Asperger’s Syndrome: 
An Enigma for Social Work

Ernst O. VanBergeijk 
Oren Shtayermman

ABSTRACT. Asperger’s Syndrome (AS), a Pervasive Developmental Disorder on the Autism Spectrum, is a burgeoning mental health concern faced by children, their families, schools, and mental health practitioners. Although it is a relatively new phenomenon, prevalence rates have increased 10 fold in the past decade. Whether this increase is a true increase in the prevalence of the syndrome has been the subject of great debate. The assessment and treatment of AS is a complicated process requiring social workers to partner with families and other helping professionals. Given the growing size of the AS population, it is critical that social workers understand the disorder, its co-morbidity, and treatment. The authors review the prevalence and history of the syndrome, current definitions, and discuss implications for social work practice, policy, and research.

KEYWORDS. Asperger’s syndrome, autism, assessment, diagnosis, autism social work
INTRODUCTION

Asperger’s Syndrome (AS) is an autism spectrum disorder that is characterized by highly impaired social skills, difficulty relating to others, a lack of flexible imaginative play, and often a preoccupation with a finite and highly specific topic. AS, which typically presents less severe symptoms than classic autism, has seen a dramatic increase in its prevalence within the last 10 years. Current estimates of the prevalence of Asperger’s Syndrome range between 0.3 to 67 per 10,000 children (Bertrand, Mars, Boyle, Bove, Yeargin-Allsop, & Decoufle, 2001; Fombonne, 2001). The numbers of children affected by this syndrome are almost double the number of children who exhibit classic autism. Recent estimates of the autism prevalence rate are in the range of 3.4-26 per 10,000 children (Yeargin-Allsopp, Rice, Karapurkar, & Doemerg, 2003; Kadesjo, Gillberg, & Hagberg, 1999). Both the popular press and scholarly researchers have documented an “explosion” in the incidence of cases of autism and autism spectrum disorders within the past decade, labeling it as an “epidemic” (Cowley, Underwood, Murr, Springen, & Sennott, 2003; Ehlers & Gillberg, 1993; Bryson & Smith, 1998; Fombonne, 2001; Fording, 2003; Nash, 2002; Ozonoff, Rogers, & Pennington, 1991). Before the 1990s, the prevalence of autism was thought to be 1 in 10,000 (Klin, Volkmar, & Sparrow, 2000; Brasic, 2001) making this spectrum of disorders relatively rare.

Children with AS are considered to be relatively high functioning in many areas of their lives which creates confusion for parents, teachers, and helping professionals in understanding the many socially difficult behaviors that a child with AS may exhibit. Because children with AS are commonly the target of negative peer interactions and have special learning needs, it is essential that an accurate diagnosis is made early in the child’s life. Social workers working with children and families, schools, or health settings may play an important role in early screening for AS, helping parents through the diagnostic process and developing and/or linking children with AS to services.

What Is Asperger’s Syndrome and How Does It Differ from Other Autism Spectrum Disorders?

Part of the complexity in answering these questions lies in the history of the disorder, the definitions of autism spectrum disorders, other disciplines’ labels for the syndrome, and the strengths of these exceptional
children. The social work profession’s lack of familiarity with the syndrome further obfuscates the answers.

In the 1940s Leo Kanner (1943) a Baltimore child psychiatrist and Hans Asperger (1944) a Viennese pediatrician, in two separate publications, describe the behavioral profiles of two similar, yet potentially distinct disorders. In these independent samples, both groups of children showed a non-purposeful disregard for social rules, a difficulty in understanding other’s emotional experience, stereotypy (e.g., hand flapping), and for those children who did possess verbal skills, an excellent memory in a finite topic. Kanner (1943) referred to the condition afflicting the children as “Autistic disturbances of affective contact.” Asperger, unaware of Kanner’s publication, labeled the children’s disorder as “Autistic Psychopathy.” It was not until 1991 when Lorna Wing documented 10 similarities between Asperger’s description and Kanner’s earlier writing on autism. Today, the disorder that Kanner described is known as “classic autism.” Asperger’s “autistic psychopathy” is simply referred to as Asperger’s Syndrome (AS).

Although the features of the clinical syndromes in both groups of children were similar, there were some distinct differences between the two groups of children. Namely, the children Asperger wrote about were higher functioning than those Kanner observed. Asperger observed fine and gross motor problems with his population. Also, the age of onset was not before three years of age. The children in Asperger’s sample had acquired language normally. In contrast, the children working with Kanner either did not develop verbal language or there was a significant speech delay. No motor problems were noted in Kanner’s writings. Asperger believed these children “possessed normal intelligence and were capable of gainful employment” (Miller & Ozonoff, 2000, p. 227). Later research on children fitting Kanner’s diagnostic criteria revealed impaired cognitive abilities and a marked inability to attain gainful employment (Miller & Ozonoff, 2000). Furthermore, Kanner’s autism is associated with mental retardation in about 65-90% of the cases (Wing, 1993; as cited in Gilberg, Nordin, & Ehlers, 1996).

The fact that both Kanner’s and Asperger’s diagnostic features of their syndromes overlap and they used similar nomenclature obfuscates the differences between the two syndromes. What further clouds the distinction between the two disorders is that in 1990 Asperger’s Syndrome was added to the International Classification of Diseases (ICD-10) as a pervasive developmental disorder. According to Wing (1991) alternative labels for the syndrome included “Schizoid Disorder of Childhood” and “Autistic Psychopathy” (p.105) in this publication. The
American Psychiatric Association finally added Asperger’s Syndrome to the *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV)* using the umbrella rubric of pervasive developmental disorders (Barnhill, Tapscott Cook, Tebbenkamp, & Smith Myles, 2002), which is alternatively known as “Autism Spectrum Disorders” (Wing, 1991).

Autism spectrum disorders are conceptualized as a continuum of syndromes ranging from Autistic Disorder to Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). The continuum includes Rett’s Disorder, Childhood Disintegrative Disorder, Atypical Autism, and Asperger’s Disorder (DSM-IV-TR, 2000). Among the autism community High Functioning Autism (HFA) is used to distinguish between individuals with classic autism symptoms (i.e., those with little or no speech) and those with speech that had a late onset.

The current diagnostic features of AS include a qualitative impairment in social relationships. The diagnosis of AS typically occurs much later than autism. Children with autism are diagnosed in early childhood because of their profound inability to interact with others. The diagnosis of autism can be made as early as 18 months and can be made reliably by 30 months of age (Gillberg, Nordin, & Ehlers, 1996). Children with AS are diagnosed on average between 6-10 years old, only after having years of difficulties learning and relating to peers (Gillberg, Nordin, & Ehlers, 1996). AS children are socially isolated and this isolation cannot be explained by other personality features such as shyness or aggressiveness (Barnhill, Tapscott Cook, Tebbenkamp, & Smith Myles, 2002; McLaughlin-Cheng, 1998; Klin, Volkmar, & Sparrow, 2000).

What limited social interaction they do engage in revolves around their own obsessive interests. Their impairment not only lies in a social skills realm, but also in speech. Although children with AS acquire speech, they have impairments in pragmatics and semantics of speech. They have difficulty providing a listener with relevant contextual information. They do not know how to begin a conversation or maintain a topic in a reciprocal exchange between themselves and another child. Consequently AS children tend to dominate a conversation on a potentially esoteric topic. This perseveration on obscure topics compounds their isolation. AS children’s speech pattern can also be distinct. They possess a pedantic style of speech (Miller & Ozonoff, 2000; Frith, 1991). This formal way of speaking often earns the child a moniker of “the little professor” (Volkmar & Klin, 2000). Another distinguishing feature of their speech is prosody. Their voice inflection and tone can be “odd,” monotone, or robotic like.
Some individuals with AS have marked abnormalities of facial expression and gestures and yet they are able to convey feeling and have some degree of empathy for others (Tantam, 1991). Not only do individuals with AS have difficulty expressing themselves, but they also have impairments in understanding verbal and non-verbal communication (Miller & Ozonoff, 2000; Barnhill, Tapscott Cook, Tebbenkamp, & Smith Myles, 2002; McLaughlin-Cheng, 1998). They understand spoken words quite literally, often do not recognize non-verbal language, and so may have difficulty comprehending jokes or sarcasm. This is not to say that individuals with AS do not have a sense of humor. However, much of the verbal humor that other individuals share will be relatively inaccessible to an individual with AS.

Asperger’s Syndrome lies between Autistic Disorder and PDD-NOS on the continuum. It is considered highly controversial as to whether or not Asperger’s Syndrome is a distinct clinical entity from High Functioning Autism (HFA) (Baron-Cohen, 2000; Miller & Ozonoff, 2000; Perrintgo, 1991; Szatmari, 1991; Szatmari, 1989; Marriage, Gordon, & Brand, 1995; Bishop 1989; Bruer, 1996; Ozonoff, Rogers, & Pennington, 1991; Prior, Eisenmajer, Leekam, Wing, Gould, Ong, & Dowe, 1998; Elder, 2001; Louiselle, 2001; Fine, 1991; Fidler, 2000). Children with high functioning autism unlike children with Asperger’s Syndrome acquire language later than neurotypical children or AS children do, and have an impairment in symbolic play (McLaughlin-Cheng, 1998; Philbin Bowman, 1988; Szatmari, Bremner, & Nagy 1989; Baron-Cohen, 2000). In addition, children with HFA do not appear to have either fine or gross motor impairments that are associated with AS by some researchers (Rhea, 2003; Prior, Eisenmajer, Leekam, Wing, Gould, Ong, & Dowe, 1998; Klin, 2000).

In terms of intellectual functioning, both HFA and AS populations range from normal to superior on standardized I.Q. tests. It should be noted that a red flag of HFA and AS is a large discrepancy between verbal and performance I.Q. This discrepancy can be well over 13 I.Q. points on the WISC-R (Ehlers, Nyden, Gillberg, Dahlgren Sandberg, Dalhgren, Hjelmquist, & Oden, 1997; Klin, Volkmar, & Sparrow, 2000; Klin, 2000). Interestingly, there is evidence to suggest that the profiles of people with AS differ from those with HFA. Individuals with AS score significantly higher on the verbal section of the WISC-R than the performance section of the test. The scores for individuals with HFA are the opposite. Their strengths lie in the performance section of the WISC-R. Individuals with HFA score more poorly on the verbal sections of the test (Prior, Eisenmajer, Leekam, Wing, Gould, Ong, &
Dowe, 1998). Within the last few years, this distinction has been contested across studies (Schriberg, McSweeney, Klin, Cohen, & Volkmar, 2001; Jolliffe & Baron-Cohen, 1999; Klin, 2000).

You Say “Pətətə.” I Say “Pətətə?”

Adding to the complexity of AS is the fact that the behavioral and cognitive profile of AS has been given a range of different labels by other professions. Just like the pronunciation of words such as “potato” or “tomato,” is influenced by the environment in which one lives, the professional environment influences the pronunciation of the symptoms we describe as Asperger’s Syndrome.

Occupational therapists often conceptualize AS “Sensory Integration Dysfunction” given the focus of this profession on how a child moves in his or her world, children who have sensory integration dysfunction are characterized as having gravitational insecurity, poor proprioceptive sense, and either under or over sensitivity to olfactory, tactile, auditory, and visual stimuli (Ayers, 1979; Kranowitz, 1998). They have difficulty learning and dealing with peers. Psychiatrists may use the term “Schizoid Personality Disorder” to refer to individuals who have AS. Under the Schizoid Personality Disorder label, these persons have social isolation, bizarre pre-occupations, and odd speech. They are perceived as strange, eccentric, cold, or aloof (DSM-IV-TR, 2000). Neuro-psychologists use the term Non-Verbal Learning Disability (NLD). Persons with NLD have “significant deficits in social perceptions, social judgment, and social interaction skills, marked deficits in nonverbal problem solving and outstanding relative deficiencies in mechanical arithmetic and compared to proficiencies in reading and spelling” (Rourke & Tsatsanis, 2000; pp. 235-236). Speech pathologists use the term Semantic Pragmatic Disorder (SPD). Individuals with SPD exhibit similar social interaction deficits as an individual with Asperger’s Syndrome (Adams, Green, Gilchrist, & Cox, 2002).

The Co-Morbidity of AS

It is highly likely that a diagnosis of AS will be accompanied by a second mental health diagnosis. Ghaziuddin, Weimer-Mikhail, and Ghaziuddin (1998) found that among 35 AS patients, 65% had an additional psychiatric diagnosis. The etiology of the co-morbid psychiatric disorder can be either endogenous or environmental in nature.
The environmental stressors for individuals with AS likely exacerbate their vulnerability to mood and anxiety disorders. Due to their social isolation, and higher levels of frustration associated with social interactions, there is high co-morbidity with both unipolar and bi-polar depression (Barnhill, 2001; Kim, Szatmari, Bryson, Streiner, & Wilson, 2000; Ghaziuddin, Weldmer-Mikhall, & Ghaziuddin, 1998; Kim, Szatmari, Bryson, Streiner, & Wilson, 2000; Rubenstein, 2001; Barnhill, 2001; Rourke, Young, & Leenaars, 1989).

Age of the patient may influence the type of secondary diagnosis they receive. Ghaziuddin et al. (1998) found that adolescents and adults were more likely to be diagnosed with depression than any other co-morbid disorder. Twenty-five percent of the children in Ghaziuddin et al.’s (1998) report had a diagnosis of depression. Fifty-three percent of teens and adults in that sample were diagnosed as depressed. These numbers are considerably higher than those of Klin and Volkmar (1997) (as cited in Martin, Patzer, & Volkmar, 2000). They found only 15% of their sample was diagnosed with depression. In a different study that was done by Tantam (2003) it was suggested that 22.2% of a sample of 234 adolescents with AS also received a previous diagnosis of anxiety and anxiety related disorders. About 19.7% of the sample was diagnosed with depression.

The unpredictability of the social environment can cause some individuals with AS to develop anxiety disorders. Compulsive rituals among individuals with AS lead psychiatrists to think that this may be a display of obsessive-compulsive disorder (OCD) (Tantam, 2000) and they may in fact have co-morbid OCD. Klin and Volkmar (1997) identified 19% of their sample of 99 AS patients as having OCD (as cited in Martin, Patzer, & Volkmar, 2000). Social phobia is a sub category of anxiety disorders where the individual displays a persistent fear of social interactions or public performance. The resultant behavior can be a panic attack when thinking about or confronted with a social situation, with which they are unfamiliar. Tantam (2000) noted that adolescents with social phobia may, in fact, have undiagnosed cases of AS, especially when there is an absence of a complete developmental history.

Children with AS are more likely to be diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) as a secondary diagnosis or even as an initial diagnosis than either teens or adults. This is not surprising given the fact that AS and ADHD share similar features and ADHD is a diagnosis of early childhood. Klin and Volkmar’s (1997) study of 99 individuals with AS found that 28% of their sample exhibited ADHD (as cited in Martin, Patzer, & Volkmar, 2000). A survey of
the Online Asperger Syndrome Information and Support Website (OASIS) found that “... 65% [of parents] indicated that their child had been initially described as one or another type of ADHD, while 44% stated that their child had a dual diagnosis of AS and a form of ADHD” (Romanowski-Bashe & Kirby, 2001, p. 69). Another survey of 514 parents of children with AS found that 42.8% had ADHD. An additional 30% of the AS children had a diagnosis of Attention Deficit Disorder (ADD) (Romanowski-Bashe & Kirby, 2001).

Tourette’s Syndrome (TS) in the general population is thought to be approximately 1 per 169 people (Ringman & Jankovich, 2001). The co-occurrence of both Tourette’s and AS would be 5 per 100 million if the two disorders were to occur randomly (Baron-Cohen, Mortimore, & Moriarty, 1999). In actuality, the prevalence of Tourette’s among the AS population is significantly higher. Volkmar, Klin, Schultz, Pauls, and Cohen (1996) recognized 2% of their AS study participants as also having Tourette’s (as cited in Klin, Sparrow, Marans, Carter, & Volkmar, 2000). This is almost four times higher than the prevalence in the general population. Ehlers and Gillberg (1993) identified 20% of school-aged children with co-morbid AS and Tourette’s in their Swedish general population study (as cited in Gillberg & Billstedt, 2000). A second Swedish population study only revealed 10% of the children who had Tourette’s also had a diagnosis of AS (Kadesjö & Gillberg, 2000). Baron-Cohen et al. (1999) contends that the co-morbidity of Tourette’s Syndrome and AS far exceeds the rate of TS and autism. They estimate that 50% of individuals with AS also have TS, whereas only between 2.6-20.3% of individuals with autism have Tourette’s Syndrome.

Implications for Social Work

The convolution of co-morbidity emphasizes the importance of a multidisciplinary approach for diagnosis, evaluation, and treatment of individuals with AS. There is a need for collaboration between social workers and pediatricians, psychiatrists, physical therapists, psychologists, teachers, speech therapists, neurologists, occupational therapists, and other service providers. Since no two individuals with AS are alike, clinicians should take special consideration to the implication the syndrome has on the individual’s day-to-day living (Klin, Volkmar, & Sparrow, 2000).

A viable and extremely important source of information in assessment is the parents. The family members are the ones that spend most of
the time with the individual, therefore, they will be able to participate and make a meaningful contribution to the evaluation process. Family members will be more likely to recall key developmental milestones such as when the child first spoke, or when they first walked, which can assist in the differential diagnosis between HFA and AS.

An area that has not been given much attention in the literature is the relationship of individuals with AS with their siblings. The sibling interactions are an important window into the level of social functioning of an individual with AS. Basic social interactions and communication patterns at home can and should be incorporated to the evaluation process as strengths of the individual.

Teachers should be included as key participants in the assessment, planning, and implementation of educational and social goals for individuals with AS. Observations that are made by schoolteachers and paraprofessionals are extremely valuable as they could specify particular areas of struggle for the individual. The day-to-day interaction in class setting with peers can serve as a mirror to the challenges individual’s with Asperger’s encounter and the strengths they may possess. In-class and after-school activities are significantly important part of a comprehensive assessment and treatment plan for an individual with AS.

An emphasis on the unique needs of the individual should be the organizing principle of a professional’s approach to working this population. Professionals working with individuals with AS not only need to keep the idiosyncratic expression of this disorder in mind, but also need to adopt a long-term case management perspective to assessment and treatment. As the individual with Asperger’s ages, the social worker will be presented with a series of challenges depending on the client’s developmental stage, level of family support, social isolation, and personal strengths. Treatment should focus on negotiating the social environment and learning situation specific social skills. Insight oriented therapies are not recommended with this population. Cognitive and behavioral therapies are more appropriate. Collaborating with speech therapists, social workers can address the client’s issues with semantic and pragmatic speech. To more effectively collaborate with school personnel and potential employers, the social worker providing treatment ought to be fluent in the workings of two Federal laws: The Individuals With Disabilities Education Act (IDEA) and Americans With Disabilities Act (ADA). As a young adult the person with Asperger’s will need work with vocational and guidance counselors to plan their post high school endeavors. Many of the individuals with AS are highly intelligent, articulate people who will need a social worker to help them match
their strengths and capabilities to appropriate post-secondary educational or vocational opportunities. These individuals go to university and hold professional positions. It is crucial that practitioners not underestimate the potential of a client with AS. Early intervention is critical to their success.

Social workers may be tempted to focus solely on the needs of the individual with AS. However, other members of the individual’s ecosystem are also in need of assistance. Once the parents of a child with AS learn of the diagnosis, they will need education and support. To help deal with a new diagnosis, social workers should create psychoeducational support groups for parents. Parenting support groups for parents of children with AS are helpful because often parents have begun avoiding social situations because of their child’s difficult behavior. These psycho-educational support groups can also be instrumental in helping the families understand the unique learning needs of children with AS and how to advocate effectively for those needs. The groups can support parents in working with schools to meet their child’s needs or help them decide when alternative school placements are necessary. There are few services specific to AS, therefore, social workers will need to link families to services and develop services in areas where there are none. Again, a case management approach is recommended, here emphasizing a need for effective communication between service providers and family members.

The siblings of children with AS may need support in understanding what it means to have a brother or a sister with this developmental disability. Because children with AS may not look like something is different about them, this can be very confusing for the siblings and peers. There may be a unique stigma attached to having a sibling who looks “normal,” but may behave oddly.

The classroom teachers and administrators are key people in the ecosystem of a child with AS. More than likely, these professionals are unfamiliar with AS. The social worker’s role is to educate principals and teachers as to the needs of children with AS, as well as the legal protections afforded to them under IDEA and the ADA. Social workers should act as a source of support for the teachers and help them manage in-class behavior of children with AS. Part of that management would involve the identification of the child’s interests and strengths and using those as a positive basis for social interaction with peers. School-based social workers should consider using small group formats with these children to reduce their sense of social isolation and to create natural opportunities to practice social skills.
Within the realm of policy, social workers should be advocating for full funding for the Individuals with Disabilities Education Act (IDEA) to help children and their families to receive special education services. Resources through IDEA should be allocated for early assessment and intervention. This would require professionals to receive training on the complexity of identifying and treating AS clients. A second policy change that social workers should advocate for is a restructuring of Social Security Disability to include monies for the treatment of AS. The monies could be directly spent on related services such as speech or occupational therapy, or Applied Behavior Analysis (ABA). Moreover, the income eligibility criterion prevents many families from receiving these costly services. Private insurance often excludes the treatment of developmental disabilities or deem the services as education related and therefore not covered by the families’ health insurance policies.

Funding for research has begun to increase. Currently, funded research focuses upon identifying genetic and neurological structures and causes of the syndrome. Some funded research has attempted to estimate the prevalence of AS. However, funding is needed to develop rapid assessment instruments with high discriminant validity. These instruments and protocols need to be able to detect early indicators of AS, thereby allowing early intervention. Funding is also needed for studies that will explore the impact the syndrome has on the individuals and their families. Furthermore, specific funding should be allocated for the evaluation of effective treatments for the syndrome. These treatments will need to incorporate a multi-disciplinary approach since the syndrome is so enigmatic.

No single profession currently possesses the knowledge and skills to effectively assess and treat a syndrome as complex as Asperger’s. The social work profession using an ecological approach can coordinate and collaborate with a team of professionals in the diagnosis and treatment of AS. With a broad perspective, the social work profession can assist the Asperger’s client and his or her family in tailoring a unique intervention plan that addresses the idiosyncrasies of the manifestation of his or her Asperger’s. Only through such collaboration can social work solve the riddle of AS.

REFERENCES


