



Hidden in Plain Sight - Women and Girls on the Autistic Spectrum: A Call to Action



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Abbreviations: AS: Asperger's Syndrome; ASD: Autism Spectrum Disorder; ASC: Autism Spectrum Condition; RRBs: Restricted and Repetitive Behaviors; FT: Fetal Testosterone

Introduction

"AS [Asperger's Syndrome] is [like] talking to another person through an intercom machine or something and somehow the wires get crossed and they get the wrong message" [1]. This quote is from a 13-year-old girl named Emily with Asperger's Syndrome, which is a condition that falls under the umbrella term of autism spectrum disorder (ASD, also called autism spectrum condition [ASC]). ASC is a developmental disability that is diagnosed significantly more in males than in females [2,3]. Most people take this fact for granted and attribute it to genuine etiology, but new research shows that this gender disparity is also caused by the way our society views and (mis- and under-) treats women on the spectrum and those with autism overall [4-8].

Historically, ASC has been deeply misunderstood, leading to inadequate diagnoses and treatment, especially when it comes to women and girls on the spectrum. This research reveals details about reasons behind this misunderstanding, and that we need to think about, diagnose, and treat women on the spectrum in a different way [1,3-8].

Overview of Autism

Autism spectrum condition is a neurological condition that arises in early childhood but may be diagnosed at any age. This condition is characterized by socio-communicative deficits, limited interests, and restricted and repetitive behaviors (RRBs) [3]. People with ASC have trouble recognizing, analyzing, and

sending social cues (such as making eye contact); they may be intensely passionate about one or two topics such as math or cats to the point of exclusion of anything else; they may fidget to express or entertain themselves or to release tension ("stimming") or be unable to adapt to changes in their routine. ASD occurs in 1 in every 54 people worldwide and has been getting increasing amounts of attention as these numbers appear to be growing – previous statistics reported a prevalence of 1 in every 68 people [2].

Gender Disparity: Diagnosis Frequency

Differences in how often autism is diagnosed in males versus females is also gaining attention. Autism spectrum condition is diagnosed in four males for every female (4:1) [1-4,7,8] however many other ratios have been proposed ranging as high as 16:11. There are some proposed scientific explanations for an increased rate of ASC prevalence in males.

These range from the genetic (female protective effect) [6,7] to the hormonal (fetal testosterone (fT)) [6] to the neurological (extreme male brain theory) [1]. Unfortunately, the research is based on symptoms and clinical presentation of ASC in males - the historical norm. It is only part of the story. The emerging question: is the more commonly accepted gender disparity of 4:1 accurate, or are we misrepresenting the actual prevalences due to our ignorance, diagnostic shortcomings, and biases?

Gender Disparity: Symptomatology, Masking, and Testing; or Why is the Diagnosis Ratio So High?

Although the number of research studies of males with ASC far outnumbers the number related to their female counterparts, we have enough evidence-based research to know that the sexes exhibit different symptoms and endure different challenges associated with their condition. Although there is variation on an individual level, there are clear sex-specific trends [8,1]. Core traits may be widely occurring, but females have more subtle symptoms, and their restricted interests (called 'special interests' by many in the community) and RRBs are more mainstream than males' [4,6]. When tested, girls repeatedly self-identified as having lower social skills, despite objective testing showing equal results for both sexes of the same age [1]. With this increased self-awareness, girls demonstrate greater abilities to avoid social conflict. "Masking", also called camouflaging, is when someone with ASD attempts to compensate for their socio-communicative challenges by mimicking age-appropriate social behaviors because of a desire to fit in or because of gendered behavior expectations. Girls' ASC symptoms are usually subtler than boys', and girls themselves make them more subtle by masking. Masking is primarily performed by females, especially those with high IQs [6]. This may be because girls' higher levels of self-awareness allow them to identify and hide their communicational symptoms [1]. So, girls with ASC (especially ones with low support needs) mask as a way to blend in with their allistic (non-autistic) peers and masking, in turn, is one reason that women on the spectrum are underdiagnosed.

Another reason for this gender disparity is the way that diagnostic tests ignore and misdiagnose female autism. The tests used to diagnose autism – the Gold Standard Diagnostic Measures (ADOS, ADOS-2, and ADI-R) – have questions that are based on male symptomatology and do not pick up the subtleties of female autism. The tests are based on research that predominantly focuses on males [1,5,6,8]. Comorbid conditions occur in females with ASD at higher rates than in their male counterparts; these conditions include anxiety, tic disorders, eating disorders, and depression [8]. Since these conditions' symptoms overlap with those of ASD, a girl's autism may be misdiagnosed as a comorbid condition [6,8].

Inadequate diagnostic tests exacerbate girls' tendency to hide their symptoms, decreasing the chances that a girl with ASC will get a timely, correct diagnosis.

Conclusion

Women and girls on the spectrum are largely hidden from the researchers, medical professionals, and others around them.

While factors such as genetics, endocrinology, and neurobiology may legitimately produce a gender disparity, deep gaps in our ability to truly see females with autism exist and intensify this disparity. Social sensitivity and resulting compensatory behaviors such as masking result in girls being tested later than boys, if ever. Biased research and testing mean that even if an autistic girl is able to get tested, she may be misdiagnosed or undiagnosed. These social factors exacerbate the gender disparity; the disparity has both a social and biological basis. This sets up a harmful self-fulfilling circle of underrepresentation in research and subsequent underdiagnosis and treatment - to use Emily's words, those who care for, treat, and research the condition has gotten the "wrong message" about autism, just like people on the spectrum and those they communicate with receive the "wrong message[s]" from each other [1]. The fact that girls on the spectrum go largely unnoticed negatively affects their mental health, autonomy, education, and employment, and not having a diagnosis prevents one from accessing autism services. In addition to having the right to a diagnosis, girls and women on the spectrum have a right to access the supports they need. Medical professionals, caregivers, and researchers in the autism world have an obligation to those they care for to recognize and understand the gender differences associated with ASC. They owe it to women and girls on the spectrum to see that ASC is not simply a "male thing" [1,4].

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