

Uncommon or Underdiagnosed? The Effectiveness of the Current Diagnostic Criteria for Autism Spectrum Disorder in Women

Alondra Gonzalez and Kathy B. Ewoldt, Ph.D
University of Texas at San Antonio
Interdisciplinary Learning and Teaching

Abstract

Children need to develop in positive learning environments with proper educational and developmental supports to achieve their highest potential and have positive postsecondary outcomes. Since students with disabilities often struggle with accessing curriculum without necessary supports, accuracy in early childhood detection and intervention of developmental delays is very important in the field of Special Education. While the diagnostic criteria of many common developmental delays are becoming more consistent and accurate at identifying children who may have special needs, there are still many factors that educators and diagnosticians are not considering when creating and evaluating said criteria. The idea of camouflaging, or “masking”, emotions or behaviors could be a factor to consider when looking at the disproportionate representation of male to female children receiving special education services in the US. Masking or camouflaging in psychology is a term that means the ability to conceal one’s emotions or reactions in order to achieve a desired outcome. This skill develops quickly in young girls, and can make diagnosing many mental health disorders or general health issues very difficult as key behaviors/symptoms can be suppressed or not severe enough for concern. If a child is masking behaviors associated with a developmental disability, like Autism Spectrum Disorder, they may not receive early childhood interventions until much later in life which may affect their success in the classroom. Knowing that masking occurs in young children, there is a need to evaluate the effectiveness of the current diagnostic criteria of Autism Spectrum Disorder and other developmental disorders to see if girls are under-diagnosed due to alternate manifestations of common signs due to gender and gender norms.

Keywords: Special education, Autism Spectrum Disorder, Early Childhood Intervention, Diagnostic Criteria, Assessment, Manifestations of Behavior, Masking

Autism Spectrum Disorder (ASD) is a developmental disorder that is commonly associated with deficits in communication, social development, and restrictive and repetitive behaviors. By 8 years-old, 1 in 54 children living in the US are estimated to be diagnosed with Autism Spectrum Disorder. ASD is seen in all gender, racial, and socio-economic groups, but is 4 times more prevalent in males than females (Maenner et. al., 2016). The reason this particular developmental disorder is more common in males is unknown, but multiple researchers believe a gender bias in diagnosis could be related to classical research population demographics for Autism research and inaccuracies in diagnostic criteria due to gender-bias in research populations (Dell’Osso et. al., 2017; see also, Beck, 2020; Tierney et. al., 2015; Went, 2016). Most autism research has historically been done with groups of predominantly male participants, and thus the diagnostic criteria is based on male behavior patterns (Beck, 2020). This gender bias in the diagnostic criteria may be the cause as to why so many young girls with ASD are not properly identified until much later in their life, like in adulthood (Beeger, 2012).

Gender Expectations and Masking

Merriam-Webster Dictionary (2021) defines masking as the ability “to conceal ones emotions or motives”, generally in order to achieve a certain reaction or outcome. When one look at this through the scope of psychology and societal rules regarding communication and emotional regulation, masking becomes a very important ability to develop in order to bond with others (Beck, 2020; Davis, 1955; Erikson, 1995; Underwood et. al., 1992). Masking is thought to develop alongside three other abilities: the ability to mirror actions of others, the ability to self soothe, and the ability to make and keep friendships/relationships (imprinting). By masking, people are able to regulate their own emotions, be more adaptable to certain situations, and feel accepted by peers and by society.

This last reason, the need to be accepted by others, is a very fundamental need that develops early on in childhood. Young children generally have an idea of what feeling and display rules are in place when dealing with adult emotions, so the ability to have an acceptable reaction to certain negative emotions becomes highly desirable in a child’s Trust vs. Mistrust stages of child development (Underwood et. al.; see also, Erikson, 1995). Theresa Davis (1995), an educational researcher, did a study in children and their ability to mask negative emotions, by having students receive an unpleasant gift in the presence of a gift giver and in the absence of one.

What she discovered was that children as young as 3 would try to “mask” their negative emotions and opinions about the gift in front of the gift giver, but in the absence of the gift giver, they would express their original feeling of displeasure with no inhibition. Davis believes that the children did not want to make the gift giver, the higher authority in this situation, upset by being voicing displeasure as a way to most likely to stay on their good side.

Success and effectiveness of their mask varied among the test population, but Davis does note that female participants are able to mask a little bit more accurately than their male counterparts, and that as children grow up in age, girls tend to develop this skill much faster (Davis, 1995). The reason this occurs may be less of a biological factor and more of an outcome of societal pressures and gender norms associated with being born female.

For example, traditionally the role of women is to provide for the needs of her family, take care of the “home front”, and provide support for those with more authority over her. As gender norms shift and women start appearing in more positions of power, we see more scrutiny when it comes to the behaviors of women. Women are held to impossible standards of perfection

when it comes to maintaining leadership roles and any behavior that can be seen as emotionally-charged or slightly unstable can be used to argue how unfit a female candidate may be in her field. Skills that suppress or change emotions become highly desirable in women as it helps support security in life, but this does not come without a cost.

This skill makes it hard for women to seek help in many aspects in life. When it comes to general health issues, gender stereotyping women as "emotional" or "sensitive" may deter many women from seeking help for health concerns until they are more serious. In terms of mental health, when women eventually do go to their providers for help, doctors are very quick to assign disorders such as Depression or Anxiety as the cause regardless of other symptoms or manifestations (World Health Organization, n.d.). It could be that doctors are hesitant to diagnose women with a more complicated mental health diagnosis just as much as women are scared to receive a diagnosis due to the stigma associated with it. However, more serious mental health concerns, when left untreated, can worsen over time and can have fatal consequences. These consequences are more severe when looking at physical health, but similarities can be seen in terms of outcomes in children who are diagnosed with Autism or other developmental disorders later in life. Early intervention is key in securing the best outcome for students with learning delays or other disabilities, but the longer it takes to start interventions, the harder it is for a child to catch up to peers, if they ever do.

Knowing what we know about masking, and its effect on women's perceptions of their own feelings, it is very likely that women could be experiencing the same behaviors as a male with autism but are more likely to mask or subdue these behaviors in order to be accepted, which would in turn make diagnosing such a disorder very hard (Beck, 2020). Unfortunately, individuals with ASD are susceptible to "anxiety, mood, and trauma and stress related disorders as well as suicidal behaviors", all which will increase in severity if left untreated (Dell'Osso et. al., 2017).

To properly diagnose girls and women with Autism Spectrum Disorder, patients themselves would have to "unmask" and freely exhibit behaviors they would otherwise try to hide, or the current diagnostic criteria and commonly used assessments for ASD would need to be calibrated to include more sub-threshold autism traits and manifestations as they occur in females due to masking (Dell'Osso et. al., 2017).

Alternate Manifestations of ASD in Women

While the idea of researching common manifestations of Autism in females is still relatively new, it is starting to gain traction as more information becomes readily available and ASD is becoming a more known and talked about disorder. Many researchers are trying to bridge the gender gap by case studies of self-identified ASD in women (Pearse, 2020; Tierney et. al., 2015; Went, 2016) or with utilizing alternative assessments with larger testing domains. Recent research points to three common signs of Autism in women: (a) a desire for female-female friendships but an inability to converse with peers of same sex (Tierney et. al., 2017; Went, 2016), (b) a sense of being different or invisible to peers or teachers (Pearse, 2020; Tierney et. al., 2015; Went, 2016), and (c) the acquisition of proper social etiquette and empathy being obtained through scaffolding-like skill building (i.e., learned behavior, not innate)(Tierney et. al., 2017). In Went (2016), investigators compiled personal accounts of multiple adult women with ASD and sorting out common themes seen in those accounts, and found that women with ASD were sensitive to sounds or smells, or had a comorbid or previously diagnosed mental health issue. While these do offer up considerations for adult women on the spectrum looking for more

applicable signs, most of her findings are unable to be used as a way to identify ASD in young children as most of these ‘common signs’ require multiple years of documentation for later evaluation and only became relevant if a previous diagnosis was ineffective in treating the original issue.

Research designed to identify more accurate diagnostic material in terms of identifying younger children with ASD evaluated recently developed assessments that consider the gender bias and were made to be more sensitive to sub-threshold autism symptoms (Cederberg, 2018; Dell’Osso et al., 2017). Dell’Osso and colleagues investigated the use of the Adult Autism Sub-threshold Spectrum (AdAS) assessment in autistic children. The 160-item questionnaire goes through 7 main domains of autism (i.e., Childhood/Adolescence, Verbal Communication, Non-Verbal Communication, Empathy, inflexibility and adherence to routines, restricted interests and ruminations, and hyper-hyporeactivity to sensory input domains) that takes into consideration multiple manifestations of the same domain deficit. The results of that study showed three distinct trends in the data; a “statistically significant effect of gender emerged for the Hypo-Hyperreactivity to sensory input domain... and in Verbal Communication”; ASD symptoms are often seen in individuals with Eating Disorders and suggests a link between anorexia nervosa and ASD in adolescent girls; and verbal deficiencies are commonly seen in girls with ASD who are academically gifted, which may lead to a possible observance of a “female phenotype of Asperger’s” (Dell’Osso et al., 2017). One shortcoming of Dell’Osso’s investigation for this particular assessment is that he was unable to determine exactly how significant the results are in terms of age of a child when the assessment is used.

Conclusion

Of the research compiled, there is a general consensus that women and young girls display key traits of Autism Spectrum Disorder in a different way than their male counterparts, but currently there is a lack of uniformity of exactly how these traits are manifested. Multiple sources state that there is a trend when it comes to reactivity of sensory inputs and diminished verbal communication in women, but cannot specifically state how these manifest in women or girls. Use of alternative assessment materials, while it shows a higher rate of diagnosis for girls and boys that do not meet the traditional threshold for ASD, are unable to provide an assessment that works throughout the lifespan and is instead limited to a specific developmental periods (early childhood/adolescence/adulthood).

Autism research is still fairly new, and the idea that gender may change how it looks in children is even newer. Research needs to continue to investigate adult women on the Autism Spectrum to determine if there were missed signs of childhood ASD that could be used for early childhood interventions. Due to the nature of ASD, every person with autism will experience autism in a different way. By extending the diagnostic criteria and increasing the sensitivity of such assessments, children with ASD are more likely to grow up with more positive outcomes post-secondary.

With further investigation, diagnosticians and relevant parties will be able to better identify these developmental disorders in early childhood and provide the needed interventions early on, which allows for the child to reach their greatest potential. However, this is not where it ends. With this new knowledge, researchers will come one step closer to understanding how women perceive emotions, feelings, and symptoms which in turn will help us to better treat them and their health. Therefore, it is important to investigate this issue.

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