# Women and Girls with Autism

## An introduction to the research

autism
west midlands

There are on average four times as many men diagnosed with autism as women. This may be because men are more affected by autism or because women are not being recognised and diagnosed. The Extreme Male Brain theory is the most famous theory that addresses this but recent research has shown that the issue may be more complex. Research evidence suggests that there is a gender bias in diagnosis, with women being less likely to be diagnosed compared to men. This may be because women are able to hide their difficulties and learn coping strategies. However, women with autism are also at higher risk of mental health problems so it is important to improve diagnosis so that they can receive support and understanding.

**A note on terminology:** the majority of this information sheet refers to 'men' and 'women'. However, in some cases, the terms 'boys' and girls' are used. This indicates that the research was done in children and not adults. All the information provided here is relevant to both adults and children.

## How many men and women are diagnosed with autism?

Autism affects around 1.1% of the population[1], with more men diagnosed than women. The current estimates say that there are around four times as many men diagnosed with autism as women, but this depends on who you are counting[2]. In people with autism and learning disabilities, there are only twice as many men diagnosed as women, whereas in people with Asperger syndrome, there are up to 10 or 11 times as many men diagnosed as women[2]. Why are more men diagnosed with autism than women? Is it because autism affects men more than women? Or is it because women are not being recognised and understood?

Although all the studies have found more men diagnosed with autism than women, they do not all agree on how many more men there are compared to women. In particular, two recent studies found an average of twice as many men diagnosed compared to women[3,4]. This is different to earlier studies saying that there are on average four times as many men diagnosed as women[2] and implies that there are more women with autism than previously thought. Furthermore, one of the studies looked at the number of boys and girls with autism over time. They found that in younger age groups, there were five times as many boys with autism compared to girls, whereas in older children, there were only twice as many boys with autism compared to girls[3]. This result suggests that there are more girls with autism than previous studies have suggested, but that they are diagnosed later[3].

From its earliest days, there has always been a male bias when describing autism. In his original cases, Kanner described 8 boys and 3 girls. Asperger only described boys and claimed to have never seen a girl with Asperger syndrome in his clinic in Austria and that he saw the first girl with Asperger syndrome in the US in the early 90s[5]. Is there any evidence backing up the claim that autism affects men more than if affects women?

### The Extreme Male Brain theory

Probably the most famous theory which addresses this claim is the **Extreme Male Brain theory**[6]. This theory is an extension of the empathising-systemising theory which

**Empathising** can be defined as the ability to identify a person's feelings and respond appropriately. It can be subdivided into cognitive empathy and affective empathy. Cognitive empathy (sometimes referred to as Theory of Mind) can be defined as the drive to identify another's mental state. Affective empathy is the drive to respond to another's mental state with an appropriate emotion. There have been a number of studies which have shown that some people with autism have difficulties with cognitive empathy but have intact affective empathy (Rogers et al., 2007).

**Systemising** is analysing or building a system which can be mechanical, natural, abstract or collective – for example an interest in trains.

says that men are more likely to have a **systemising** brain whereas women are more likely to have an **empathising** brain[6,7]. The researchers calculate how empathising or systemising a person's brain is by giving them questionnaires measuring empathising and systemising. Men tend to score higher in the systemising questionnaire whereas women tend to score higher on the empathising questionnaire. When they looked at people with Asperger syndrome or high functioning autism they found that they scored even higher on the systemising questionnaire than men did, suggesting that people with Asperger syndrome or high functioning autism might have an extreme version of the male brain[7].

Studies that try to measure empathising and systemising directly using tasks like trying to guess what a person's emotions are just by looking at their eyes (to measure empathy) or trying to find a simple shape in a more complex figure (to measure systemising) have also found that women seem to do better at the empathising tasks whereas men seem to do better at the systemising studies. Furthermore, people with Asperger syndrome or high functioning autism seem do worse than men in the empathising studies and do better than men in the systemising studies[8–10]. These results indicate that when looking at empathising and systemising, people with Asperger syndrome or high functioning autism do seem to have an extreme male brain.

The researchers next wanted to know whether or not a person's brain structure would match the extreme male brain theory. Some areas of the brain are bigger in men and some are bigger in women. The researchers looked at areas which are related to empathising and systemising and found that areas which are typically largest in women and smaller in men were even smaller in people with Asperger syndrome or high functioning autism. Similarly, areas which were typically smallest in women and larger in men were even larger in people with Asperger syndrome or high functioning autism[6,11]. So the researchers found that brain structure also followed an extreme male pattern. Finally, the researchers wanted to know how this came about, why do people with Asperger syndrome or high functioning autism show an extreme form of the male brain? The researchers suggested that foetal testosterone might be involved. Whether a person is a man or a woman is determined by their sex chromosomes. Women have two X chromosomes and men have an X chromosome and a Y chromosome. On the Y chromosome there is a gene called SRY. Activation of this gene triggers the development of testes. These then produce testosterone which takes over the role of masculinisation (making male traits). It is important to note that women also produce testosterone, but much less of it and in a less concentrated form. The idea is that higher levels of testosterone during development result in more masculinisation (male traits). There are a few ways of measuring this and when researchers did this they found indications that women may have been exposed to the lowest levels of testosterone during development, men may have beene exposed to higher levels and people with Asperger syndrome or high functioning autism may have been exposed to the highest levels[12–15].

The research outlined here forms the basis for the Extreme Male Brain theory. However it is important to note that these original studies **did not separate out the men and women with Asperger syndrome or high functioning autism**. This means that it would not have been possible to say whether or not there are differences between men and women with autism. Furthermore, there were always significantly more men than women in the Asperger syndrome or high functioning autism group, meaning that the results would likely have given a male picture of autism. The researchers did run further studies looking specifically at whether or not there were differences between men and women with Asperger syndrome or high functioning autism in empathising and systemising, as well as the AQ (Autism Spectrum Quotient, which measures autistic traits) and did not show any differences [16–20]. However, in most of these studies they again used more men than women in the Asperger syndrome or high functioning autism samples. Interestingly, in one of the few studies where they compared equal numbers of men and women with Asperger syndrome and high functioning autism, despite finding no differences in empathising or systemising, they did find that women scored higher than men on the AQ, which means they were reporting more autistic traits than men. What made this finding even more interesting was when they looked at communication skills using the ADOS, a tool which is sometimes used to diagnose autism, they found that women were better at communicating than men. So this study found that although women

were better at communicating than men, they also reported more autistic traits. This implies that their communication skills may mean that some women are not identified as having autism, even though they may report more autistic traits[21]. This interesting result demonstrates how useful it is to look at the same number of men and women with Asperger syndrome or high functioning autism: a result that may have been missed if less women had been used gives an interesting insight into why women may not be being diagnosed.

It is not just studies looking at the extreme male brain theory that use more men than women in their Asperger syndrome or high functioning autism groups. Many other areas in autism research also use more men than women. For example, studies looking at brain volume use around eight times as many men as women[22] and studies looking at brain activation while a person does tasks use around fifteen times as many men as women[23]. This means that research often produces a male picture of autism and that we do not understand enough about women with autism.

## Are there differences between men and women with autism?

Despite this, there are studies looking at differences between men and women with autism. Studies looking at head circumference suggest that boys with autism have larger heads than the neurotypical population, whereas girls with autism have smaller heads than the neurotypical population[24]. Studies looking at brain structure have also shown differences between men and women with autism. Men with autism seem to have brains that look like neurotypical women's whereas women with autism seem to have brains that look like neurotypical men's[25]. In this study, the researchers suggested that only women with autism may have an extreme male brain whereas men may have a more feminised brain. This finding is different to what was found in other studies on brain structure and the extreme male brain and suggests that changes in brain structure may be more complicated than researchers initially though. Indeed, it is more likely that brain structure in autism is much more complex than 'male-like' or 'female-like' and that much more research is needed to understand the differences in brain structure, what they mean and how they happen. Other studies have found differences between men and women when looking at how the brain develops[24,26,27], genetic profile[28,29] and markers found in the blood[30.] These studies which show differences between men and women with autism demonstrate that it is indeed important to study both men and women with autism to get a full picture of how autism presents.

## Are there any biological reasons why more men might be affected by autism than women?

There is some research which suggests that men may be more susceptible to autism than women. Studies looking at genetics have found that women may be protected from autism risk. These studies found that although men and women showed the same number of autism susceptibility genes, men showed a higher severity of autism than women[31,32]. These studies suggest that somehow, women may be less affected by autism susceptibility genes and may need to have more susceptibility genes to show signs of autism. These results still need to be replicated and there needs to be more research looking at how and why this is happening. However, they do seem to show that there may be a biological reason why women may not be affected by autism as much as men.

## Women are being underdiagnosed.

Although this may be the case, at present, many women with autism are undiagnosed. There are a number of reasons why this is happening. As mentioned earlier, there has always been a male bias when describing autism[5]. However, although Kanner described 8 boys and 3 girls, he also noted differences between the boys and this, suggesting that autism may be expressed differently in girls[5]. Despite this observation, all subsequent descriptions of autism have been based on a male picture of autism. This means that if autism is indeed expressed differently in women, women may

not be identified as having autism. Furthermore, the classic diagnostic tools used to diagnose autism are all designed around a male picture of autism and it is well known that these tools are at present not suitable for diagnosing women[33,34]. One diagnostic tool, the ASSQ-REV, was revised to try and include more markers which would be suitable for girls. However, they found that even with these markers, the tool was still not suitable for diagnosing girls. The researchers highlighted that some of the questions asked would be answered differently by boys and girls and could lead to girls not being diagnosed. For example, one question looked at whether the child had a best friend. The researchers found that 70% of boys would say that they didn't have a best friend, whereas only 30% of girls would say this. Therefore, the girl that has a best friend may not be considered to have many social difficulties and may miss out on a diagnosis[33]. Of course, a child is not diagnosed based on one question, but their study highlighted a number of areas where boys and girls answered the questions differently, which could lead to girls missing out on diagnosis.

Studies looking at diagnosis in clinics have shown a clear gender bias in diagnosis[35–38.] In a study where the researchers started off by looking at autistic traits, then looked at who was diagnosed later, they found that even when men and women are matched for severity of autism, it is more likely that the man will be diagnosed with autism than the woman[37]. This happens most often in people with Asperger syndrome and may explain why there are currently 10 times as many men diagnosed with Asperger syndrome compared to women[35,38]. The reasons for this gender bias in diagnosis include, as mentioned above, the fact that the diagnostic tests and descriptions of autism are all based on a male picture of autism, but may also be due in part to the extreme male brain theory which in some cases has been misinterpreted to mean that women cannot have autism.

Diagnostic manuals, which provide guidance on how to diagnose autism, have not addressed the differences between men and women with autism in the past. However, the DSM-5 (the diagnostic manual written by the American Psychiatric Association which is sometimes used in the UK), which was released in May 2013, brings up this issue. The DSM-5 includes the following sentence:

> *"In clinic samples females tend to be more likely to show accompanying intellectual disability, which suggests that girls without accompanying disability or language delays may go unrecognised, perhaps because of subtler manifestations of social and communication difficulties."[39]*

Although this is not a description of autism in women, it is a good start as it specifically says that women with autism may be being undiagnosed because they may not have as many social or communication difficulties, or they can hide them better. It is a call for more research on women with autism so that recognition and diagnosis can be improved.

## Why are women being missed?

Although there is not much research on how autism is expressed differently in women, there are a few studies which address this. A recent study looked at emotion recognition. People with autism do not tend to be able to identify emotions as well as the neurotypical population. This study looked at 3,666 children and identified children with autistic-like communication difficulties (133 boys and 88 girls). They wanted to know how good they were at identifying emotions on faces. They found that boys with autistic-like communication difficulties were not able to identify the emotions as often as girls with autistic-like communication difficulties or the neurotypical population (the girls with autistic-like communication difficulties performed almost as well as the neurotypical population). This result suggests that girls with autistic-like communication difficulties are able to identify emotions. However, the researchers then used a second task, which involved identifying emotions using interactions between a triangle and a circle. This task takes away the human element of emotion recognition and uses only social cues to identify the emotions. In this task, neurotypical children were correctly able to identify the emotions. However, neither boys nor girls with autistic-like communication difficulties were able to identify the emotions. This result suggests that although girls with autistic-like

communication difficulties may be able to identify emotions when they are on faces, they still have difficulty identifying them when no faces were involved. This suggests that they have somehow learnt how to identify emotions on faces[40]. This study gives us a clue as to why women with autism may not be being identified. They may be learning coping strategies to hide themselves within the neurotypical population. However, they may still have difficulties which may make it difficult for them to cope with the demands of a neurotypical world.

Observation studies have also given some clues as to why women may not be being identified[5]. Girls may find it easier to imitate social actions that they see in other children. Girls may be more aware that they need to be social and so try to participate in games, although they rarely initiate games themselves. One reason why girls may know they need to be social is that from birth, we interact with babies in a gender biased way. This happens whether or not we try and avoid dressing babies in pink or blue. So girls are brought up to be more social and therefore know that this is how they should behave[36]. In primary school, girls with autism tend to be mothered by other girls and may be supported and included by their peers. Because they are included in a group, teachers may not notice that there is a problem. On the other hand, boys with autism are more likely to be bullied, or they may be more disruptive at school making them more noticed[41-43]. Girls tend to have more difficulties in secondary school when girls' relationships with each other become much more complicated. Girls may have one special friend and they may care what their peers think and worry about this[5].

Girls may show differences in how they acquire speech. Girls with autism tend to use new words when they learn them while boys with autism may not. This means they may not be identified as having language delay, which could result in girls not being diagnosed. On top of that, our society expects girls to be chattier than boys. However, girls may not use "meaningless" chatter in social situations, but instead they may say what they think and may not understand the subtleties in social situations (in this way, they are similar to boys)[5].

Girls with autism may be more like to have a rich and elaborate fantasy world and imaginary friends than boys. However, there may not be much shared activity with peers in this imaginary world. In the same way, when they play with dolls, girls may follow a script and may not be able to predict the consequences of the actions of others5. Girls may also show less restricted repetitive and stereotyped patterns of behaviour[44].

Whereas boys with autism tend to have technical hobbies which mean they stand out from their peers, girls' interests may be similar to neurotypical girls' (for example animals, horses or classical literature). However, girls with autism may have a more intense interest in these things. Girls may compile books of people's names, colour of hair or facts about celebrities for example[5].

Girls tend to internalise things and camouflage their difficulties[43]. This can result in mental health issues. Indeed, there is evidence that women with autism are more likely to develop mental health problems such as anxiety, depression or obsessive compulsive disorder compared to boys. They may also be more at risk of developing anorexia[5,43]. Therefore it is important that girls are diagnosed so that they can get the appropriate support and understanding.

Although there may be some biological evidence that women may be less affected by autism than men, there is still a lot that needs to be done to ensure that women are identified, diagnosed and supported in a gender appropriate way. Understanding the true numbers of women with autism, how to diagnose them and how autism affects their lives will help us to have a greater understanding of autism in general.

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