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## IAN RESEARCH REPORT #12: GIRLS WITH ASD

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The Interactive Autism Network (IAN), the nation's largest online autism research project, has collated information about thousands of children with an autism spectrum disorder (ASD) from across the States. Boys with ASD outnumber girls by quite a margin. To what extent is this due to a real difference in the occurrence of autism in boys and girls? To what extent might this be due to some girls with ASD having a different profile than most boys with ASD (such that they remain undiagnosed more often)? What have we learned so far from the girls participating in the IAN Project? How are they similar to boys, and how do they differ? What are parents of daughters with ASD telling us about their journey?

### Please Note: These Findings Are Preliminary

The analyses presented here by the Interactive Autism Network are preliminary. They are based on information submitted via the Internet by parents of children with autism spectrum disorders (ASD) from the United States who choose to participate. They do not generalize to the larger population of parents of children with ASD. The data have not been peer-reviewed – that is, under evaluation by researchers expert in a particular field – or been submitted for publication. IAN views participating families as research partners, and shares such preliminary information to thank them and demonstrate the importance of their ongoing involvement.

### GIRLS WITH ASD: ORPHANS TWICE OVER

For many years, it has been a challenge to find research focused on girls with ASDs. Researchers, who found it difficult to recruit enough boys for their studies, thought it nearly impossible to recruit a comparable number of girls. "Scientists have tended to focus on boys from studies because it is difficult to find sufficiently large numbers of them," *The New York Times* reports. Yale researcher Ami Klin, recognizing the problem, has dubbed girls with autism "research orphans." <sup>1</sup>

Girls with ASD may be orphans in another way. They may simply remain undiagnosed and therefore invisible to researchers. Researchers looking at differences between boys and girls with ASD have often not found much difference. <sup>2,3</sup> Is this because there is no difference, or because only girls with ASD who most resemble boys with ASD are diagnosed and therefore included in studies?

Researchers have identified a number of reasons girls, especially those on the "milder" end of the autism spectrum, may not get diagnosed, including the notion that they may have a different profile than boys with ASD. <sup>4,5</sup> If they are a little more socially able than the boys, run into social trouble at an older age than the boys, and have fewer disruptive behaviors than the boys, they end up misdiagnosed, or even missed altogether?

In the *extreme male brain theory of autism*, researchers have suggested that most men tend to be better at "systemizing" or focusing on phenomena that follow rules and are predictable, like trains on their tracks, or planets in their orbits, while most women tend to be better at "empathizing" or reading others' mental states or emotions and responding appropriately. For girls with ASD, on the other hand, are even better at systemizing (and worse at empathizing) than the average male. <sup>6</sup> Could having a female version of the "extreme male brain" give you a different profile? Could it be that some girls with milder ASD behave or function differently than mildly affected boys? Researchers in the U.K. found many undiagnosed higher functioning children in British schools. What they said of all higher functioning children may go double for higher functioning girls:

*"These children may use strategies to mask their social and communication difficulties... They may be quiet and cooperative"*

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*school and not difficult to manage and therefore teachers may not be aware that they have difficulties. Primary schools in th are typically small and foster a supportive and nurturing environment. It may not be until these children move to secondary s that their true differences are revealed."*

In line with these ideas, a mother participating in IAN said of her daughter: "She was not diagnosed early on. She was in a reg class from Kindergarten through third grade. Since she was a girl, she did fine because the other girls loved her. (I don't know because most of the time she ignored them.) She was well behaved, too."

GIRLS WITH ASD PARTICIPATING IN IAN

Like many researchers, the IAN Research team has not found a great deal of difference between the boys and girls with ASD participating in our project. What we must keep in mind, however, is that there is a real possibility girls are missing from our s You need a professional diagnosis to join IAN Research. If some girls, perhaps those with high functioning ASD, are diagnos or not at all, those girls are not represented in IAN.

BOYS AND GIRLS WITH ASD: SIMILARITIES

Looking at the children who are participating in IAN Research, we find little difference between boys and girls in many areas, including the percentage of boys or girls who have lost skills or regressed, are verbal or nonverbal, or have been diagnosed w treated for a co-occurring condition such as depression. (See Table 1.)

Table 1. Boys and Girls with ASD Similar on Many Measures

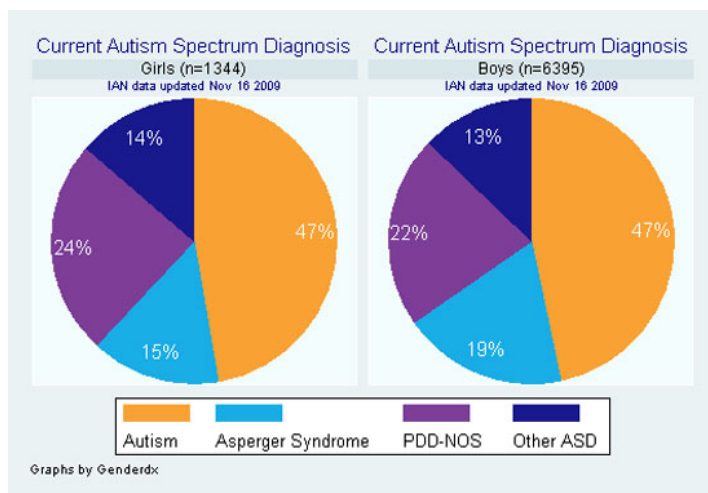
	Girls	Boys
Average age when joined IAN Research	7.8 years	7.8 years
Average age at first ASD diagnosis	4.0 years	3.9 years
Lost skills or regressed	40%	43%
Nonverbal	16%	14%
Bipolar disorder	4%	3%
Depression	8%	7%
Anxiety	20%	19%
ADHD	27%	29%

Regardless of a child's gender, a loss of previously acquired skills or abrupt behavior change was cause for alarm. One moth of her daughter, "She had always been the belle of the ball. Then, out of nowhere, she lost interest in others, and began withd in groups of even familiar people." Another parent reported, "It seemed like overnight she wasn't interested in other people. S stopped kissing us, and didn't respond to her name...."

Like parents of sons, many parents of daughters reported that their child had been diagnosed with or treated for one or more occurring conditions such as attention deficit hyperactivity disorder (ADHD), bipolar disorder, or depression -- something tha make life especially difficult for children with ASD and their families. <sup>8 9</sup> "She has always been prescribed Dexedrine, the only psychostimulant that seems helpful, because she never stops moving," one mother said of her daughter with an ADHD diagn "Our girl exhibits many behaviors associated with anxiety," said another, "like generalized fears, panic attacks (which include vomiting, sweating, and wild tantrums), and aversion to many social situations."

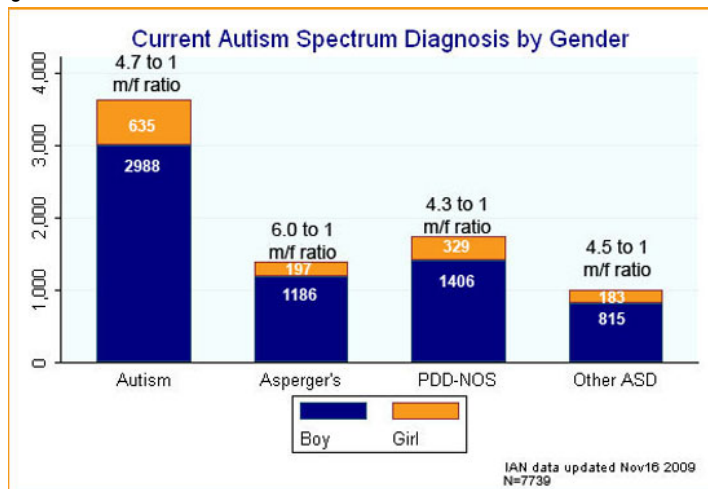
As is shown in Figure 1, the current ASD diagnoses of the girls participating in IAN do not differ much from the boys' diagnos although it appears girls are somewhat less likely to receive an Asperger's diagnosis than boys.

Figure 1.



The proportion of boys to girls for each type of ASD diagnosis is close to the 4 or 5 to 1 ratio reported in the autism literature with the exception of Asperger's syndrome. What has been reported for Asperger's is a ratio of between 9 and 11 boys for ev [12](#) [13](#) When we last calculated this figure based on our IAN data three years ago, we found a male to female ratio of 9 to 1 for children with Asperger syndrome, which is in line with these other estimates. Now, three years into the IAN Research project, ratio has changed to 6 to 1. It may be that increasing awareness of both ASD in girls and the Asperger's profile is leading to r frequent diagnosis of high functioning girls, although we do not have sufficient data to make that claim.

**Figure 2.**



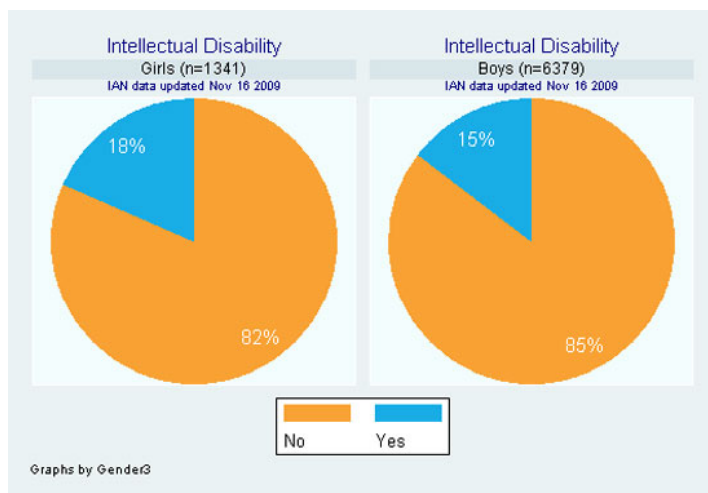
#### BOYS AND GIRLS WITH ASD: DIFFERENCES

The IAN data do reflect some differences between girls and boys with ASD that have also been noted in the research literatu the past such differences have been interpreted to mean that girls are either *not* affected or are *severely* affected, although t same facts may provide support for the notion that it is only severely affected girls who receive an evaluation and diagnosis the girls who are more mildly affected are overlooked.

For example, it has long been reported that girls with ASD are more likely to suffer cognitive impairment than boys. While the male/female ratio for children with ASD and *no* intellectual disability is about 4 or 5 to 1, the ratio of boys to girls *with* intellec disability is closer to 2 to 1. [10](#) [13](#) [14](#)

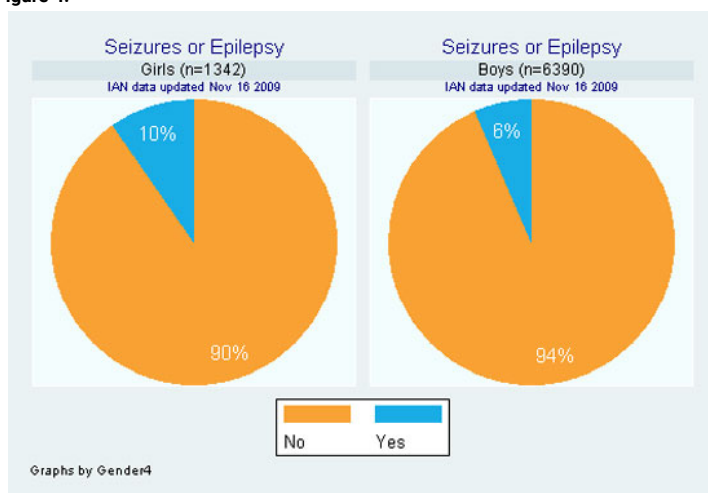
Our results reflect this difference: the male/female ratio for those without mental retardation is 4.8 to 1 overall, which is very to what has been reported elsewhere. We also find a greater proportion of girls with intellectual disability, where the male/fel ratio is 3.7 to 1. This is a result of the fact that girls are more likely to be diagnosed with a cognitive impairment. (See Figure

**Figure 3.**



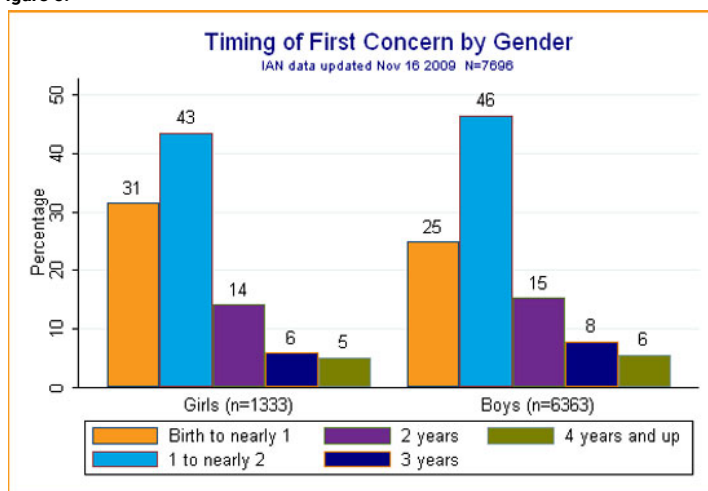
Similarly, more girls than boys with ASD participating in IAN are diagnosed with seizures or epilepsy (9.6 vs. 6.4%). (See Figure 4.)

**Figure 4.**



In addition, parents of girls are more likely to report having been worried about their child's development before the age of 12 months – again, a possible measure of severity. (See Figure 5.)

**Figure 5.**



Parents reflecting on their first worries about their daughter often mentioned noticing a lack of interest in caregivers from early on. "Within the first week after birth I became concerned that she was deaf because she didn't look at people when they spoke or she never looked at me while nursing," said one mother. Some described very difficult babies, while others described babies who were undemanding to the point of seeming disengaged. "My daughter would not move or do anything for herself," another mother said. "She would just watch TV and lie on the floor and not do anything. If anyone were in my house, they would not know I had a baby. She was too quiet and would not cry or request anything. A very good baby, but *too* good, that is what was scary." Others noted girls who had had little eye contact, staring at lights, fans, or the ceiling for hours.

It is likely that girls with these distinctive autistic behaviors would receive a diagnosis sooner rather than later. Again, we do not know if high functioning girls, whose issues might be masked until they are older, are being diagnosed as frequently as high functioning boys. One mother's story illustrates what *might* be happening to girls. She had not wondered about her daughter until her son was diagnosed with high functioning autism. It was only after she learned to recognize subtle signs that she "began to wonder at his older sister's many, many sensitivities and wonder if Asperger's might apply to her." Until that time, she had not though have her daughter evaluated.

It will be very interesting to see if and how facts and figures about girls with ASD change over time. Will we find little change, conclude that girls, especially high functioning girls, are truly outnumbered by boys 10 to 1? Or will we learn to recognize a different ASD profile in girls, such that increasing awareness leads to more girls with an ASD diagnosis? Only time, and thorough research, will tell.

## AN EXCLUSIVE ARTICLE ON GIRLS WITH ASD BY SHANA NICHOLS

Researcher Shana Nichols, author of *Girls Growing Up on the Autism Spectrum: What Parents and Professionals Should Know about the Pre-teen and Teenage Years*, has written an exclusive article for IAN Community. Read it [here](#).

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