

Autism in Women and Nonbinary People

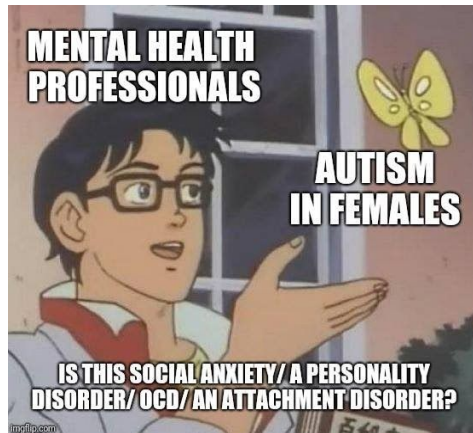
The Status Quo:

- “Autism Awareness” educational materials typically emphasize the higher rates of diagnosis in boys/men.
- Autism is most often represented as being associated with white male children.
- Girls and women who have pursued an autism evaluation have been told things like “girls can’t have autism.”
- Autistic people (particularly those labeled with an intellectual disability) are assumed to be cisgender; nonbinary autistic people may have trouble accessing education, community, and supportive services in relation to their gender identity
- Topics that disproportionately impact adult Autistic women tend to be under-researched at best (such as interactions between sensory processing differences and puberty, menstruation, pregnancy, or menopause).

Autism may be underrepresented amongst girls/women and nonbinary people for many reasons:

- The criteria for autism was developed by studying boys, as happens in many areas of research
- Socialization of women and girls may lead to higher rates of girls and nonbinary people using masking/camouflaging to hide autistic traits. For example, girls might receive more specific instruction and policing of behaviors in regards to how they move, talk, and interact with others.
- It has been observed that Autistic girls and nonbinary children may have special interests that are seen as more socially acceptable or appropriate for their gender. For example, many autistic girls report having special interests in areas like animals, fashion, celebrity culture, tv shows, cosmetics, and the arts.
- A young girl who does not interact with others in a normative way might be labeled as shy or quiet, and this might be considered a desirable characteristic in a young girl rather than a pathologized one.
- In some cases it may be a self-fulfilling prophecy: professionals who are trained to believe that autism occurs predominantly in boys/men may be predisposed to see a person as autistic if they are a boy/man.
- Autistic characteristics and symptoms of distress related to autistic life experiences may result in women and girls receiving many other diagnoses prior to being diagnosed with autism, in particular,

eating disorders, borderline personality disorder, obsessive compulsive disorder, and anxiety and mood disorders.



Aspergirls: The Female Phenotype

- Some people have compiled lists of traits and experiences believed to be common to autistic women. These trait lists move elaborate beyond DSM criteria to describe common lived experiences.
- Many autistic women/nonbinary people identify strongly with the experiences of other autistic women/nonbinary people.
- Some women use terms like “aspergirl” to self-identify, while others find this terminology (and anything associated with the label Aspergers) to be distasteful at best. *Do not refer to someone as an aspergirl unless they have already indicated that they identify with the term!*
- As the idea of the “female phenotype of autism” spread, many autistic people noted that nonbinary people and men/boys may also show this ‘alternative phenotype’.
- Many people argue against the idea of a female phenotype of autism because of the large numbers of nonbinary people and men who strongly fit this profile. Examining the role of autism for women and nonbinary people may show us ways that we need to reconsider autism in boys and men too.
- Some refer to “atypical autism” instead of a female phenotype in order to be inclusive of all genders, although this phrase is also used within a medical framework to describe “sub-threshold autism,” making the term quite unclear (people who describe a “female phenotype” are not describing a ‘sub-threshold condition’ but rather a pervasive and significant auticity).

Autistic women and girls ...

- are experiencing “late diagnosis” or adult diagnosis at increasing rates because their autism was not identified at an early age; many women receive an autism diagnosis only after their children are diagnosed and a lifetime of feeling different from their peers
- ... are at elevated risk of sexual abuse throughout the lifespan

- ... develop a variety of coping skills to deal with overwhelming emotions and sensations, including imagination and creativity (like retreating into a fantasy world or creating works of art), mental processing (like counting, categorizing), and engaging in a topic of special interest.
- ... may study fiction/books, TV shows, and movies, magazines, and other materials in an attempt to make sense of socializing and interaction. Some people might imitate these materials, or someone they know in real life, in an attempt to communicate/ behave “appropriately.” This imitation can be either/both subconscious and conscious. Some Autistic girls, women, and nonbinary people excel at imitation so much they can become accomplished actresses. However, masking is also associated with increased distress from problems like anxiety, depression, and suicidal ideation.
- ... may manifest “restricted interests and repetitive behaviors” in a way that is considered acceptable in girls, for example, by collecting and lining up dolls or by listening to the same song over and over again while practicing a dance routine or memorizing the lyrics.
- ... may have common co-occurring conditions, whether diagnosed or not, including ADHD, Ehlers-Danlos syndrome, dysautonomia (particularly POTS), alexithymia, prosopagnosia, anxiety and mood disorders, obsessive compulsive traits, food sensitivities and gastrointestinal issues.
- ... may stim in ways that are less noticeable than hand flapping, like picking at nails, skin, and hair, playing with her hair or pacing; stims might be completely hidden from view such as curling toes up inside her shoes.
- ... may go to great lengths to communicate and socialize “correctly” by rehearsing interactions prior to having them, preparing scripted responses to expected questions, and using an “internal coach” to self-talk themselves through an interaction
- ... may struggle with executive functioning to a high degree even if she is given labels like “gifted” or “high functioning,” this can cause difficulty with daily activities like leaving the house to go to school, preparing a meal, or getting ready to go to bed. Constantly thinking of her movements and the next step in the process can be overwhelming, and this can lead to further exhaustion, burnout, and shutdowns/meltdowns.
- ... often respond to standard treatments in atypical ways: this can include atypical responses to medication and medical treatments AND therapeutic methods and treatments.
- ... may be highly empathetic, to the point of emotional volatility; can lead to a strong sense of social justice and a passion for animals and the natural world; this empathy can extend to inanimate objects and concepts including numbers and words. She may struggle to show her empathy and concern for others in a way that they recognize.
- ... may be highly conscious about limitations due to confronting them daily, even if others do not recognize the extra effort she takes to work around limitations
- ... may have an increasingly hard time in middle and high school as the social demands on girls become more intense.
- ... may have unique linguistic profiles (see Boorse, et al. 2019)

What about nonbinary people?

- Trans and nonbinary autistic people have largest been ignored by research.
- Autistic people identify as something other than cisgender at remarkably higher rates than non-autistic people

Get to know Autistic Women and Nonbinary People!

There's more to us than Temple Grandin!

- Judy Endow
- Ann Memmott
- Jen Msumba
- Kassiane Sibley
- Jessica Benham
- Paige Layle
- Julia Bascom
- Lydia XZ Brown
- Rachel Cohen-Rottenburg
- Sharon DaVanport
- Karyl Frankiewicz
- Morenika Giwa-Onaiwu
- Daryl Hannah
- Susan Boyle
- Amy Sequenzia
- Ivanova Smith
- There are so many more ... Autistic women are everywhere - in every industry and occupation, in every country, province, and city - even when we are not recognized as such.

Continue learning ...

Continuing Education:

"Women and Girls" learning module from the National Autistic Society
(CE course - 120 min) - Learn about traits of "atypical autism" common in women & girls
<https://www.autism.org.uk/professionals/training-consultancy/online/women-and-girls.aspx>

This is a highly recommended training module that can count towards your CMTEs. One reason I liked this course was not only did it provide quality educational material but it taught it through an engaging, interactive electronic platform. This is not just a slideshow presentation with some cheesy videos.

Books:

What Every Autistic Girl Wishes Her Parents Knew
pub. Autism Women's Network

* Highly recommended!!!

Camouflage: The Hidden Lives of Autistic Women
Dr. Sarah Bargiela, art by Sophie Standing

Organizations:

Autism Women and Nonbinary Network (AWN)

Research (n.b. these are not intended to be APA citations):

Bargiela, Steward, & Mandy. (2016). The experiences of late-diagnosed women with autism spectrum conditions: an investigation of the female autism phenotype. doi: 10.1007/s10803-016-2872-8. Retrieved from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5040731/>

Beck, Lundwall, Gabrielsen, et. al. (2020). Looking good but feeling bad: “Camouflaging” behaviors and mental health in women with autistic traits. Retrieved from: <https://journals.sagepub.com/doi/full/10.1177/1362361320912147>

Boorse, J., Cola, M., Plate, S. et al. (2019). Linguistic markers of autism in girls: evidence of a “blended phenotype” during storytelling. *Molecular Autism* 10(14). <https://doi.org/10.1186/s13229-019-0268-2>. Retrieved from: <https://molecularautism.biomedcentral.com/articles/10.1186/s13229-019-0268-2>

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Other Reading:

“Autism - It’s Different in Girls” from Scientific American MIND:
<https://www.scientificamerican.com/article/autism-it-s-different-in-girls/>

Samantha Craft’s “Females and Autism/Aspergers Checklist” from the Art of Autism
<https://the-art-of-autism.com/females-and-aspergers-a-checklist/>
Women with autism hide complex struggles behind masks, from Spectrum News
https://www.spectrumnews.org/opinion/viewpoint/women-autism-hide-complex-struggles-behind-masks/?gclid=CjwKCAiAhbeCBhBcEiwAkv2cY5ZIPjfm05sHZ3sKLf4SgjErfXNDcnVxIn_IKNIBZ7VACu1bRnRibxoCyNYQAvD_BwE

Girls on the Spectrum are Being Overlooked, from Duke Integrated Pediatric Health:
<https://ipmh.duke.edu/news/girls-autism-spectrum-are-being-overlooked>