

OPINION, SPECIAL REPORT SUBARTICLE, VIEWPOINT

DSM-5 may better serve girls with autism

BY WILLIAM MANDY

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The newest edition of the *Diagnostic and Statistical Manual of Mental Disorders*, the DSM-5, overtly acknowledges that females with autism may have features that differ from those of males with the disorder. That's a radical — and welcome — departure from the previous edition, the DSM-IV.

One of the most striking features of autism is its gender ratio. Males are four times more likely than females to receive an autism diagnosis, and at the high-functioning end of the autism spectrum there are as many as nine males for every female.

One interpretation of this is that girls are simply much less prone to autism and that, compared with boys, they **require greater disturbances in brain development**, as seen by their intellectual disability, for any autism features to be visible.

The DSM-IV had little to say about gender differences in autism, but it did appear to subscribe to this view, noting that males more commonly have autism, and that females with the disorder “are more likely ... to exhibit more severe mental retardation.”

However, the high male-to female ratio in diagnosed autism is compatible with an alternative interpretation: There may be a distinct, female-typical presentation of autism that the current diagnostic criteria and **diagnostic tests miss**, because those criteria were mainly **derived from studying the disorder in males**. What's more, the female autism phenotype may be especially **difficult to detect in those with average intelligence** and above.

Empirical support:

This idea of a distinct female presentation is often voiced by women with autism, parents and clinicians — and, more recently, has started to receive empirical support^{1,2}. Reflecting this, the DSM-5 includes a brief subsection on ‘Gender-related diagnostic issues’ that says:

In clinic samples females tend to be more likely to show accompanying intellectual disability, which suggests that girls without accompanying intellectual disability or language delays may go unrecognized, perhaps because of subtler manifestation of social and communication difficulties.

Through that sentence, the DSM-5 suggests there are meaningful sex differences in autism's presentation, but says little about what they are. This is entirely proper, as an empirically based consensus on the female autism phenotype is not yet available.

In this sense, the architects of the DSM-5 have laid down a challenge to researchers: Provide an account of the female phenotype, so that clinicians can learn to better identify, and help, females on the autism spectrum.

Fortunately, there is a thriving and rapidly expanding field of research that is already seeking to meet this challenge. At the **International Meeting for Autism Research** in May in San Sebastián, Spain, people with autism, parents, clinicians, teachers and researchers from around the world came together for the second meeting of the **Female Profile in ASD** special interest group. Their aim was to **promote better understanding** of and support for females with autism.

The group identified a number of questions that require systematic investigation, including whether autism manifests more subtly in females and is misdiagnosed, for example as an anxiety or personality disorder, whether repetitive behaviors in females with autism present in more socially normative ways, and whether females with the disorder have a greater capacity to compensate for their difficulties.

Diverse approaches, in fields ranging from molecular genetics to sociology, with much in between, will be required to grapple with these questions. There will need to be a dynamic exchange between researchers and clinicians, with information being passed in both directions. In particular, the voices of people with autism must influence both the research agenda and the way in which findings are then implemented clinically. The group identified a number of questions that require systematic investigation, including whether autism manifests more subtly in females and is misdiagnosed, for example as an anxiety or personality disorder, whether repetitive behaviors in females with autism present in more socially normative ways, and whether females with the disorder have a greater capacity to compensate for their difficulties.

The DSM-IV said almost nothing about the female autism phenotype. The DSM-5 has acknowledged it as a possibility without defining it. If current work on autism gender differences bears fruit, the next iteration of the DSM should provide an empirically based description of the female phenotype.

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Even when females with autism are identified, they often receive their diagnosis later than their male equivalents³. One simple and measurable goal for researchers and clinicians should be to eliminate this diagnostic delay from clinical practice within the next decade.

I suspect such progress would be accompanied by a decrease in the male-to-female ratio in autism spectrum disorder, meaning that more females on the autism spectrum would receive the targeted support and understanding that sometimes accompanies an autism diagnosis.

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References:

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