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Story by David Cox • 3mo • 7 min read

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Girls tend to respond to their autism internally, developing anxiety which may appear more like shyness - Liam Tooher

For many decades it was thought that men were very much more likely to be autistic than women. Some studies placed the ratio of autistic males to females as high as 16:1. In the last decade, however, researchers at University College London have shown that the true prevalence is closer to 3:1. Yet women are still often under diagnosed.



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This happens for a number of reasons. Boys are more likely to externalise their troubles and be disruptive at school, while girls tend to internalise, developing anxiety which can be read as shyness. The typical core differences – in social communication, understandings and interests – are the same between the genders but manifest in different ways, and our cultural expectations of how boys and girls behave means that the struggles of autistic girls can fly under the radar.

The early skew when it comes to gender began with the world's first ever study of autism, published in 1943. The American psychiatrist Dr Leo Kanner identified 11 children, three girls and eight boys who he described as all having a powerful desire for sameness and a resistance to unexpected change. It made history around the world, but the assumptions about gender stuck.



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"For a very long time, people only really thought that autism occurred in boys," says Dr Rachel Moseley, an autism researcher at Bournemouth University, who herself is autistic and was only diagnosed in adulthood. "Although there were sporadic cases where we saw autism in girls, they were seen almost as one-offs."

But as [our understanding of autism has grown](#), researchers and doctors have begun to realise that the neurological differences which underpin autism manifest quite differently between the sexes, with many autistic women going undiagnosed.

This is gradually changing, according to experts. Prof William Mandy, a neurodevelopmental researcher at UCL who led the 2017 study, says: "It's important to stress that there is likely still widespread underdiagnosis of autistic girls and women, but the evidence suggests that in the UK, this tendency is gradually being counteracted."



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So why have autistic women slipped beneath the radar and what are the characteristics of autism in females?

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- Understanding the difference between the sexes when it comes to autism diagnosis
- Traits of autism in women
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# Understanding the difference between the sexes when it comes to autism diagnosis

Autism was first given official recognition in the Diagnostic and Statistical Manual of Mental Disorders, the major classification system used by psychiatrists to reach diagnoses, back in 1980. But the original diagnostic criteria were narrow and focused on children under three – a lack of interest in other people, fixations, and language impairments.

In the last four decades, the criteria have widened to encompass difficulties with:

- Making friendships
- Restricted and repetitive interests
- Either verbal or nonverbal communication delays

Dr Moseley says that the clinical descriptions of these traits tend to be more relevant to autistic men, and as a result, many parents, teachers, nurses and practitioners remain largely unaware of what autism tends to look like in women.

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“The girls who are diagnosed are those who display more obvious differences, more stereotypical male type presentations,” she says.

## Traits of autism in women

Dr Moseley says that the same core differences in social communication, understandings and interests remain the same between autistic men and women, but they manifest in different ways. Our differing cultural expectations of the genders can also mean that the struggles of autistic girls are more likely to fly under the radar.

Autistic traits in girls and boys	
Girls are more likely to:	Boys are more likely to:
Internalise their feelings	Externalise struggles
Develop anxiety and appear shy	Be disruptive at school
Mask/ camouflage their social challenges and mimic non-autistic behaviour	Be fixated on something unusual for their age and gender

 Autism in women: Signs and diagnosis  
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As an example, Dr Moseley says that autistic boys are also more likely to externalise their struggles, leading to notably disruptive behaviour at school, while this is more unlikely to be the case with girls. Research has shown that girls tend to respond to their autism internally, developing anxiety which may appear more like shyness.

“It’s not the case with all autistic girls, but they’re more likely to internalise and be very quiet and nervous which again makes their difficulties less likely to be picked up,” she says. “There’s a cultural thing here, because a little girl being a bit shy is seen as more

normal. So when a little boy is very quiet, withdrawn and excluded from the peer group, it's more likely to be flagged."

The same can be true when it comes to the general autistic trait of showing a strong interest in one thing. "An autistic boy might be fascinated by tin can artwork or something really unusual for his age and gender, whereas an autistic girl might take an interest in 'My Little Pony' or something expected," says Dr Moseley. "But the way they engage with that interest is very different than with a non-autistic girl. They might choose to colour categorise the dolls or collect facts about them."

The brain systems involved in social behaviour also develop more quickly in girls which may enable autistic girls to be better at camouflaging. Research has shown that on average, autistic girls tend to be better than boys at masking their social challenges and mimicking their non-autistic counterparts. "They can do this in really varied and ingenious ways, down to the level of the way they speak, how they stand, and how they will kind of try and integrate with their social group," says Dr Moseley. "As a result, they're more likely to be on the fringes of social groups, rather than completely excluded."

Perhaps as a result, autistic women report more challenges relating to a heightened response to sensory stimulation – such as an increased sensitivity to strong smells, textured fabrics, or loud noises – than communication differences.

However, Dr Moseley notes it is also important to stress that these

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## Diagnosing autism in women

Prof Mandy explains that there is no blood test or brain scan which can be used to obtain a diagnosis of autism, but instead clinicians reach a diagnosis in three main ways:

1. Asking questions about a person's experiences
2. collecting information from someone who has known them well throughout infancy, childhood and adolescence
3. making observations about their behaviour

"It is ever more common for people, especially in adulthood, to self-identify as autistic based on thinking about their experiences over their lifestyle," he says. "In part, this reflects the fact that in the UK, demand for autism assessment is outstripping capacity with many having to wait several years between referral and assessment."

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## Impact of late diagnosis on women

Approximately 80 per cent of autistic women remain undiagnosed at age 18, which in turn can have severe consequences for mental health as well as making them more vulnerable to sexual exploitation. One study found that 70 per cent of women in an inpatient eating disorder clinic had undiagnosed autism.

Psychologists have also found that as girls grow older, and their relationships become more complex, autistic girls start to stand out to a greater degree and experience more bullying and social



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isolation, which also makes them more vulnerable to developing anxiety and depression. Prof Mandy says that common experiences also include being overwhelmed by their sensory environment, and generally having high levels of distress.

“When looking at research involving autistic women talking about their lives, there’s a common story of girls being left to navigate adolescence and the transition to adulthood without the support and understanding that can come from an autism diagnosis,” says Prof Mandy. “We now know that a significant minority, perhaps up to 20 per cent of women with anorexia nervosa, are autistic.”

Dr Moseley says that having undiagnosed autism can also intensify various life stages which women can already find difficult, such as postpartum pregnancy and the menopause.

“Menopause seems to exacerbate a lot of those features of being autistic, because a lot of the features of being autistic really shine out when we’re stressed or in distress,” she says. “Anxiety goes through the roof, social differences which were previously being masked become more apparent, so eye contact or processing what other people are saying in real time is more difficult, communicating with others are more difficult. People’s sensory experiences also change and become more extreme.”

## Support options

There is some support available to autistic people including:

- [SEE Autistic Women](#)
- [Appeer](#)
- [Auti-MS](#)
- [Autistic Girls Network](#)

However, says Prof Mandy, this is not enough.

“Broadly [support] needs to be directed at improving the fit between the autistic person and their environment,” he says. “After all, autistic people tend to live in a world that was built by and for the non-autistic majority, so they often exist in environments that are unaccommodating or even downright hostile.”

Because the label of autism can also carry a significant amount of stigma, Dr Moseley says that it is extremely important to help autistic women and indeed any autistic person, develop a positive sense of identity.

“So very often we grow up with this perception if we’re diagnosed with autism that we’re disordered, different or damaged, and studies are showing now that strength-based approaches are really important. Helping autistic young people and also adults to identify their strengths, where they can fit in, in the world and really helping them to build those things as a point of self-worth.”

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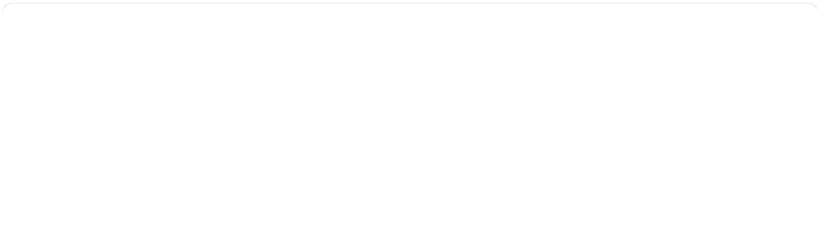
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Study uncovers a previously unknown genetic link to autism



# spectrum disorder

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New research published in *The American Journal of Human Genetics* has identified a previously unknown genetic link to autism spectrum disorder (ASD). The study found that variants in the *DDX53* gene contribute to ASD, providing new insights into the genetic underpinnings of the condition.

ASD, which affects more males than females, encompasses a group of neurodevelopmental conditions that result in challenges related to communication, social understanding and behaviour. While *DDX53*, located on the X chromosome, is known to play a role in brain development and function, it was not previously definitively associated with autism.

In the study published today, researchers from The Hospital for Sick Children (SickKids) in Canada and the Istituto Giannina Gaslini in Italy clinically tested 10 individuals with ASD from 8 different families and found that variants in the *DDX53* gene were maternally inherited and present in these individuals. Notably, the majority were male, highlighting the gene's potential role in the male predominance observed in ASD.

[Read the full story here.](#)

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