The Gender Gap in Asperger Syndrome: Where are the Girls?

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Abstract

Although there has been a dramatic increase in the recognition of autism spectrum disorders over the past decade, a significant gender gap has emerged in the diagnosis of milder forms, such as high functioning autism and Asperger syndrome. Statistics indicate that while boys are being referred and identified in greater numbers, this is not the case for girls. Girls are also diagnosed at later ages compared to boys. In this article, the author discusses possible explanations for the underidentification of girls with high functioning autism and Asperger syndrome. A case vignette is used to illustrate the gender differences relevant to the understanding and timely diagnosis of girls with this autism spectrum condition.

Keywords

Asperger syndrome, autism spectrum, diagnosis, gender differences, social skills

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Asperger syndrome is an autism spectrum disorder characterized by problems in social relatedness, empathic communication and understanding, and circumscribed interests in the presence of generally age-appropriate language acquisition and cognitive functioning (Volkmar & Klin, 2000). Students with Asperger syndrome often experience problems related to their social deficits and are at risk for academic underachievement, school drop-out, peer rejection and internalizing problems such as anxiety and depression (Safran, 2002; Wilkinson, 2005). Although there has been a dramatic increase in the number of children diagnosed with autism spectrum disorders over the past decade, a significant gender gap has emerged in the identification of milder forms, such as high functioning autism and Asperger syndrome. Statistics indicate that while boys are being referred and identified in greater numbers, this is not the case for girls (Attwood, 2006; Ehlers & Gillberg, 1993; Wagner, 2006). For example, referrals for evaluation of boys are ten times higher than for girls (Attwood, 2006). Girls are also diagnosed with autism spectrum disorders at later ages relative to boys (Goin-Kochel, Mackintosh, & Meyers, 2006). This gender gap raises serious questions because many female students with Asperger syndrome are being overlooked and may not receive the appropriate educational supports and services. The consequences of a missed or late diagnosis include social isolation, peer rejection, lowered grades, and a greater risk for mental health and behavioral distress such as anxiety and depression during adolescence and adulthood.

When I think of my earliest years, I recall an overwhelming desire to be away from my peers. I much preferred the company of my imaginary friends-

-Liane Holliday Willey (1999)

Why are fewer girls being identified? Why do parents of girls experience a delay in receiving a diagnosis? Are there gender differences in the expression of the disorder? Answers to these questions have practical implications in that gender specific variations may have a significant impact on identification practices and the provision of educational services for children with autism spectrum disorders (Thompson, Caruso, & Ellerbeck, 2003). Although few studies have examined gender differences in the expression of autism, we do have several tentative explanations for the underidentification and late diagnosis of girls with Asperger syndrome. This article discusses these possibilities and provides a case vignette to illustrate the gender differences relevant to the understanding and timely diagnosis of girls with Asperger syndrome.

Gender Roles

Gender role socialization is critical to understanding why girls with Asperger syndrome are being underidentified (Faherty, 2006). Since females are socialized differently, autism spectrum disorders may not manifest in the same way as typical male behavioral patterns (Bashe & Kirby, 2005). For example, girls might not come to the attention of parents and teachers because of better coping mechanisms and the ability to “disappear” in large groups (Attwood, 2007). Girls on the higher end of the spectrum also have fewer special interests, better superficial social skills, better language and communication skills, and less hyperactivity and aggression than boys (Gillberg & Coleman, 2000). Likewise, girls are more likely than boys to be guided and protected by

same gender peers and to have special interests that appear to be more gender appropriate (Attwood, 2006). These characteristics lessen the probability of a girl being identified as having the core symptom of autism spectrum disorder: an impairment in social skills. In fact, it may be a qualitative difference in social connectedness and reciprocity that differentiates the genders (Attwood, 2007; Kopp & Gillberg, 1992). As a result, parents, teachers, and clinicians may not observe the obvious characteristics associated with the male prototype of higher functioning autism spectrum conditions such as Asperger syndrome (Kopp & Gillberg, 1992; Nyden, Hjelmquist, & Gillberg, 2000).

Although each case is unique, the following vignette provides an example of how gender specific differences contribute to the diagnostic gender gap in Asperger syndrome. The case of Heather is based on the author's own clinical experience with students with autism spectrum disorders. Identifying information has been removed or altered to ensure confidentiality. Bulleted comments have been inserted throughout the case presentation to illustrate links between constructs, diagnostic criteria, and differences in phenotypic expression between boys and girls.

Table 1: Weblinks for Additional Information

Autism Research Centre
(http://www.autismresearchcentre.com/arc/default.asp)

Autism Society of America
(http://www.autism-society.org/)

National Autistic Society
(http://www.nas.org.uk/)

Online Asperger Syndrome Information and Support (OASIS)
(www.aspergersyndrome.org)

Organization for Autism Research (OAR)
(www.researchautism.org)

The Council for Exceptional Children (CEC)
(www.cec.sped.org)

Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH)
(www.teacch.com)

Yale Child Study Center
(http://www.med.yale.edu/chldstdy/autism/)

Case Example: Heather

Heather is currently a fourth grade student who was diagnosed with Asperger syndrome and found eligible for special education and related services. Developmental history indicates that Heather spoke her first words by 12-18 months and used sentences and communicative phrases by approximately

24 months. She sat unsupported at six months, crawled at nine months, and walked by 14 months. Although no obvious social problems were reported, Heather's parents recalled their daughter's temperament as being inhibited and "slow to warm up." She was also a "fussy" eater and had difficulty transitioning to different food textures. Despite some parental apprehension regarding early development, they were advised by their pediatrician that Heather's social and communicative functioning did not seem typical of a specific developmental disorder or delay and did not warrant an evaluation.

- *Although social and communication symptoms are the most reliable indicators of autism spectrum disorders in young children, they are very difficult to identify. For example, we have no precise definitions of milestones for social skills development compared to motor and language skills (Stone, 2006). There are also some pediatricians who prefer to take a "wait-and-watch" approach, hoping children will catch up. Unfortunately, this can delay early identification and intervention.*

Heather was enrolled in a preschool program three days per week where she was observed to marginally participate in most activities and was considered a happy and placid child. Following an unremarkable preschool experience, Heather attended a combined kindergarten-first grade class in an early childhood center. In class, she was observed to be a quiet and reserved student who usually stayed on the periphery of the group. She was also described as a shy, undemanding, and even-tempered student who was unassuming and soft spoken. While Heather appeared to enjoy a special friendship with another girl at school, she preferred solitary activities such as creating small, imaginary worlds with blocks and figures and playing games involving puppies or kittens for extended periods of time. Her teacher voiced some concern over Heather's reluctance to engage in reciprocal conversation and difficulty maintaining focus in the classroom. At home, Heather was viewed as a "sweet" and amicable child who was compliant and well-liked by friends and relatives. Yet, Heather's parents were also troubled about their daughter's periods of aloofness, inattentiveness, and lack of initiative and social responsiveness.

The most salient feature appeared to be a significant qualitative impairment in reciprocal social behavior and responsiveness.

- *Social communication and pragmatic deficits may not be readily discernible because of a non-externalizing behavioral profile, passivity, and lack of initiative. Girls who have difficulty making sustained eye contact and appear socially withdrawn may also be perceived as "shy," "naive," or "sweet" rather than having the social impairment associated with an autism spectrum disorder (Wagner, 2006).*

Heather was evaluated by the school and found to have age-appropriate skills. The school psychologist concluded that Heather was a shy, immature, and fearful student whose ability to perform academically was most likely affected by an early-onset anxiety disorder, word retrieval problems, and/or a

central auditory processing deficit. Several academic recommendations were offered.

- *The diagnosis of another disorder often diverts attention from autism-related symptomatology. In many cases, girls tend to receive unspecified diagnoses such as a learning disability, processing problem, or internalizing disorder. A recent survey of women with Asperger syndrome indicated that most received a diagnosis of anxiety or mood disorder prior to being identified with an autism spectrum disorder (Bashe & Kirby, 2005). Unfortunately, a misdiagnosis can delay or prevent implementation of the appropriate interventions and treatment. As a result, many girls may not receive the assistance and understanding that could make an importance difference in their lives (Wagner, 2006).*

Heather's second grade experience was characterized by continuing difficulties in relating and communicating with peers and adults, transitioning problems, poor task completion, and occasional oddities in behavior. Teacher reports described Heather as an anxious student with a limited affect, mild eye gaze avoidance, and a tendency to withdraw when presented with complex or over stimulating social situations. Heather's parents were also concerned with Heather's lack of social contacts and marginal school progress. They reported that she had few neighborhood friends, seemed socially detached, and typically enjoyed activities such as dressing up, acting out Disney videos, playing with her Barbie dolls, and talking to an imaginary friend.

Social communication and pragmatic deficits may not be readily discernible because of a non-externalizing behavioral profile.

- *The perseverative and circumscribed interests of girls with autism spectrum disorders may appear to be age-typical. Girls who are not successful in social relationships and developing friendships might create imaginary friends and elaborate doll play that superficially resembles the neurotypical girl (Attwood, 2006).*

Although Heather did not present with behavioral challenges such as temper tantrums or "meltdowns," she often refused to respond to teacher requests and failed to participate in classroom activities. She was also perceived as "odd" by her peers and seemed to be in her own little world. It was increasingly evident from parent and teacher reports, clinical observations across settings, and cognitive and adaptive behavior assessments that Heather might be exhibiting symptoms characteristic of an autism spectrum disorder. The most salient feature appeared to be a significant qualitative impairment in reciprocal social behavior and responsiveness. An adaptive behavior assessment conducted across settings indicated a moderate deficit in socialization relative to same age peers; further reflecting Heather's ongoing difficulty in mastering the personal and social demands of both her home and school environments. Even though Heather demonstrated no specific deficit on norm-referenced measures of cognitive, language, and academic functioning, significant problems were evident with pragmatic and qualitative social communication. Heather's pattern of behavior was con-

sidered consistent with many of the features displayed by children with mild or "high functioning" autism spectrum conditions. A formal diagnosis of Asperger syndrome was offered more than two years after Heather was initially enrolled in school.

- *Although girls may appear less symptomatic than boys, both genders share similar profiles. Research suggests that when IQ is controlled, the main gender difference is a higher frequency of idiosyncratic and unusual visual interests and lower levels of appropriate play in males compared to females (Lord, Schopler, & Nevicki, 1982). As a result, the behavior and educational needs of boys are much more difficult to ignore and are frequently seen by teachers and parents as being more urgent, further contributing to a referral bias (Kopp & Gillberg, 1992).*
- *Over reliance on the male model with regard to diagnostic criteria contributes to a gender "bias" and underdiagnosis of girls (Kopp & Gillberg, 1992; Nyden et al., 2000). Clinical instruments also tend to exclude symptoms and behaviors that may be more typical of females with autism spectrum disorders.*

Conclusion and Recommendations

Heather's case vignette illustrates how girls with Asperger syndrome may have a different profile than boys, which in turn, might not be recognized as an autism spectrum disorder (Thompson et al., 2003). While the gender gap in Asperger syndrome has yet to be empirically investigated, if girls do process language and social information differently than boys, then clinical and educational interventions based largely on research with boys may be inappropriate. As a result, girls may receive less than optimal academic and behavioral interventions and not realize their potential. Further research is urgently needed to examine the similarities and differences between males and females to determine whether the diagnostic definition of Asperger syndrome is valid for both boys and girls (Attwood, 2007). If gender specific variations do exist, then the predictive validity of the diagnosis and developmental course may well differ between the sexes. In the meantime, educators and school personnel should question the presence of an autism spectrum disorder in female students who may be referred for internalizing problems such as anxiety or depression. Additionally, when a girl presents with a combination of social immaturity, perseverative or circumscribed interests, limited eye gaze, repetitive, social isolation, high levels of anxiety and attention problems, and is viewed as "passive" or "odd" by parents, teachers or peers, the likelihood of an autism spectrum disorder should be considered (Wagner, 2006).

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