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Gender and autism

This section explores some of the issues relating to autism and gender, including ideas about why more men and boys are diagnosed than women and girls.

"Autism is more diverse than originally thought, with new ideas being put forward every day. In fact, it's a case of 'the more we know, the less we know', particularly in how gender affects individuals with autism."

– Dr Judith Gould, Consultant Clinical Psychologist and Director, The Lorna Wing Centre for Autism

What's the gender split in autism diagnoses?

Statistics show that more men and boys than women and girls have a diagnosis of autism. Various studies, together with anecdotal evidence have come up with men/women ratios ranging from 2:1 to 16:1.

- Brugha's 2009 survey of adults living in households throughout England found that 1.8% of men and boys surveyed had a diagnosis of autism, compared to 0.2% of women and girls.
- Hans Asperger thought no women or girls were affected by the syndrome he described in *Autistic psychopathy in childhood* (1944), although clinical evidence later caused him to revise this thinking.

- In Leo Kanner's 1943 study of a small group of children with autism there were four times as many boys as girls.
- In their much larger 1993 study of Asperger syndrome in mainstream schools in Sweden, Ehlers and Gillberg found the same boy to girl ratio of 4:1.
- In 2015, the ratio of men to women who use NAS adult services was approximately 3:1, and in those that use NAS schools it is approximately 5:1.
- Lorna Wing found in her paper on sex ratios in early childhood autism that among people with 'high-functioning autism' or Asperger syndrome there were as many as 15 times as many men and boys as women and girls, while in people with learning difficulties as well as autism the ratio of men and boys to women and girls was closer to 2:1.

This could suggest that, while women and girls are less likely to develop autism, when they do they are more severely impaired. Alternatively, it could suggest 'high-functioning' women and girls with autism have been underdiagnosed, compared to men and boys.

Is autism harder to diagnose in women and girls?

Women and girls with Asperger syndrome may be better at masking their difficulties in order to fit in with their peers and have a more even profile of social skills in general.

Attwood (2000), Ehlers and Gillberg (1993) and Wing (1981) have all speculated that many women and girls with Asperger syndrome are never referred for diagnosis, and so are simply missing from statistics, even though they are equally in need of diagnosis and support.

This might be because the diagnostic criteria for Asperger syndrome are based on the behavioural characteristics of men and boys, who are often more noticeably 'different' or disruptive than women and girls with the same underlying deficits.

Gould and Ashton-Smith (2011) say that because women and girls on the autism spectrum may present differently from men and boys, diagnostic questions should be altered to identify some women and girls with autism who might otherwise be

missed. Dr Judith Gould discussed late diagnosis and misdiagnosis in women on BBC Radio 4's Women's Hour in December 2016.

At The National Autistic Society's Lorna Wing Centre for Autism, emphasis is placed on the different manifestations of behaviour in autism as seen in women and girls compared with men and boys.

The Centre has seen a steady increase in the number of women and girls referred for diagnosis, which suggests an historic bias towards men and boys in the diagnostic criteria for autism.

Just as for men and boys, diagnosis is the starting point for providing appropriate support for women and girls on the autism spectrum. A timely diagnosis can avoid many of the difficulties they experience throughout their lives.

How does autism present differently in women and girls?

Gould and Ashton-Smith (2011) identified the different way in which girls and women present under the following headings: **social understanding, social communication, social imagination** which is highly associated with **routines, rituals** and **special interests**. Some examples are below.

MASKING SYMPTOMS

Girls are more able to follow social actions by delayed imitation because they observe other children and copy them, perhaps masking the symptoms of Asperger syndrome (*Asperger's and girls* by Tony Attwood, 2007).

INTERACTING SOCIALLY MORE OFTEN

Girls are often more aware of and feel a need to interact socially. They are involved in social play, but are often led by their peers rather than initiating social contact. Girls are more socially inclined and many have one special friend.

BEING SUBJECT TO GREATER SOCIAL EXPECTATIONS

In our society, girls are expected to be social in their communication. Girls on the spectrum do not 'do social chit chat' or make 'meaningless' comments in order to facilitate social communication. The idea of a social hierarchy and how one

communicates with people of different status can be problematic and get girls into trouble with teachers.

HAVING MORE ACTIVE IMAGINATIONS AND ENGAGING IN PRETEND PLAY MORE OFTEN

Evidence suggests that girls have more active imaginations and more pretend play (Knickmeyer, Wheelwright and Baron-Cohen, 2008). Many have a very rich and elaborate fantasy world with imaginary friends. Girls escape into fiction, and some live in another world with, for example, fairies and witches.

HAVING INTERESTS WHICH ARE SIMILAR TO OTHER GIRLS

The interests of girls in the spectrum are very often similar to those of other girls – animals, horses, classical literature – and therefore are not seen as unusual. It is not the special interests that differentiate them from their peers but it is the quality and intensity of these interests. Many obsessively watch soap operas and have an intense interest in celebrities.

The presence of repetitive behaviour and special interests is part of the diagnostic criteria for an autism spectrum disorder. This is a crucial area in which the male stereotype of autism has clouded the issue in diagnosing women and girls.

How does the diagnostic framework cater for these differences?

The current international diagnostic criteria for autism (in ICD-10) do not give examples of the types of difficulties experienced by women and girls.

In order to recognise the different behaviours, it is important to take a much wider perspective regarding the social, communication and imagination dimensions in addition to the special interests and rigidity of behaviour.

Women and girls learn to act in social settings. Unenlightened diagnosticians perceive someone who appears able, who has reciprocal conversation and who uses appropriate affect and gestures as not fulfilling the criteria set out in the international classification systems. Therefore a diagnosis is missed.

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A proper diagnosis and full assessment of needs requires more than a checklist. It is only by asking the right questions, taking a developmental history, and observing the person in different settings that it becomes clear that the individual has adopted a social role which is based on intellect rather than social intuition.

The fact that girls with undiagnosed autism are painstakingly copying some behaviour tends not to be picked up and therefore any social and communication problems they may be having are also overlooked. This mimicking, and the repressing of their autistic behaviour, is exhausting, perhaps resulting in the high statistics of women with mental health problems (Dale Yauill-Smith, 2008).

Other theories to explain the gender split

An exaggeration of normal gender differences

Another theory to help explain the gender imbalance in diagnoses is based on evidence that, in the general population, women and girls have better verbal skills, while men and boys excel in visuo-spatial tasks (Wing, 1981).

There may be a neurological basis for this, so that autism can be interpreted as exaggeration of 'normal' sex differences.

But environmental and social factors may also play a part in differences in ability across men and boys, and women and girls. This means that no direct analogy can be drawn between the poorer verbal skills of boys and the higher incidence of autism in men and boys.

Professor Simon Baron Cohen and the Autism Research Institute (ARC) have developed an 'extreme male brain' theory of autism (2002). This relates to thinking about sex differences in general within the dimensions of 'empathising' and 'systemising' and autism as an extreme of the male 'systemising' dimension. This theory has been powerful in shaping public perception of the condition.

In 1964, Bernard Rimland pointed out that, overall, men and boys tend to be more susceptible to organic damage than women and girls, whether through hereditary disease, acquired infection or other conditions. Since it is now almost universally

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accepted that there is an organic cause for autism, it should therefore not be surprising that men and boys are more vulnerable to it than girls and women.

A genetic explanation

In recent years, researchers have put forward a genetic explanation for the differences in the numbers of women and girls being diagnosed with autism to the numbers of men and boys.

David H Skuse suggested in 2000 paper that the gene or genes for autism are located on the X chromosome. Girls inherit X chromosomes from both parents, but boys only inherit one, from their mothers.

Skuse's hypothesis is that the X chromosome which girls inherit from their fathers contains an imprinted gene which 'protects' the carrier from autism, making girls less likely to develop the condition than boys.

This theory has been used to support Asperger's view that autism and Asperger syndrome are at the extreme end of a spectrum of behaviours normally associated with 'maleness'. Such behaviours can be extremely useful in areas of life such as engineering and science, where attention to detail and single-mindedness may be more valuable than social skills, for example.

Lord and Schopler (1987) have outlined several possible mechanisms for the transmission of autism on the sex-linked X chromosome, and also for autosomal transmission (ie involving non-sex chromosomes).

However, these are merely theoretical models and researchers are still a long way from identifying a simple genetic cause for autism. It is likely that several genes on different chromosomes will be found to be associated with autism. This means that Skuse's theory, based on the X chromosome alone, may not represent the full picture.

Read about real experiences of autistic women.

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