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## AUTISM

# The Missing Autistic Girls

In the past two decades, autism diagnoses have soared—but new research shows that girls have frequently been overlooked, leaving them without crucial support.

By *Carly Berwick*

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On a recent hot summer afternoon, eight women sat at a table drawing and crafting at **Felicity House** (<https://felicity-house.org/>), the world's first community space devoted solely to women with autism. Opened just two years ago, the historic town house in the middle of New York City is a haven for women with a condition that limits their ability to communicate and interact with others.

The women who gather here have spent much of their lives seeking to understand how and why their brains work differently. While making art, learning poker, or attending classes, they're able to talk to others who share similar experiences—confusing social interactions where they “said the wrong thing” or bosses or coworkers who've asked, “What's wrong with you?”

The women turned the conversation to high school, bringing up memories and reflections of living with autism spectrum disorder (ASD) during their school years.

“I was a good test taker, but that doesn’t mean my executive functioning was up to par,” remembers Allison, who switched high schools to a “less pressurized one” because she needed to “go at my own pace.”

Many women at Felicity House discovered they had autism when they were older, missing a key intervention window that might have made their experiences at school and home easier. Far from being alone, they’re part of a group sometimes called “***the lost generation***

(<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC5040731/>).”

Autistic women are diagnosed much less frequently—***and often at an older age***

(<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4767258/>)—than boys or men. In the past two decades, as more research on ASD has been conducted, diagnoses among children have soared. Between 2000 and 2012, the percentage of kids diagnosed with autism more than doubled, and today, ***one in every 68 children*** (<https://www.cdc.gov/ncbddd/autism/data.html>) is diagnosed with the condition, according to the Centers for Disease Control and Prevention (CDC). Yet the large majority of these diagnoses are for boys, who are diagnosed more than four times as often as girls.

That may start changing soon due to a ***growing body of new research***

(<http://www.nih.gov/news-events/news-releases/nih-awards-100-million-autism-centers-excellence-program>) finding that autistic girls are dramatically underrepresented in autism diagnoses—often overlooked or misdiagnosed—due to a mistaken assumption that autism exhibits in the same way in girls and boys.

“We’ve found that while boys and girls with autism are facing similar problems in school and at home, some of their underlying brain functions are different,” said Kevin Pelphrey, a leading autism researcher and director of the ***Autism and Neurodevelopmental Disorders Institute***

(<https://autism.gwu.edu/>) at George Washington University. “This results in some differences in the symptoms of the autism and suggests the need to tailor treatment approaches by gender.”

and how best to treat it. Funded by the National Institutes of Health, the project brings together top autism researchers from around the country to explore different facets of the gender bias in autism, including genetics, brain imaging, and behavioral development—a significant breakthrough for autistic girls and the field of autism research.

In the coming months, Pelphrey and his team will start ***putting the findings into practice*** (<http://magazine.gwu.edu/the-autism-sex-bias>) with the launch a new, 10,000-square-foot center for autism diagnosis and therapy at the university.

## DANGEROUS BLIND SPOTS

The researchers have already found biological and social differences in how boys and girls exhibit signs of autism, but the misconceptions around the disorder have been a long time in the making, and undoing them won't happen overnight.

Popular stereotypes and generalities have played a role, priming parents and teachers to look for telltale signals of autism such as hand flapping and verbal tics, failure to make eye contact, or a laser-like fixation on trucks or dinosaurs. And researchers, reacting to the apparent prevalence of autism among males, may have unknowingly created a gender bias in the science itself—by conducting their research predominantly on autistic boys and men, and then forming conclusions about the condition that have been applied to girls and women as well.

For autistic girls, whose lives can be changed by early diagnosis, the mutually reinforcing trends in culture and science represent a dangerous blind spot. The ***new research is finding*** (<https://med.stanford.edu/news/all-news/2015/09/girls-and-boys-with-autism-differ-in-behavior-brain-structure.html>) that autistic girls may display fewer repetitive behaviors than boys and tend to be more social, verbal, and engaged. Autistic girls are also more likely to be obsessive and have a harder time regulating emotions, leading to diagnoses of other problems like anxiety and obsessive compulsive disorder (OCD) instead of autism.

The American Academy of Pediatrics recommends that all children ***be screened for autism*** (<http://www.aap.org/en-us/about-the-aap/Committees-Councils-Sections/Council-on-Children-with-Disabilities/Pages/Recent-Information.aspx>)

opportunity to diagnose girls is an increased risk for serious mental and physical health problems and lifelong struggles in school, work, and personal lives.

## CAMOUFLAGING THE SIGNS

School provides another **window for invention** (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5040731/>) for girls who may have slipped under the radar.

By the time a child starts school, the autism gender differences can be more magnified, says Connie Kasari, a researcher on the NIH study and a professor of psychological studies at the University of California, Los Angeles. **Kasari's research** (<http://www.kasari.org/>) has focused on how autistic boys and girls interact and socialize in different K–12 school settings, such as the playground.

Girls tend to camouflage their autism symptoms more and engage differently with peers and adults than autistic boys, she says. Sometimes these social interactions make it even harder to pick up on the signs of autism because girls tend to try harder socially and have a greater desire to make friends. Girls will often **turn inward** (<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4269475/>) when they sense they are not fitting in or understanding social situations, while boys may act out their frustration, becoming upset and signaling an undiagnosed behavioral issue more clearly.

“If you are an adult in the school yard, you may notice boys with autism. They may try to enter a group and if they get rejected, they walk away,” said Kasari. “Girls tend to be more persistent. They hover. It might seem they are doing OK. But if you look closer, you will see they are not.”

Especially when autistic girls are more verbal or higher functioning, their autism symptoms may also present themselves as other problems like **depression** (<https://www.ncbi.nlm.nih.gov/pubmed/19582563>), anxiety, attention-deficit/hyperactivity disorder (ADHD), or **anorexia** (<https://spectrumnews.org/features/deep-dive/the-invisible-link-between-autism-and-anorexia/>), which are more easily identified and diagnosed, researchers have found.



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That was the case with Allison Hamilton-Rohe's daughter, whose teachers first suspected she had ADHD, before realizing she was autistic.

Talkative, sociable, and prone to frequent hugging, the girl was diagnosed with autism at the age of 8, after a "very difficult year at school," says Hamilton-Rohe, noting her trouble concentrating in a seemingly chaotic class and frequent temper tantrums over small changes—particularly at the end of a busy day.

Hamilton-Rohe had asked her daughter's school to look into an evaluation three years earlier, but dropped it because the school thought it wasn't necessary. Eventually, her daughter's inability to process lots of stimuli at once, need for structure and time alone, and one-track mind led to a diagnosis of autism, she says.

"When I tell people she is autistic, they have a hard time because she does look at them, talk to them, and ask questions," said Hamilton-Rohe. "They expect autism to show up like it does in *Rain Man*."

Hamilton-Rohe's family decided to move to Montgomery County, Maryland, in hopes of getting support for the girl within general education classrooms there. The school district has programs for students with autism within general education schools and classrooms, and has ***opened autism resource centers***

(<http://www.washingtonexaminer.com/boom-in-autistic-students-prompts-new-montgomery-school-centers/article/2503541>)

at both the elementary and secondary levels to address the growing number of autistic students.

## LEARNING TO NAVIGATE

As with Hamilton-Rohe's daughter, the experiences of autistic girls—both their diagnoses and services—often depend on what kind of classroom or school they're in. A broad CDC-backed study of 11 states, for example, ***found that the ratio of boys to girls***

(<https://www.cdc.gov/mmwr/volumes/65/ss/ss6503a1.htm>) diagnosed with autism depended somewhat on the diagnostic services available within a district or school—schools with strong special education services had more comprehensive evaluations and earlier diagnoses for students.

Man.

Like many large districts, the 35,000-student Minneapolis Public Schools has both self-contained classrooms and inclusion programs for the nearly 900 students with autism.

While the more than 4-to-1 ratio of boys to girls diagnosed with autism applies in MPS, the district reports differences in how autistic boys and girls interact socially and what they're interested in, affirming the new research.

One particular gender-specific challenge the district notes is helping older autistic girls—even as early as fourth grade—discuss their changing bodies and navigate interactions with the opposite sex.

It's important to be as direct as possible, say district special ed teachers, scripting conversations and noting the appropriate time to give hugs. The discussion can take a particular urgency for older girls, who may not be aware when social rules are being broken or manipulated—a prospect particularly frightening for girls who are undiagnosed and could run a greater risk for sexual predation or abuse.

Without support, autistic girls can face a number of challenges and be “isolated and mistreated,” resulting in anxiety and depression, according to Julia Bascom, executive director of the **Autistic Self-Advocacy Network** (<http://autisticadvocacy.org/>), an organization run and composed of people with autism.

“By the time a child is in middle school, they know they are different. If they aren’t given a reason, they come to the same conclusion—that something is wrong with them,” said Bascom, who is also on the board at the Felicity House. “The suicide rate for autistic individuals is nine times the general population. This information saves lives.”

## CORRECTING THE IMBALANCE

It may take a decade for the autism research on girls *to correct the imbalance in diagnoses* (<http://journals.sagepub.com/doi/abs/10.1177/1362361316681481?journalCode=auta&>). When it does, there could be twice as many diagnoses for girls, and benefits for the entire field, as scientists refine or discard outmoded theories.

girls.

Some districts, like the nation's largest, in New York City, have found that it helps to pair general education teachers with special education teachers in a co-teaching model, where teachers share classroom responsibilities and both receive specialized training in teaching students with autism. Called the **ASD Nest Support Project** (<http://steinhardt.nyu.edu/asdnest/about>), the program helps ensure that all teachers know how to identify and support children with autism and serves more than 1,200 autistic students in 43 schools in the district.

And Pamela Ventola, a researcher on the NIH study on girls with autism and a professor at Yale University's Child Study Center, has found that a long-standing behavioral intervention called **Pivotal Response Treatment** (<https://www.autismspeaks.org/what-autism/treatment/pivotal-response-therapy-prt>) (PRT) helps girls in particular.

PRT motivates children with ASD to learn typical behaviors, such as fluid speaking or give-and-take conversations, by having parents and **practitioners ask questions** ([http://autismpdc.fpg.unc.edu/sites/autismpdc.fpg.unc.edu/files/PRT\\_procedures\\_learner.pdf](http://autismpdc.fpg.unc.edu/sites/autismpdc.fpg.unc.edu/files/PRT_procedures_learner.pdf)) such as "Can I play with you?" or "What is that?" to get a child to verbalize or take turns in an everyday play setting with immediate positive feedback. Ventola is now working with Connecticut's New Haven Public Schools to bring her research to the classroom by helping teachers implement PRT with autistic students.

It's not too late for adult women with autism either, after they leave the supports of school and home.

Thanks to the growing awareness of the particular experience of women with autism, a handful of female-only autism networks have emerged, among them social outings for teens called "Girls' Nights Out" at **Yale's Autism Program** ([http://childstudycenter.yale.edu/autism/clinical\\_services/initiative/](http://childstudycenter.yale.edu/autism/clinical_services/initiative/)) and at the **University of Kansas** ([http://www.kumc.edu/school-of-medicine/cchd/girls-night-out-\(gno\).html](http://www.kumc.edu/school-of-medicine/cchd/girls-night-out-(gno).html)) Medical Center, and Felicity House, whose programming re-creates school-based supports in some ways, but without the fraught experience of being an adolescent.

"When you graduate, it's like, no more [individualized education program], no more help," reflected Lauren at Felicity House on an afternoon this summer. "So it's nice to have a place where people

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