

## NEWS

# Diagnostic tests for women with autism fall short

BY ANN GRISWOLD

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Women with autism show fewer **repetitive behaviors** than men with the condition on a standard diagnostic test. This difference may lead to a 'partial' diagnosis for many women, qualifying them for only limited services, according to the largest study of **adults with autism** to date.

Clinicians may diagnose just **1 girl with autism for every 10 boys** in children of average intelligence, and her diagnosis may be **years overdue**, according to some reports. Most diagnostic assessments are **based on research in boys with autism** and may be biased toward behaviors typically seen in these boys. So it is unclear whether fewer **girls have autism**, or whether the features of autism in girls and women are simply **distinct and harder to recognize**.

Either way, girls who go undiagnosed in childhood may find it difficult to obtain an autism diagnosis later, suggest the new findings, which appeared 22 January in *Autism*<sup>1</sup>.

A primary reason for this difficulty may be that women don't show repetitive behaviors and restricted interests — or don't show them in a way that is obvious to caregivers or clinicians.

"The most striking thing is the difference in repetitive behaviors between males and females," says **Grainne McAlonan**, clinical reader in translational neurodevelopment at Kings College London and a senior researcher on the study. "That may have an impact on the way we recognize autism in females, and consequently whether those females get access to services."

The study points to the possibility that women and men with autism present differently and may benefit from diagnostic tools that take gender differences into account.

## Gender gap:

Researchers evaluated 935 men and 309 women, all 18 to 75 years old, who were referred to an autism specialty clinic by their primary physician. They used a standard assessment that relies on parent or caregiver reports, called the Autism Diagnostic Interview-Revised (ADI-R), to document the behavior of 630 adults when they were children. They used a standard clinical measure, the **Autism Diagnostic Observation Schedule** (ADOS), to directly evaluate the social and repetitive behaviors of another 408 adults for whom parent reports were not available. Researchers administered both tests to an additional 206 participants.

Based on the test results and a psychiatric exam, 72 percent of the men and 66 percent of the women received an autism diagnosis.

Researchers then narrowed their analysis to adults with autism who have at least average intelligence — a particularly challenging group to diagnose. They examined gender differences in autism signs on each of the three diagnostic domains in the World Health Organization's diagnostic bible, the **International Classification of Diseases (ICD)-10**: social interaction, communication, and repetitive behaviors or restricted interests.

Most women they diagnosed had dramatic signs in one domain, usually either communication or social interaction, and moderate or mild signs in the other two. By contrast, men typically showed moderate signs across all three domains.

The study highlights potentially important differences in the profiles of men and women with autism, says **Thomas Frazier**, director of the Center for Autism at the Cleveland Clinic in Ohio, who was not involved in the study. Men with autism tend to have features that span several diagnostic criteria, whereas women often show severe impairment in only one area, he says.

## Muddled memory:

About a quarter of the men and a third of the women with autism qualified for only a 'partial' diagnosis under the ICD-10 because they showed signs in only two of the three domains.

But these sex differences were relatively minor, given the sample of more than 1,200 adults, says **Sander Begeer**, assistant professor of developmental psychology at the VU University Amsterdam in the Netherlands. "Given the adequate power of the study, one would expect sex differences to show up here if there were any."

The women and men differed most starkly in whether they displayed repetitive behaviors and restricted interests, and even there, the difference was only apparent on the ADI-R. This means that parents and caregivers tended to recall far fewer repetitive behaviors during childhood for the women than for the men.

The findings suggest that although women may display repetitive behaviors as adults, researchers

who rely on the ADI-R to diagnose might not flag them, resulting in a higher rate of ‘partial’ autism diagnoses in women.

Still, the ADI-R is perhaps the best way to identify these behaviors, McAlonan says. “The repetitive behaviors criteria really must come from the ADI-R because the ADOS is not very good at identifying these behaviors [in adults].”

Doctors in the U.S. who use the criteria in the *Diagnostic and Statistical Manual of Mental Disorders* may diagnose **people lacking repetitive behaviors** with **social communication disorder** rather than autism.

## Subtle signs:

“These women had severe social and communication deficits, but they were not getting a full autism diagnosis because they didn’t meet criteria for repetitive behaviors,” says study investigator **C. Ellie Wilson**, who is now a postdoctoral researcher at the University of Seville in Spain. “This is potentially problematic when you think about clinical support and the resources available to them.”

Girls who appear to lack repetitive behaviors may simply have subtler ones than boys do. Because playing with dolls is typical for girls, someone might not notice, for example, that the girl is spending more time moving the dolls around than imagining a conversation between them, Wilson says.

A study published 2 March in *Autism* is consistent with previous reports suggesting that girls with autism act out simpler scenarios with their dolls than do typically developing girls. Play complexity is roughly similar in girls and boys with autism, the researchers reported<sup>2</sup>.

Neither the ADOS nor the ADI-R measure the severity of traits, which may be key to spotting sex differences, says Begeer. Nor did the researchers look for differences in types of repetitive behavior or sensory sensitivities. In studies of adults, such details can be hard to get because the ADI-R relies on parent or caregiver recollections from decades past.

“We really need to do prospective studies to try and identify what sex differences there might be,” Wilson says.

## REFERENCES:

1. Wilson C.E. *et al. Autism* Epub ahead of print (2016) [Pubmed](#)
2. Harrop C. *et al. Autism* Epub ahead of print (2016) [Pubmed](#)