise specified (PDD-NOS) (Volkmar, State, & Klin, 2009).

Asperger's *Autistic Psychopathy in Childhood* was first translated into English by Uta Frith in 1991. Since that time, there has been an increasing awareness of ASDs with reported increases in the referral rate for a diagnostic assessment of AS worldwide (Attwood, 2007). It is clear from Asperger's accounts, which are strikingly similar to those of Kanner, which he thought of autism as a personality type/disorder rather than a mental illness. He states, "the nature of these children is revealed most clearly in their behavior towards other people. Indeed, their behavior in the social group is the clearest sign of their disorder" (Asperger, 1944/1991, p. 77). Like Kanner, he acknowledged that autism is found in the intellectually able as well as the less able (Asperger 1944/1991, p. 58). Asperger (1944/1991) also noted, "a disturbance of active attention" (p. 76) and in almost all of the children he came across, "a special interest which enables them to achieve quite extraordinary levels of performance in a certain area" (p. 45).

AS is diagnosed four to five times more frequently in males than females (APA, 2000; Gillberg, 1998). The incidence among females may be underreported due to differences in socialization and an ability to camouflage difficulties (Attwood, 2007).

Autism as a distinct disorder first appeared in the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) in 1980 under the name “infantile autism” and was later changed to “autistic disorder” in 1987 in the revised DSM-III (Goldstein & Ozonoff, 2009; Sanders, 2009). Prior to 1980, children demonstrating autistic characteristics would have fallen under the criteria for childhood schizophrenia (Wing & Potter, 2002). Both Kanner and Asperger noted that cognitive and social developments are stable in autism and not regressive like in schizophrenia (Sanders, 2009). Kanner (1943) explains that the onset of schizophrenia in children is preceded by essentially average development, but in autism, there is an “extreme aloneness from the very beginning of life” (p. 248). He adds that the basic desire for aloneness and sameness remains essentially unchanged (Kanner, 1943). Likewise, Asperger (1944/1991) states that there is a lack of contact (shutting off of relations between self and the outside world) from the start in autism, while there is a progressive deterioration or loss of contact in schizophrenia.

Autism was first included as a disability category in the Individuals with Disabilities Education Act (IDEA) in the United States in 1991 (Wing & Potter, 2002). The 2004 amendments define autism as follows:

(c)(1)(i) Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three that adversely affects a child’s educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.

(ii) Autism does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance, as defined in paragraph (c)(4) of this section.

(iii) A child who manifests the characteristics of autism after age three could be identified as having autism if the criteria in paragraph (c)(1)(i) are satisfied.

(U.S. Department of Education, 2011)

The IDEA definition, like DSM-IV diagnostic criteria includes the autistic triad of deficits.

IDEA differs however, in that classification is allowed after age three. This is important since many individuals with higher-functioning ASD (Asperger syndrome and PDD-NOS) are often diagnosed at a later age (Wilkinson, 2010).

Diagnostic Criteria

Asperger's Disorder first appeared as a subtype of autism under Pervasive Developmental Disorders in the DSM-IV in 1994 and in the International Classification of Diseases-10th edition (ICD-10) in 1993 (Attwood, 2007; Wing, 2005). Essential diagnostic features of AS in the DSM-IV include: severe and sustained impairment in social interaction; restricted, repetitive patterns of behavior, interests, and activities; and clinically significant impairment in social, occupational, or other important areas of functioning (APA, 2000).

Absence of communication and cognitive delay in AS are the diagnostic criteria that differentiate it from autism in the revised DSM-IV (APA, 2000; Sanders, 2009).

According to the DSM-IV, individuals with AS have variability in cognitive functioning with strengths in areas of verbal ability (e.g. vocabulary and rote auditory memory) and weaknesses in non-verbal areas (e.g. visual-motor and visual-spatial skills). Associated features

include motor clumsiness, symptoms of overactivity and inattention, and an association with other mental disorders, including depressive disorders (APA, 2000).

Today, there is controversy over whether or not AS is a separate disorder or simply autism with a higher intelligence quotient. Frith (2004) explains that the genetic argument (there is increased risk among siblings of individuals with both autism and AS), biological evidence of brain pathology present in autism regardless of IQ, and cognitive and behavioral information all point to AS as a milder variant of autism on the spectrum of autism disorders.

Furthermore, the distinguishing criteria, absence of language delay, in DSM-IV is seen as problematic since it is not well defined (Sanders, 2009) and cannot reliably discriminate between the two disorders (Mayes & Calhoun, 2003). The criteria of Christopher Gillberg has been claimed to most closely resemble the original descriptions of Asperger (Attwood, 2007). These criteria published in 1989 and elaborated in 1991 actually include delayed language development as one of the diagnostic criteria for AS (Gillberg, 2002).

The precedence rule in DSM-IV means that cases that appear to meet criteria for both autism and Asperger's get a diagnosis of autistic disorder (APA, 2000; Klin, 2009). Studies indicate that clinicians and researchers ignore the overlap and do not strictly apply DSM-IV criteria for autism and AS (Mayes & Calhoun, 2003). Instead, AS is often used for those with ASDs who are higher functioning or who have an IQ in the normative range or higher (Klin, 2009). It has been suggested that AS and high-functioning autism are not distinct conditions and that AS should be viewed at the high-functioning end of the autism spectrum (Attwood, 2007; Mayes & Calhoun, 2003; Tyron, 2006; Wing, 2005). Another perspective argues that "autism is really Asperger's syndrome with specific language impairment. Asperger's syndrome can be

thought of as the primary deficit. Autism occurs when a deficit in language development is superimposed on AS” (Reitzel & Szatmari, 2003, p. 52).

Draft language in the DSM-V scheduled for publication in 2013 excludes the differentiating criteria for AS and in fact removes all subgroups under ASDs (APA, 2011). This is seen as controversial for those worried about the loss of their label and eligibility for services. Frith (2004) explains that a special label for the least severe makes sense and abandoning it would mean losing the historical context and wealth of information around it. In addition, a diagnosis of AS is seen by many as less stigmatizing.

The DSM-IV diagnostic criteria has also been criticized for not including pedantic use of language and unusual prosody and for failing to make reference to problems of sensory perception and motor clumsiness under criteria for AS (Attwood, 2007). Researchers note that problems of responses to sensory inputs are found to be the most consistently impairing symptom present from early childhood and should be included in the DSM-V if not as essential criterion at least as a note (Wing, Gould, & Gillberg, 2011).

Although Asperger provided detailed descriptions, he did not provide clear diagnostic criteria (Attwood, 2007; Gillberg, 2002). Because experts continue to disagree on criteria, diagnosing higher-functioning subtypes of the autism spectrum remains complex and the boundaries between autism, AS, and PDD-NOS become blurred (Volkmar, State, & Klin, 2009). As a result, researchers and clinicians use different criteria and definitions, making it nearly impossible to compare and interpret findings across studies (Klin, 2009; Mayes & Calhoun, 2003; Klin, Pauls, Schultz, & Volkmar, 2005). There is growing consensus among those who work with children with ASDs that differences between the higher functioning subtypes are not particularly useful. Empirical evidence supports unitary treatment of high functioning autism

and AS in terms of interventions and strategies used to improve outcomes (Attwood, 2007; Donaldson & Zager, 2010; Wilkinson, 2010). Volkmar and colleagues, (2009) suggest that distinguishing between subtypes is not as important as building treatment based on a profile of strengths and weaknesses. Furthermore, they state that cognitive functioning and communicative speech levels are probably the best predictors of outcome for individuals with ASDs (Volkmar, State, & Klin, 2009).

Comorbidity

Comorbid conditions associated with AS include depression, anxiety disorders including obsessive-compulsive disorder, eating disorders, bipolar disorder, attention deficit hyperactivity disorder (ADHD), Tourette's and tic disorders, epilepsy, dyspraxia and dyslexia (Attwood, 2007; Deprey & Ozonoff, 2009; Tantom, 2003). Separating out the core symptoms of an ASD from other conditions is complex, making the evaluation of comorbidity challenging (Depry & Ozonoff, 2009).

Prevalence

The prevalence of ASDs is substantially greater than previously recognized. Possible explanations for the increase include greater awareness among parents and professionals, a widening of diagnostic criteria, greater availability of services, and environmental causes. However, diet considerations, environmental pollutants, antibiotics, allergies, and the triple vaccine for measles, mumps and rubella (MMR) have not been scientifically validated as causing autism making it unclear whether there has been a genuine rise in the numbers of children with ASDs (Wing & Potter, 2002).

The Centers for Disease Control (CDC, 2006) indicates that nearly 1% or one child in every 110 in the United States was classified as having an ASD. An estimated 52% of those

diagnosed with ASDs are in the high functioning range (IQs above 70) (Whitby & Mancil, 2009). Prevalence rates for AS are not easily determined. This is in part due to a lack of consensus regarding diagnostic criteria, the merging of the borderlines of the autistic spectrum and differences in applying diagnostic criteria in clinical practice (Klin, 2009; Mayes & Calhoun, 2003; Wing, 2005). Attwood (2007) reports that the prevalence rate for AS is about one in 250 children or 0.4% using the Gillberg diagnostic criteria.

Etiology

The etiology of Asperger's is unknown. Strong evidence from twin studies point to genetic factors as a likely cause (Wing & Potter, 2002). In addition, studies using brain imaging reveal differences in specific structures and systems in the brain (Attwood, 2007). Asperger observed similar traits related to his syndrome in family members of the children he worked with, particularly in fathers or male relatives (Klin, Pauls, Schultz, & Volkmar, 2005; Wing & Potter, 2002). Recent research also indicates a significant percentage of children with AS have first-degree relatives with a similar profile of abilities and behavior (Attwood, 2007). Currently, there is general agreement that AS is a neuro-genetic disorder or a genetic disorder with brain variation or dysfunction as the root cause (Frith, 2004; Gillberg, 1998).

Both Kanner and Asperger suspected that the condition they were writing about was due to genetic or neurological factors (Attwood, 2007; Goldstein & Ozonoff, 2009). Kanner, however suggested that it could be influenced by parenting. This and the psychoanalytic theory of the time led to the belief that the child-rearing methods of parents were the cause of autism (Goldstein & Ozonoff, 2009). Bruno Bettelheim (1959) theorized that the behavior of autistic children was the result of their parents' inhumanity leading to deep inner rejection and total emotional isolation. Despite the lack of scientific evidence to support this view, parents were

directly blamed until the 1980s and considered to have unrealistic expectations. In addition, families were considered to be in need of and were expected to listen and trust the wisdom of professionals (Hecimovic & Gregory, 2005). Fortunately, research helped to change and shape attitudes to see families as partners in providing services. This is reflected in IDEA, which authorizes family participation in the educational decision-making process (Hecimovic & Gregory, 2005).

Assessment

Those with AS comprise a very heterogeneous group with tremendous variation in specific skills and deficits. Some individuals show excellent adaptation, leading relatively normal lives while others can hardly cope, needing constant supervision (Frith, 2004).

A comprehensive assessment is critical to determine how best to intervene to improve outcomes (Frith, 2004; Manjiviona, 2003). Developmental screenings identify children who should undergo a more thorough evaluation. In a review of rating scales for detection of AS in school-age children, Campbell (2005), concludes that the Krug Asperger's Disorder Index (KADI; Krug & Arick, 2003) shows the strongest reliability and validity. Measures also showing promise include the Autism Spectrum Screening Questionnaire (ASSQ; Ehlers, Gillberg, & Wing, 1999) and the Childhood Autism Spectrum Test (CAST; Scott, Baron-Cohen, & Brayne, 2002).

Comprehensive assessments include a developmental and medical history, medical evaluation, parent and teacher interviews and direct observation. Cognitive, academic, adaptive behavior, and communication and language assessments are conducted as part of a comprehensive assessment. Other areas for investigation include sensory processing, executive function and attention, motor skills, and behavioral or emotional problems (Goldstein, Ozonoff,

Cook, & Clark, 2009; Manjiviona, 2003; Reitzel & Szatmari, 2003; Wilkinson, 2010). Because multiple evaluators are typically involved in the assessment process, a case coordinator is needed to organize, integrate and communicate information as well as assist in formulating a treatment plan (Goldstein et al., 2009).

Research shows that early intervention is critical for improving outcomes for ASDs (Wilkinson, 2010). A diagnosis of AS is often not made until after school begins because there are cognitive strengths and symptoms are less severe. The average age of a confirmed diagnosis is 5.5 years for autism and 11 years for AS (Frith, 2004; Wing & Potter, 2002). The good news is that there is greater awareness and even acceptance of differences exhibited by individuals with AS. Diagnoses are occurring at younger ages, meaning more children are receiving early intervention services (Weiss, 2008). A comprehensive assessment examining the profile of skills and disabilities, aids in the development of intervention strategies to address social, communication and behavioral deficits.

Characteristics, Implications and Intervention

The profile of individuals with AS is complex and experts disagree on specific characteristics (Mayes & Calhoun, 2003). Issues of developmental delay are of primary concern in children with AS. Impairments in socialization and communication and the tendency to focus on specific interests persist and last throughout the lifetime of individual's with AS (Gillberg, 1998; Graetz & Spampinato, 2008). These underlying problems often show up and can be perceived differently in adulthood, especially for those who develop additional psychiatric problems such as anxiety and depression (Frith, 2004; Gillberg, 1998). For many, the deficits in social interaction, communication and behavioral adjustment can be disabling, impacting opportunities for socialization, education and employment. Asperger (1944/1991) describes the

social disturbance as “egocentric in the extreme” (p. 81). He explains that it is not deliberate, rather there is a genuine defect in understanding of other people (Asperger, 1944/1991). Frith (2004) adds that this makes it extremely difficult to form long-term relationships. Strong evidence exists that cognitive behavioral therapy (CBT) is effective for targeting social skills and treating anxiety and depression (Attwood, 2007; Wilkinson, 2010). For those with more severe symptoms medication may be indicated.

A review of the literature points to a profile of academic functioning with deficits in the areas of comprehension, written expression, graphomotor skills, linguistically complex materials, complex processing across all domains, and problem solving (Whitby & Mancil, 2009). Risk of academic failure is heightened by impairments in attention, pragmatic language difficulties, and a tendency to suffer from low self-esteem (Manjiviona, 2003). Essential elements of effective educational intervention for high-functioning students with an ASD can be found in the Treatment and Education of Autistic and related Communication handicapped Children (TEACCH) model (Kunce, 2003; Ryan et al., 2011; Wilkinson, 2010). TEACCH has been used to educate students with autism for over three decades, demonstrating efficacy across different age and ability levels (Ryan et al., 2011). Independent functioning is maximized by taking advantage of visual and rote memory strengths of children with ASD through the use of explicit instruction and visual supports in a structured environment.

A recent large-scale study of 156 adolescent’s with AS found average to above-average IQs but a marked gap in adaptive behavior skills (Myles, et al., 2007). Other characteristics found include a lack of ability to empathize, a deficit in recognizing their own needs, overt and covert behavioral issues (possibly related to sensory concerns), and average skills in providing order and predictability (Myles, et al., 2007).

Another study of children and adolescents with ASDs found that challenging behaviors such as physical aggression, property destruction, verbal aggression, self-injurious behavior, stereotypies and tantrum like behaviors are persistent and stable over time (Matson, Mahan, Hess, Fodstad, & Neal, 2010). The authors of the study point to the need for a greater focus on these behaviors and the effects of early intervention. Tantam (2003) explains that catastrophic reactions such as screaming, shouting, swearing, breaking things, biting, scratching, hitting and running away are some of the most common behavior problems in children with AS. Careful assessment to determine events or situations that trigger the behavior in an effort to control by prevention is considered to be an essential part of a positive behavioral support plan (Marks, Hudson, Schrader, Longaker, & Levine, 2006; Tantam, 2003). Antecedent management is the term used by behaviorists when referring to this strategy. In the Antecedent-Behavior-Consequence model, a triggering event (the antecedent) occurs and a behavior results in something happening (the consequence) (Marks et al., 2006). The goal for students with AS is to avoid the problem behavior altogether.

Functional assessments identify the physical and environmental factors that affect learning and help to determine ways to address challenging behaviors. Information is gathered through interview, direct observation and systematic manipulations and is then used to help prevent behaviors by adapting the environment, teaching replacement skills and modifying tasks (Weiss, 2008). Many successful interventions incorporate applied behavioral analysis (ABA) based on B. F. Skinner's concept of operant conditioning and first proven effective for children with ASD by Ivar Lovaas (Ryan et al., 2011). ABA is a systematic process requiring consistent, intense, almost constant feedback and correction of behavior. At the beginning of intervention, one-on-one instruction is recommended. Parent participation is critical to help ensure

generalization. Interaction is lessened as new behavior becomes more automatic replacing the old (Ryan, et al., 2011).

An uneven pattern of skills and deficits and an inability to generalize new skills learned often leads to confusion and frustration between teachers and students with AS. In addition to antecedent management, noncontingent reinforcement (NCR) and self-management or self-monitoring programs are seen as effective methods for managing behavior (Marks et al., 2006). According to Marks and colleagues (2006), both NCR in which reinforcers (e.g. computer play) are provided on a fixed time schedule and on a noncontingent basis (the student does not have to earn it), and self-management plans where students are taught to monitor their own behavior, result in positive behavior while still holding the student accountable.

Trends and Issues

Since introduction of Asperger's Disorder in the DSM-IV, the definition and diagnosis continue to be areas of debate among practitioners, researchers, and clinicians. A shift from categorical classification towards a dimensional approach seems likely with language proposed in the DSM-V. It remains to be seen if focus will shift from subcategories to areas of dysfunction and what the effect will be on efficacy of treatment and eligibility for services in schools. What is clear is that the social impairment (the hallmark of AS) is such that individuals require support and effective intervention regardless of their ability level. Researchers agree that understanding and treating aspects of dysfunction is more important than studying diagnostic subgroups (Prior, 2003; Volkmar, State, & Klin, 2009; Wing, 2005). Mark Durand (2005) points to the promise of fruitful collaboration when he states that, "Knowledge of basic processes such as socialization, emotion, and communication is informing remediation efforts, and clinical concerns are in turn informing basic research" (p. 90).

We know from research that early intervention is critical and that adaptations are possible using research-based strategies in a collaborative fashion to meet individual needs. Providing accommodations and support promotes access in college for individuals with AS. In addition, assistance provided beyond the school years increases the chance of a successful outcome (Howlin, 2003). Prior (2003) points to the need for long-term follow up as an area of research that should take priority. These kinds of studies will help determine if advances made in understanding and improving skills of students with AS result in meaningful changes.

The impairments of AS create lifelong challenges requiring specialized help in the educational, social, and psychological domains. Because the patterns and profiles of people with AS changes with development, ongoing formal and informal assessment is necessary to determine needs. It is important that parents, teachers and professionals working with students with ASDs communicate and have accurate and up-to-date knowledge of assessment tools, and developmental and educational strategies (Hogan & Marcus, 2009). An online Google search for “autism” reveals over 76 million pages devoted to the topic and approximately 14 million pages for “Asperger” (Sept., 2011). With an explosion in media coverage in the last two decades, not all information disseminated is accurate. Staying abreast of current practice and research is beneficial for individuals with AS and helps to separate out theories not based on scientific fact.

Tantum (2003) points to the need for educating others when she explains that fear of AS can lead to bullying and victimization. Remediating this requires an awareness and commitment of teachers and professionals. Caring teachers who are able to capitalize on strengths and special interests can help those with AS reach their academic potential, leading to productive and fulfilling lives. Asperger (1944/1991) emphasizes the need for true understanding and genuine affection, stating that autistic children are capable of strong feelings. He explains that behind the

cool and objective interaction, the children he observed showed a “surprising sensitivity to the personality of the teacher” and essential to their management and guidance is a “proper knowledge of their peculiarities as well as genuine pedagogic talent and experience” (Asperger, 1944/1991, p. 48). Teachers and professionals who possess these qualities along with current information on best practices stand the best chance of improving outcomes for individuals with Asperger’s syndrome.

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