

Let's Talk About Sex

*Differences in the Expression and
Experience of Autism Based on Sex*

By Sarah Hudson





Illustration of a girl masking autism
 "puzzle" by Psyon from Wikimedia (CC BY-SA 3.0). Adapted by Sarah Hudson

Picture a child with autism. How do you know they have autism? Do they act a certain way? Do they look a certain way? What is the gender of the child you imagined?

Chances are, when you imagine a child with autism, you imagine a boy, maybe even someone you know. If so, you are in the majority. Autism, or Autism Spectrum Disorder (ASD) as it's been referred to in more recent years, is a developmental disorder with a diagnosis ratio of around four to five males for every one female diagnosed^{1,2}. While it is common to see a higher prevalence of males with developmental disorders, the disparity between diagnosis ratio of males and females begs an important question: Is it true that ASD affects males more frequently than females, or have the ways in which we researched and defined autism made it so that we only know how to recognize autism in male populations? Recent

discoveries in developmental neuroscience suggest the latter, and have acknowledged the problematic nature of the fact that almost all of the data that we use to understand autism has been performed on almost exclusively male participants^{3,4}. This wouldn't be an issue if the diagnosis rate of autism was identical for both men and women. However, the discrepancy between the ratio of men and women diagnosed with autism is significant enough to question whether the criteria for autism diagnosis is accurate and applicable to all populations. To understand this inconsistency, we need to understand the history of autism diagnoses.

History of Autism

The discovery of autism is usually associated with Austrian psychiatrist Leo Kanner, who began seriously studying the disorder in the 1940s^{3,5}. However, descriptions of autism in psychiatry date back to

the beginning of the 20th century. In 1911, Swiss psychiatrist Eugene Bleuler, described people with autism as having a very severe form of schizophrenia, a disorder he also discovered³. Bleuler described autistic individuals as people who suffered from 'infantile wishes' and attempted to avoid reality by creating their own hallucinated fantasies³. From then until more dedicated research in the 1940s, autism was described as a symptom of a specific and severe form of schizophrenia³. It wasn't until Kanner began acknowledging autism as its own unique developmental disorder that more accurate descriptions of autistic symptoms began. Kanner described symptoms of unnecessary word repetition, extreme loneliness, and an 'anxiously obsessive desire for the maintenance of sameness'³. He also noted cases of individuals with autism symptomatology and impressive intelligence, acknowledging the disorder as one of development rather than cognition. Kanner's research sparked the movement to further understand behaviors of autism over the next few decades. Yet it wasn't until the early 1980s that autism was included in the Diagnostic and Statistical Manual of Mental Disorders, more commonly known as the DSM, version III⁴. This meant that autism was not considered a condition in its own right, but a symptom of more severe psychiatric disorders. This lack of dedicated research means that the understanding of autism in these four decades was extremely limited, which allowed for uneducated and often cruel assumptions to be perpetuated about people affected by the condition. For many years, professionals cited cold parenting techniques as the cause of autism, further propagating the negative stigma behind the disorder. In addition, as was common practice

in the 20th century, women were scarcely included as research participants for psychiatric disorders such as autism, and were usually purposefully excluded from research because of the belief that hormonal changes in women would confound the experimental results. Because of this lack of inclusion in research, the female experience of autism was rarely acknowledged in academia. Even Hans Asperger, a famous early autism researcher and namesake of 'Asperger's Syndrome,' believed at one point that autism did not affect females at all, a viewpoint that he did eventually change⁶.

Once autism was eventually included in the DSM and was validated as an observable disorder, diagnosis rates increased exponentially. With the new inclusion, more individuals formerly diagnosed with schizophrenia and a host of personality disorders were properly diagnosed with

autism³. This increase in diagnosis leads to a marked improvement in social awareness of autism and the formation of an autism community. Today, there are many successful people who live with autism, and the stigma around the diagnosis has lessened significantly in the last few decades. Nevertheless, our understanding of ASD is still growing each year, and each new discovery is important for the understanding of treatment of the community as a whole.

What Is Autism?

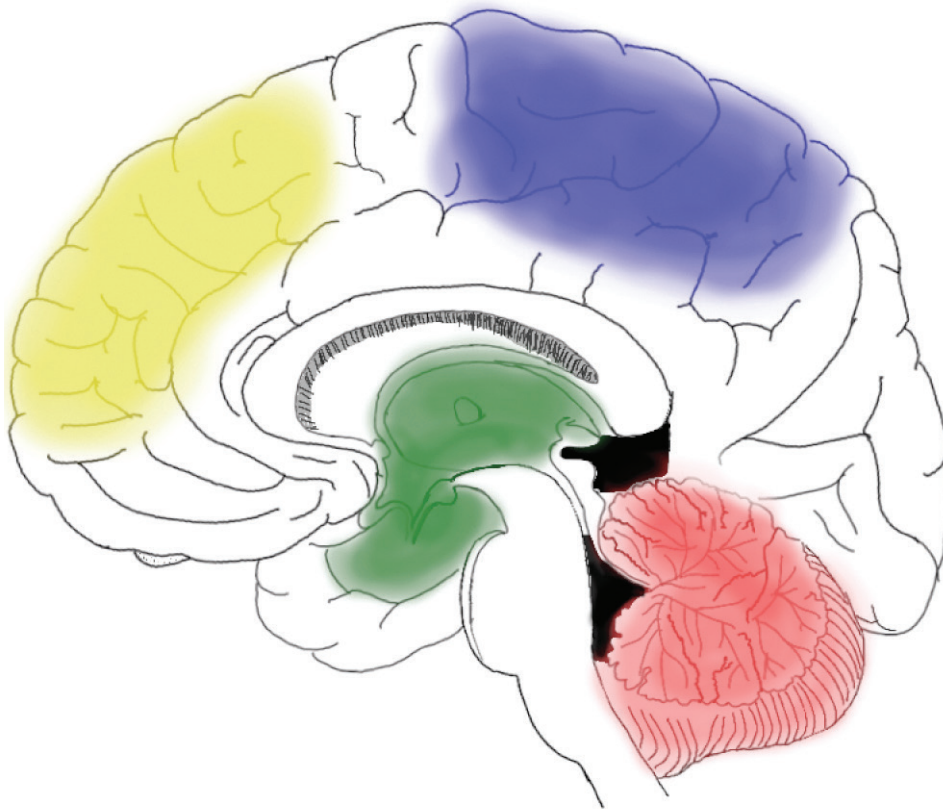
The idea that autism may be expressed differently between men and women begs important questions: Are males and females suffering from the same disorder? How can we be sure that what we are observing is autism?

Although the possible nuances in the expression of autism are innumerable, we

know that, at its core, autism is a developmental psychiatric disorder that affects communication and behavior¹. This means that the symptoms of autism stem from some hindrance in an individual's ability to communicate and behave compared to a neurotypical, or 'normally' functioning, individual. As we will soon explore, the symptoms commonly expressed in both male and females with autism fall into this category. Additionally, there are distinct neuroanatomical differences that are observed in autism that are expressed in both males and females with ASD. Recent research, however, seems to have uncovered slight sex-related differences in the neuroanatomy of ASD that could be connected to the differences in symptoms exhibited by males and females.

The Expression of Autism as We Understand It

Autism, as previously discussed, is a spectrum disorder. This means that it is characterized by a broad range of symptoms that not every individual diagnosed with autism may suffer from. Therefore, symptoms displayed by individuals with the same diagnosis of 'autism' can be as mild as difficulty making eye contact and reading social situations to severe epilepsy and complete lack of vocalization¹. Even with this broad range of possible symptoms, a few specific, core symptoms that have been consistently attributed to ASD throughout the years, most of which you probably recognize. This includes difficulty making eye contact, repetitive or obsessive behaviors, unusual fixations on specific subjects or items, difficulty with imaginative play, lack of facial expressions, extreme sensory sensitivity, and difficulty or inability



Side view of the right hemisphere of the brain. Brain regions affected by autism are shaded: frontal cortex (yellow), parietal cortex (blue), limbic system (green), and the cerebellum (red)
By Mike Birkhead from Wikimedia (CC BY 4.0)

to behave appropriately in social situations¹. These are also among the most universally recognized symptoms of ASD, and are some of the main behaviors noted when diagnosing an individual with ASD⁷. However, while these findings are well-established, we must always keep in mind that almost all of the studies used to describe autism come from observing the male autistic experience

Neuroanatomy of Autism

One of the most popular explanations related to the neuroanatomy of individuals with ASD is that it is caused by improper connectivity between neurons in certain brain areas⁸. This idea comes based on the understanding that, during early childhood development, children with autism experience an above-average growth of neurons and neural connections in the brain^{1, 8}. Typically exponential growth of neurons in children is normal during development, as children are learning new concepts and skills constantly. During late childhood, neurotypical brains go through a process called 'pruning,' in which neural connections in the brain that are deemed unnecessary or redundant are removed to conserve energy, commonly known as the "use it or lose it" phenomenon. However, the brains of children with autism do not adequately prune, or remove, the connections made during development, leaving autistic individuals with more neural connections than are necessary for a particular area⁸. While having an abundance of neurons may not sound like a bad thing, having too many neurons can make it difficult to send signals efficiently from one neuron to the next. Imagine it like this: you and your many siblings are trying to tell your mom a story.

When only one person is telling the story, it is much easier to follow along the timeline. However, when everyone starts speaking at once to try to convey their version of the story, it becomes a lot more difficult to follow. This over-excitation of neurons can cause severe problems, such as seizure disorders, in some autistic individuals.

Although there are many specific brain areas of the brain that are responsible for the countless possible symptoms of ASD, the general areas associated with autism expression are the frontal lobes, the limbic system, the cerebellum, and the parietal cortex⁹. Although it is difficult to ascribe specific symptoms to specific areas, we do know generally how improper function of certain areas of the brain are related to general abnormalities related to autism. The frontal lobes are responsible for executive function and decision making, and impairments in this area usually revolve around difficulty with comprehending social norms and the desire for consistency and sameness in autistic individuals, such as only being able to eat meals at specific times of the day⁹. The limbic system is responsible for emotional regulation, and dysfunction of this system in autism is associated with social deficits and increased anxiety^{7,9}. The cerebellum is a large structure that sits below the brain and is responsible for many functions, including movement regulation, coordination, balance, speech, and the sense of where your body is in space, and dysfunction in this areas likely results in issues with fine motor control and ability to understand body language⁹. The parietal cortex is responsible for a host of functions including integration of sensory information and movement coordination. In autism, improper function of the parietal cortex leads

to the extreme sensitivity to certain sensory stimuli⁹. Very broadly, these areas can be associated with the behavioral abnormalities commonly observed in autism. There has, however, been promising research pointing to a sexual dimorphism in the neuroanatomy of ASD.

Sex and Its Relation to Autism: Neuroanatomy of Sex Differences

As the understanding of ASD grew in the 21st century, so too did the acknowledgement that sex may be a defining variable of autism symptomology. Within the past decade, more focus and funding has gone into understanding the sex-specific neuroanatomical and behavioral differences observed in autism, with promising results. Consistent findings show sex-related differences in the neuroanatomy of females with ASD that correlate with differences in certain behaviors. Specifically, neuroimaging research has found consistent sex-related differences in the size of the limbic system and cerebellum in females with ASD compared to their male counterparts^{7,10,11}. Based on these sex-based variations, we can attribute some of the behavioral differences observed in women with ASD. Although women with autism do show signs of increased anxiety compared to males, the difference in limbic system size could also be attributed to the more impacted social deficits seen in males with ASD⁷. Additionally, differences in cerebellar are consistent with differences in fine-motor control between men and women, with men showing more disturbances in fine-motor function than women¹⁰. These, however, are not the only behaviors that distinguish autism expression in men and women.

Sex-Based Differences in Expression

Although we are able to attribute some sex-based differences in autism symptomology to differences in neuroanatomy, the research is still too novel to attribute all observed behavioral nuances to neuroanatomical differences. It is commonly accepted that behaviors such as trouble making eye contact and repetitive, stereotypical gestures are hallmarks of ASD¹. Nonetheless, increased focus in research on the female expression of ASD has questioned the universality of these symptoms. Modern research has found that, when compared to boys with ASD of similar intelligence, girls with ASD showed far less expression repetitive stereotypic behaviors, in addition to being less engaged with “unusual” interests, showing far more interest in subjects similar to their neurotypical peers¹²⁻¹⁵. Additionally, girls with autism showed far more imaginative play, use and recognition of facial expressions, and exhibited more instances of spontaneous echolalia, or unnecessary word repetition, than males with ASD¹³⁻¹⁵. Girls with autism also seemed to express more of the emotional symptoms related to ASD, such as anxiety and depression, when compared to boys¹²⁻¹⁵. Even though researchers aren’t totally clear with why these differences in symptoms occur, they have a very real impact on the women they affect.

Contemporary findings of sex-related differences in ASD patients have also uncovered a completely new symptom of autism that had not been considered in males: a behavior termed by the autistic community as “masking” or “camouflaging”^{2,8,16,17}. This is best described as the way in which

individuals, usually women, with autism constantly hide their autistic traits when interacting with others, like keeping up a continuous public façade¹⁷. Many people can empathize with the idea of feeling like a different person in public than in private. However, for women with autism, this feeling is ever present when they’re interacting with their peers, and this struggle of constantly feeling the need to monitor and control their behavior is described as exhausting. One mother describes her daughter’s own struggle with this:

“[W]hen she’s doing her job she’s a very professional lady, but ordinary things, ordinary life exhausts her. She is exhausted just by the business of running an ordinary life”¹²

This constant feeling of fatigue just by merely existing in public is all too familiar in women with autism, and for those who lack the proper diagnosis, this exhaustive loneliness can feel debilitating.

Problems Concerning a Lack of Understanding of Female Autism

Although there have been promising discoveries in understanding the sexual dimorphic nature of ASD, our understanding of the female expression of autism is still in its infancy. As we previously mentioned, the commonly cited ratio for autism expression in males vs females is around four or five to one¹⁸. However, when we consider the level of functioning an individual has, the ratios become even more

concerning. In high-functioning ASD, the diagnosis ratio is around nine men diagnosed for every one woman diagnosed; conversely, in low-functioning ASD, the ratio is a lot closer, with the diagnosis rate being two men diagnosed to every one woman¹. This inconsistency between high and low-functioning ASD individuals is even more telling of the difficulty of diagnosing females with less-severe ASD. The belief behind these extreme discrepancies is as simple as this: low-functioning ASD is easier to recognize. Since symptoms of low-functioning ASD usually involve lack of an ability to vocalize, seizures, and self-harming behavior, the signs for both males and females are much more conspicuous to their caretakers.

As we continue to emphasize, our understanding of the nuanced behavioral differences exhibited by females with ASD has barely scratched the surface. It is not uncommon for psychiatric professionals to not recognize and therefore not diagnose a woman with ASD. As one woman describes:

“When I mentioned the possibility to my psychiatric nurse she actually laughed at me...I asked my mum, who was a [general practitioner] at the time...if she thought I was autistic. She said, ‘Of course not’. At the time, a good 10 years ago now, there just wasn’t much information about how girls presented, and from what she knew, I was nothing of the sort”²

Because of this, it is not uncommon for women to go undiagnosed until middle or late adulthood, and often, the descriptions of their experiences pre-diagnosis are heartbreakingly similar. Stories are often riddled with instances of improper diagnoses or complete dismissal from psychiatric professionals^{2,16}. These women express common feelings of weariness in their

diagnosis, feeling as if they are constantly being forced to advocate for themselves in their pursuit of effective treatment. This unease is only heightened when it comes to functioning in public, when each human interaction feels like an uphill battle to appear 'normal':

*"It's very draining trying to figure out everything all the time, everything is more like on a manual, you've got to use one of those computers where you have to type every command in"*².

There is also a common feeling of a loss or total absence of identity when women describe their experiences with masking pre-diagnosis:

*"I honed something of a persona which was kind of bubbly and vivacious, and maybe a bit dim, because I had nothing to say other than adult novels. So I cultivated an image, I suppose, that I brought out to social situations as my partner's girlfriend, that was not 'me'"*².

Masking is often accompanied by feelings of loneliness, as individual's feel as if interacting as their authentic self will lead to social isolation. Nonetheless,

whether masking is an additional symptom of ASD or a coping mechanism to fulfill an individual's need for connection, the emotional consequences of masking are extremely real and important in understanding how to treat all individuals with ASD¹⁷.

Where Do We Go from Here?

The diagnosis of ASD may seem daunting to a neurotypical person, but for a woman or girl struggling in silence, it can be extremely empowering and a positive life-change. Increased social awareness of autism spectrum disorder has allowed for more individuals on the spectrum to be vocal about their experiences with autism and how their diagnosis has impacted their life in a positive manner:

*"Something that I really appreciate about having the diagnosis is actually being in this club now where people talk about their experiences and having so many echoes of my own"*²

Famous individuals on the spectrum such as animal scientist

Temple Grandin and Greta Thunberg actually cite their autism as a kind of superpower, and say that their condition helps them to see the world differently than other people. However, although there are many inspirational stories of higher-functioning individuals accepting and taking pride in their diagnosis, many individuals who function at the lower end of the spectrum and those who remain undiagnosed still struggle with the symptoms of ASD. Continued research into the potential causes of ASD are vital to both the improvement of autism treatment and a more comprehensive understanding of what autism looks like in all its forms. ■



REFERENCES

1. Autism Statistics and Facts. *Autism Speaks* (2020).
2. Autism spectrum disorder. *Mayo Clinic* (2018).
3. Evans, B. How autism became autism. *History of the Human Sciences*, 26(3), 3–31 (2013).
4. Zeldovich, L. The evolution of 'autism' as a diagnosis, explained. *Spectrum News* (2019).
5. Nuwer, R & Spectrum. A Brief History of Autism Research. *The Atlantic* (2016).
6. Gender and autism. *National Autistic Society* (2019).
7. Zhang, W. et al. Revisiting subcortical brain volume correlates of autism in the ABIDE dataset: effects of age and sex. *Psychological Medicine*, 48(4), 654– 668 (2017).
8. Picci, G., Gotts, S. J., & Scherf, K. S. A theoretical rut: revisiting and critically evaluating the generalized under/over-connectivity hypothesis of autism. *Developmental Science*, 19(4), 524–549 (2016).
9. Ecker, C. The neuroanatomy of autism spectrum disorder: An overview of structural neuroimaging findings and their translatability to the clinical setting. *Autism*, 21(1), 18–28 (2016).
10. Alaerts, K., Swinnen, S. P., & Wenderoth, N. Sex differences in autism: a resting-state fMRI investigation of functional brain connectivity in males and females. *Social Cognitive and Affective Neuroscience*, 11(6), 1002–1016 (2016).
11. Chen, C., & Horn, J. D. V. Developmental neurogenetics and multimodal neuroimaging of sex differences in autism. *Brain Imaging and Behavior*, 11(1), 38–61 (2016).
12. Beggiato, A. et al. Gender differences in autism spectrum disorders: Divergence among specific core symptoms. *Autism Research*, 10(4), 680–689 (2016).
13. Lai, M.-C., Lombardo, M. V., Auyeung, B., Chakrabarti, B., & Baron-Cohen, S. Sex/Gender Differences and Autism: Setting the Scene for Future Research. *Journal of the American Academy of Child & Adolescent Psychiatry*, 54(1), 11–24 (2015).
14. Mandy, W. et al. Sex Differences in Autism Spectrum Disorder: Evidence from a Large Sample of Children and Adolescents. *Journal of Autism and Developmental Disorders*, 42(7), 1304–1313 (2011).
15. Werling, D. M., & Geschwind, D. H. Sex differences in autism spectrum disorders. *Current Opinion in Neurology*, 26(2), 146–153 (2013).
16. Milner, V., McIntosh, H., Colvert, E., & Happé, F. A Qualitative Exploration of the Female Experience of Autism Spectrum Disorder (ASD). *Journal of Autism and Developmental Disorders*, 49(6), 2389–2402 (2019).
17. Russo, F. The costs of camouflaging autism. *Spectrum News* (2018).