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# Autism and Asperger syndrome underdiagnosed in women, researchers say

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Autism and related conditions are being underdiagnosed in women and teenage girls, with many cases being confused with eating disorders or other problems, researchers say.

With symptoms such as social isolation, communication difficulties or a fanatical interest in categorising objects or obscure mathematical problems, autism has previously been seen as a male preserve.

Up to 80 per cent of diagnosed cases of autism are in boys, with the proportion rising to an estimated 15 male cases for every female with Asperger syndrome, a milder form of the condition. However, researchers due to speak at Britain's first academic conference on the issue will suggest that many more girls are on the autistic spectrum than previously thought, with doctors and parents failing to notice or misinterpreting the telltale signs.

Cases at the less severe end of the spectrum, where sufferers do not have speech problems and can have high IQs but have difficulties interpreting the world and its complex social rules, are thought to be particularly underdiagnosed.

"Girls are less likely to have language delay than boys with autism, so all the right boxes get ticked when they are toddlers and their autism can get missed," said Richard Mills, research director of Research Autism, the charity that is organising the conference this month. "Autistic girls are also more likely to be outwardly social when they are younger whereas boys are less so."

Boys commonly have autistic spectrum conditions diagnosed aged 5 to 7, whereas girls are usually adolescent or older, if they receive a correct diagnosis at all.

Dr Mills's own research, due for publication this year, suggests that even when girls are screened for autism it is not picked up. In a study of 60 patients at an English psychiatric hospital, none had an autistic condition diagnosed after routine screening, despite 11 later being shown to have been confirmed cases.

"What was happening was that other diagnoses were being made — personality disorder or perhaps schizophrenia," Dr Mills said. "This is possibly because most tests were developed around male characteristics of autism."

Last year a survey of 7,500 British adults suggested that about 600,000 people in Britain suffer from an autistic spectrum condition but that rates are far higher among men (1.8 per cent of the population) than women (0.2 per cent).

It is unclear how many cases in girls are not being diagnosed but charities and patients' groups say that a growing number of adult women are contacting them, having recognised themselves in autistic characters on television or through articles about autism, and are relieved finally to discover why they are "different". Dr Mills believes that because it is assumed that autism is rare in girls, doctors are less likely to consider it. "I have spoken to parents of girls who have said that the first response from the doctor has been, 'She is a girl, it is highly unlikely to be autism'. Not just GPs but paediatricians too."

A further barrier to diagnosis is that girls are often better at masking the symptoms, such as difficulties with language, because they tend to be more advanced than boys, less disruptive and able to compensate

better for their problems. Girls are also much less likely to have an obsessive lifelong interest in collecting facts, as boys with autism commonly do.

Janet Treasure, an expert on eating disorders at the Institute of Psychiatry, King's College London, said that women or girls on the autistic spectrum often focused on diet or calorie control, which became their obsession. About one in five women with an eating disorder is thought to be on the autistic spectrum.

A study led by Professor Treasure on 150 women with acute anorexia or bulimia suggests that up to 60 per cent also develop the psychological signs of autism. "Those who are severely underweight and unwell, with serious disruption of eating patterns, share a lot of the cognitive and emotional styles common to autism," she said. "Their poor nutrition means that they can't see the bigger picture, they focus on detail and have a rigid way of thinking, finding it hard to adapt."

These psychological symptoms were lessened when most of the women gained weight. But "girls with autism are at high risk of getting into a pattern of behaviour that can cause a vicious cycle of problems", said Professor Treasure. "It is important that people notice and try to stop it."

Campaigners are worried that the lack of diagnosis can have catastrophic effects. Low self-esteem can cause self-harming and even suicide, and social naivety can lead to bullying and sexual exploitation.

Mark Lever, the chief executive of the National Autistic Society, said: "We are extremely concerned that many women with autism may be going undiagnosed. So many tell us that trying to get a diagnosis feels like an insurmountable hurdle and they have to fight tremendous battles to get the help, support and services they desperately need.

"Autism is a serious, lifelong and disabling condition and without the right support it can have a profound effect on individuals and families."

### **Autism and Asperger syndrome**

— Autistic spectrum disorders (ASDs) are developmental conditions that can vary from child to child, and from mild to severe. Their symptoms are grouped into three broad categories:

— Problems with social interaction, such as a lack of understanding and awareness of other people's feelings.

— Impaired communication skills, such as delayed language development and an inability to start or take part in conversations.

— Unusual patterns of thought and physical behaviour, including repetitive physical movements. The child can become upset if the routines are broken.

— There is currently no cure for ASD, but there are a range of treatments that can improve the symptoms.

— There are three main types of ASD: autistic disorder (also known as "classic autism"); Asperger syndrome (milder symptoms that affect social interaction); and pervasive developmental disorder (children who have some symptoms of either).

— ASDs are uncommon but not rare. In England it is estimated that 1 in every 100 children has an ASD.

— In the past, many children with an ASD may have been labelled as "slow" or "shy".

— Kim Peek, the most famous autistic savant and inspiration for the film *Rain Man*, died aged 58 in December. He could read eight books a day, taking just ten seconds to read a page.

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