Women and girls on the autism spectrum

Dr Elisabeth Hurley is the research officer at Autism West Midlands. She has delivered a number of workshops and conference talks on women and girls with autism. She has also recently produced the book “Ultraviolet Voices – Stories of Women on the Autism Spectrum” which is a collection of personal experiences written by women and girls with autism.

That there are on average four or five times as many boys with autism than girls, is a commonly used statistic when it comes to autism. But when you dig deeper this statistic turns out to be much more complicated and reveals some interesting possibilities to consider when thinking about girls with autism.

First of all, the above ratio is an average. When you look at different populations, different trends appear. In people with autism and an accompanying learning difficulty, there are only twice as many boys compared to girls. At the other end of the spectrum, in people with Asperger syndrome or high functioning autism, there are around 10 times as many boys with autism as there are girls. These numbers suggest that we are more likely to see a girl with autism if she has an accompanying learning difficulty. But what they don’t mean is that girls with autism without an accompanying learning disability do not exist.

A number of researchers have speculated over the past few years that girls may be being misdiagnosed or missing out on diagnosis altogether. This might be due to girls learning to hide their difficulties, being more socially aware and wanting to have friends. It may also be due to our understanding of autism being largely based on boys, which means that we do not pick up on characteristics that appear more often in girls.

And indeed there is evidence that girls are missing out on diagnosis. Studies show that girls are diagnosed later and that the time between when concern is first registered and when a diagnosis is received is longer. Further, we find that, under the same conditions and in children with similar features, boys are still more likely to receive a diagnosis than girls. In part due to this lack of recognition, girls with autism are more likely to develop mental health problems such as anxiety or depression.
So if girls are missing out on diagnosis, is our initial statistic accurate? Are there really four or five times as many boys with autism as girls? Two recent studies seem to challenge this ratio. In a large scale Danish study looking at incidence rates of ASDs over time, they found that the ratio had dropped from between 5 and 8 times as many boys with autism compared to girls, down to only 3 times as many on average\(^1\). A smaller study in Sweden found an average of 2.6 times as many boys as girls, with similar ratios in people with learning difficulties (2.7 times as many boys) and people without learning difficulties (2.5 times as many boys). Furthermore, they found that the ratio changed at different ages. In younger children (at age 8), there were, on average, five times as many boys compared to girls. But at age 18, there were only twice as many boys as girls. This really highlights the idea that girls are being diagnosed later as they are not picked up in the count at age 8\(^1\). These findings are encouraging though as they show that we are moving towards better diagnosis of girls.

In the past, the male stereotype of autism has prevented girls and women from being diagnosed and understood. In turn, the lack of diagnosed women and girls has perpetuated the male stereotype of autism. This means that women and girls with autism have been subjected to a vicious cycle of misdiagnosis and misunderstanding. However, I believe that we are now seeing a change. The latest version of the DSM-5 recognises that there are differences between boys and girls with autism and that more needs to be done to understand how girls present differently\(^1\). There is now a greater focus on understanding how girls present differently and work is being done on how to recognise and support girls with autism. We need to continue to push for more understanding of women and girls with autism to ensure that they receive the support they need.

**Dr Elisabeth Hurley will be co-chairing the women and girls on the autism spectrum conference in October 2014, for more information please visit the NAS upcoming conferences page.**
References


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