

The Invisible Girls

New research suggests that autism often looks different in females, many of whom are being misdiagnosed and missing out on the support they need

By Maia Szalavitz



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hen Frances was an infant, she was late to babble, walk and talk. She was three before she would respond to her own name. Although there were hints that something was unusual about her development, the last thing her parents suspected was autism. “She was very social and a very happy, easy baby,” says Kevin Pelphrey, Frances’s father.

Pelphrey is a leading autism researcher at Yale University’s world-renowned Child Study Center. But even he did not recognize the condition in his daughter, who was finally diagnosed at about five years of age. Today Frances is a slender, lightly freckled 12-year-old with her dad’s warm brown eyes. Like many girls her age, she is shy but also has strong opinions about what she does and does not want. At lunchtime, she and her little brother, Lowell, engage in some classic sibling squabbling—“Mom, he’s kicking me!”

Lowell, seven, received an autism diagnosis much earlier, at 16 months. Their mom, Page, can recall how different the diagnostic process was for her two children. With Lowell, it was a snap. With Frances, she says, they went from doctor to doctor and were told to simply watch and wait—or that there were various physical reasons for her delays, such as not being able to see well because of an eye condition called strabismus that would require surgical treatment at 20 months. “We got a lot of different random little diagnoses,” she recalls. “They kept saying, ‘Oh, you have a girl. It’s not autism.’”

In fact, the criteria for diagnosing autism spectrum disorder (ASD)—a developmental condition that is marked by social and communication difficulties and repetitive, inflexible patterns of behavior—are based on data derived almost entirely from studies of boys. These criteria, Pelphrey and other researchers believe, may be missing many girls and adult women because their symptoms look different. Historically the disorder, now estimated to affect one out of every 68 children in the U.S., was thought to be at least four times more common in boys than in girls. Experts also believed that girls with autism were, on average, more seriously affected—with more severe symptoms, such as intellectual disability. Newer research suggests that both these ideas may be wrong.

Many girls may, like Frances, be diagnosed late because autism can have different symptoms in females. Others may go undiagnosed or be given diagnoses such as attention-deficit/hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD) and even, some researchers believe, anorexia. As scientists study

how this disorder plays out in girls, they are confronting findings that could overturn their ideas not only about autism but also about sex and how it both biologically and socially affects many aspects of development. They are also beginning to find ways to meet the unique needs of girls and women on the spectrum.

It’s Different for Girls

Scientists in recent years have investigated several explanations for autism’s skewed gender ratio. In the process, they have uncovered social and personal factors that may help females mask or compensate for the symptoms of ASD better than males do, as well as biological factors that may prevent the condition from developing in the first place [see box on page 54]. Research has also revealed bias in the way the disorder is diagnosed.

A 2012 study by cognitive neuroscientist Francesca Happé of King’s College London and her colleagues compared the occurrence of autism traits and formal diagnoses in a sample of more than 15,000 twins. They found that if boys and girls had a similar level of such traits, the girls needed to have either more behavioral problems or significant intellectual disability, or both, to be diagnosed. This finding suggests that clinicians are missing many girls who are on the less disabling end of the autism spectrum, previously designated Asperger’s syndrome.

In 2014 psychologist Thomas Frazier of the Cleveland Clinic and his colleagues assessed 2,418 autistic children, 304 of them girls. They, too, found that girls with the diagnosis were more likely to have low IQs and extreme behavior problems. The girls also had fewer (or perhaps less obvious) signs of “restricted interests”—intense fixations on a particular subject such as dinosaurs or Disney films. These interests are often a key diagnostic factor on the less severe end of the spectrum, but the examples used in diagnosis often involve stereotypically “male” interests, such as train timetables and numbers. In other words, Frazier had found further evidence that girls are being missed. And a 2013 study showed that, like Frances, girls typically receive their autism diagnoses later than boys do.

Pelphrey is among a growing group of researchers who want to understand what biological sex and gender roles can teach us about autism—and vice versa. His interest in autism is both professional and personal. Of his three children, only his middle child is typical. Kenneth, Pelphrey jokes, has classic “middle-child syndrome” and complains that his siblings “get

FAST FACTS

AUTISM IN GIRLS

- 1 One in 68 children in the U.S. is affected by autism—but new research suggests that current diagnostic methods overlook girls, meaning even more kids may be on the spectrum.
- 2 Behavioral and preliminary neuroimaging findings suggest autism manifests differently in girls. Notably, females with autism may be closer to typically developing males in their social abilities than typical girls or boys with autism.
- 3 Girls with autism may be harder to diagnose for several reasons, including criteria developed specifically around males and overlapping diagnoses such as obsessive-compulsive disorder or anorexia.



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away with murder because they can blame it on their autism.”

Pelphrey is now leading a collaboration with researchers at Harvard University, the University of California, Los Angeles, and the University of Washington to conduct a major study of girls and women with autism, which will follow participants over the course of childhood through early adulthood. The researchers want “every bit of clinical information we can get because we do not know what we ought to be looking for,” Pelphrey says. Consequently, they are also asking participants and family members to suggest areas of investigation because they know firsthand what is most helpful and most problematic.

Girls in the study will be compared with autistic boys, as well as typically developing children of both sexes, using brain scans, genetic testing and other measures. Such comparisons can help researchers tease out which developmental differences are attributable to autism, as opposed to sex, as well as whether autism itself affects sex differences in the brain and how social and biological factors interact in producing gender-typical behaviors.

Already Pelphrey is seeing fascinating differences in autistic girls in his preliminary research. “The most unusual thing we keep finding is that everything we thought we knew in

terms of functional brain development is not true,” he says. “Everything we thought was true of autism seems to only be true for boys.” For example, many studies show that the brain of a boy with autism often processes social information such as eye movements and gestures using different brain regions than a typical boy’s brain does. “That’s been a great finding in autism,” Pelphrey says. But it does not hold up in girls, at least in his group’s unpublished data gathered so far.

Pelphrey is discovering that girls with autism are indeed different from other girls in how their brain analyzes social information. But they are not like boys with autism. Each girl’s brain instead looks like that of a typical boy of the same age, with reduced activity in regions normally associated with socializing. “They’re still reduced relative to typically developing girls,” Pelphrey says, but the brain-activity measures they show would not be considered “autistic” in a boy. “Everything we’re looking at, brain-wise, now seems to be following that pattern,” he adds. In short, the brain of a girl with autism may be more like

The old idea that there is only one girl on the autism spectrum for every four boys with the disorder is almost certainly wrong, as is the notion that autism is more severe in girls.

the brain of a typical boy than that of a boy with autism.

A small study by Jane McGillivray and her colleagues at Deakin University in Australia, published in 2014, provides behavioral evidence to support this idea. McGillivray and her colleagues compared 25 autistic boys and 25 autistic girls with a similar number of typically developing children. On a measure of friendship quality and empathy, autistic girls scored as high as typically developing boys the same age—but lower than typically developing girls.

Pelphrey is finding that autism also highlights normal developmental differences between girls and boys. Sex hormones, he says, “affect just about every structure you might be interested in and just about every process you might be interested in.” Although boys generally mature much later than girls do, the differences in brain development appear to be quite big—far larger than the differences in behavior.

Masking Autism

Jennifer O’Toole, an author and founder of the Asperkids Web site and company, was not diagnosed until after her husband, daughter and sons were found to be on the spectrum. On the outside, she looked pretty much the opposite of autistic. At Brown University, she was a cheerleader and sorority girl whose boyfriend was the president of his fraternity.

But inside, it was very different. Social life did not come at all naturally to her. She used her formidable intelligence to become an excellent mimic and actress, and the effort this took often exhausted her. From the time she started reading at three and

Researchers suspect that comparing boys and girls on the spectrum will reveal more about autism, as well as the ways in which gender affects typical development.

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—Psychologist Kevin Pelphrey,
Yale University

throughout her childhood in gifted programs, O’Toole studied people the way others might study math. And then, she copied them—learning what most folks absorb naturally on the playground only through voracious novel reading and the aftermath of embarrassing gaffes.

O’Toole’s story reflects the power of an individual to compensate for a developmental disability and hints at another reason females with autism can be easy to miss. Girls may have a greater ability to hide their symptoms. “If you were just judging on the basis of external behavior, you might not really notice that there’s anything different about this person,” says University of Cambridge developmental psychopathologist Simon Baron-Cohen. “It relies much more on getting under the surface and listening to the experiences they’re having rather than how they present themselves to the world.”

O’Toole’s obsessive focus on reading and finding rules and regularities in social life is far more characteristic of girls with autism than boys, clinical experience suggests. Autistic boys sometimes do not care whether they have friends or not. In fact, some diagnostic guidelines specify a disinterest in socializing. Yet autistic girls tend to show a much greater desire to connect.

In addition, girls and boys with autism play differently.

Studies have found that autistic girls exhibit less repetitive behavior than the boys do, and as the 2014 findings from Frazier and his colleagues suggest, girls with autism frequently do not have the same kinds of interests as stereotypical autistic boys. Instead their pastimes and preferences are more similar to those of other girls.

Frances Pelphrey’s obsession with Disney characters and American Girl dolls might seem typical, not autistic, for example. O’Toole remembers compulsively arranging her Barbie dolls. Furthermore, although autism is often marked by an absence of pretend play, research finds that this is less true for girls.

Here, too, they can camouflage their symptoms. O’Toole’s behavior might have seemed like typical make-believe to her parents because she staged Barbie weddings just like other little girls. But rather than imagining



GALLERY STOCK

she was the bride, O'Toole was actually setting up static visual scenes, not story lines.

Also, unlike in boys, the difference between typical and autistic development in girls may lie less in the nature of their interests than in its level of intensity. These girls may refuse to talk about anything else or take expected conversational turns. "The words used to describe women on the spectrum come down to the word 'too,'" O'Toole says. "Too much, too intense, too sensitive, too this, too that."

She describes how both her sensory differences—she can be overwhelmed by crowds and is bothered by loud noise and certain textures—and her social awkwardness made her stand out. Her life was dominated by anxiety. Speaking broadly of people on the spectrum, O'Toole says, "There is really not a time when we're not feeling some level of anxiety, generally stemming from either sensory or social issues."

As she grew up, O'Toole channeled her autistic hyperfocus into another area to which culture frequently directs women: dieting and body image, with a big dollop of perfectionism. "I used to have a spreadsheet of how many calories, how many grams of this, that and the other thing [I could eat]," she says. The resulting anorexia became so severe that she had to be hospitalized when she was 25.

In the mid-2000s researchers led by psychiatrist Janet Treasure of King's College London began to explore the idea that anorexia might be one way that autism manifests itself in females, making them less likely to be identified as autistic. "There are striking similarities in the cognitive profiles," says Kate Tchanturia, an eating disorder researcher and colleague of Treasure's at King's College London. Both people with autism and those with anorexia tend to be rigid, detail-oriented and distressed by change.

Furthermore, because many people with autism find certain tastes and food textures aversive, they often wind up with severely restricted diets. Some research hints at the connection between anorexia and autism: in 2013 Baron-Cohen and his colleagues gave a group of 1,675 teen girls—66 of whom had anorexia—assessments measuring the degree to which they had various autism traits. The research found that women with anorexia have higher levels of these traits than typical women do.

No one is suggesting that the majority of women with anorexia also have autism. A 2015 meta-analysis by Tchanturia and her colleagues puts the figure at about 23 percent—a rate of ASD far higher than that seen in the general population. What all of this suggests is that some of the "missing girls" on the spectrum may be getting eating disorder diagnoses instead.

Further, because autism and ADHD often occur together—and because people diagnosed with ADHD tend to have higher levels of autism traits than typical people do—girls who seem easily distracted or hyperactive may get this label, even when autism is more appropriate. Obsessive-compulsive behavior, rigidity and fear of change also occur in both people with autism and those with OCD, suggesting that autistic females might also be hidden in this group.



Girls with autism tend to show a higher interest in socializing and learning the rules of interaction than boys. This can make them more adept but also makes social exclusion especially painful.

Double Standards

Even when young women are comparatively "easy" to diagnose, they still face many challenges in the course of development—particularly social ones. This was the case for Grainne.

Her mother, Maggie Halliday, had grown up in a large Irish family and could see early on that her third child, Grainne, was different. "I knew from when she was a couple of months old that there was something not right," Halliday says. "She didn't like to be held or cuddled. She could make herself a dead weight and just—you couldn't pick her up."

Although Grainne's IQ tests are in the low normal range, the results do not capture either her abilities or her disabilities well. Today the teenager's intense interests are boy bands and musical theater. Despite being extremely shy, she blooms on stage and loves to sing. "The play she's in, when they deliver the script, within a week, she has everybody's part memorized and every song in the score memorized," Halliday says.

Because of a genetic condition, Grainne is short: 4'7"—and a half, she insists. And although she is laconic and does not tend to initiate conversation, she is also bubbly and smiles frequently, clearly interested in connecting. She weighs what she does say very carefully. For example, when asked whether she thinks autistic girls are more social than boys with autism, Grainne says, "Some might be," not wanting to generalize.

THE AUTHOR

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Of course, adolescence is difficult for most kids, but it is especially challenging for autistic girls. Many can cope with the far simpler world of elementary school friendships, but they hit a wall with the “mean girls” of junior high and the subtleties of flirting and dating. Moreover, puberty involves unpredictable changes such as breast development, mood swings and periods—and there are few things that autistic people hate more than change that occurs without warning. “She would like to have a boyfriend—that’s why she loves the boy bands,” says Halliday, adding that she thinks Grainne may not understand what such a relationship would really mean.

Unfortunately, the autistic tendency to be direct and take things literally can make affected girls and women easy prey for sexual exploitation. O’Toole herself was the victim of an abusive relationship, and she says the problem is “endemic” among women on the spectrum, particularly because so many are acutely aware of their social isolation. “When you feel

you’re too difficult to love, you’ll love for crumbs,” she says.

In this way, autism may be more painful for women. Autistic people who do not seem interested in social life probably do not obsess about what they are missing—but those who want to connect and cannot are tormented by their loneliness. A study published in 2014 by Baron-Cohen and his colleagues found that 66 percent of adults with the milder form of ASD (so-called Asperger’s) reported suicidal thoughts, a rate nearly 10 times higher than that seen in the general population. The proportion was 71 percent among women, who made up about one third of the sample.

Until very recently, few resources have been available to help autistic girls through these difficulties. Now researchers and clinicians are starting to fill these gaps. For example, Rene Jamison, an assistant clinical professor at the University of Kansas Medical Center, runs a program in Kansas City called Girls Night Out. Aimed at helping affected girls navigate ado-



The Protected Sex

Simon Baron-Cohen, a professor of developmental psychopathology and director of the University of Cambridge’s Autism Research Center, has helped develop several of the major theories that are guiding current thinking about autism. One of these hypotheses, which he is continuing to test, is the “extreme male

brain” theory, which first appeared in the literature in 2002. The idea is that autism is caused by fetal exposure to higher than normal levels of male hormones, such as testosterone. This occurrence shapes a mind that is more focused on “systemizing” (understanding and categorizing objects and ideas) than “empathizing” (considering social interactions and other people’s perspectives).

In other words, autistic minds may be stronger in areas where male brains, on average, tend to have strengths—and weaker in areas where females, again, speaking broadly, are the superior sex. (When it comes to individuals, of course, these averages do not say anything about a particular man or woman’s ability or capacity—nor do the differences necessarily reflect immutable biology rather than culture.)

Numerous recent studies have supported Baron-Cohen’s idea. In 2010 he and his colleagues found that male fetuses exposed to higher levels of testosterone in amniotic fluid during pregnancy tend to grow up to have more autism traits. A 2013 study he co-authored, led by his Cambridge colleague Meng-Chuan Lai, found that the brain-scan differences seen in children with autism occurred most often in regions that tend to vary by gender in typical children.

In 2015 Baron-Cohen and his colleagues published results

of an analysis of a large group of amniotic fluid samples from Denmark that are linked to population registries of mental health. They found that in boys, having an autism diagnosis was linked with higher levels of fetal testosterone and various other hormones, but the first cohort tested had too few girls with autism, so they are analyzing later births to see if the same results will be found. Further evidence came from a large Swedish study, also published last year, that found a 59 percent increased risk of giving birth to a child with autism among women with polycystic ovary syndrome—an endocrine disorder involving elevated levels of male hormones.

Few scientists—including Baron-Cohen—think that the extreme male brain theory is the whole story. A second idea emerges when looking at the typical strengths of women. If having female hormones and a female-type brain structure increases the ability to read the emotions of others and makes social concerns more salient, it might take a greater number of genetic or environmental “hits” to alter this capacity to the level where autism would be diagnosed. This idea is known as the “female protective” hypothesis.

Along these lines, several studies have shown that in families with affected daughters, there are higher numbers of mutations known as copy-number variations than there are in families where only boys are affected. A 2014 study by geneticist Sébastien Jacquemont of the University of Lausanne in Switzerland and his colleagues found that there was a 300 percent increase in harmful copy-number variants in females with autism, compared with males.

If either—or both—of these hypotheses is correct, then there will always be more boys than girls on the spectrum. “I imagine that once we’re very good at recognizing autism in females, there will still be a male bias,” Baron-Cohen says. “It just won’t be as marked as four to one. It might be more like two to one.”

—M.S.



New programs are helping young and adult women with autism master skills that are crucial to greater independence and confidence, including socializing and self-care.

ing to address such “superficial” concerns can cause serious life problems and restrict independence.

Even many highly intelligent girls on the spectrum have difficulties with washing their hair, wearing deodorant and dressing appropriately, Jamison says. Some of this behavior is linked to sensory issues; other aspects of the problem are related to difficulty following the appropriate sequence of behavior when doing something you think is unimportant. “When Grainne was in seventh grade, I had to tell her it was against the law not to wear a bra,” Halliday says of her daughter, who found bras uncomfortable. Grainne also did not want to wear deodorant—saying, almost certainly accurately, that the boys smelled worse.

The Girls Night Out group does fun activities, ranging from having manicures to playing sports. Typical girls who get school credit for volunteering provide mentoring and talk about boys and other issues the girls might not want to discuss with adults. “One of the things that we really work on is getting them to try new things to figure out what they might like,” Jamison says.

In New York City, Felicity House, which its founders tout as the world’s first community center for women on the spectrum, opened in 2015. Funded by the Simons Foundation, it occupies several floors of a spectacular Civil War-era mansion near Gramercy Park and offers classes and social events so autistic women can get to know and support one another. Five of the autistic women who helped to found Felicity House met a few weeks before it opened to talk about life on the spectrum. Only two had been diagnosed as children—one with Asperger’s and another with what she said was “ADHD with autistic tendencies.” Of the other three women, two had struggled with depression before their diagnosis as adults.

lence, it focuses on specific issues such as hygiene and dress. Although this emphasis might seem trivial or a concession to gender stereotypes, in fact, fail-

Emily Brooks, 26, is a writer studying for her master’s in disability studies at City University of New York. She identifies as gender queer and believes gender norms cause many problems for people on the spectrum. She noted, to broad agreement, that boys are allowed far greater leeway to deviate from social expectations. “If a guy does something that is considered socially inappropriate... his friends may sometimes encourage some of those behaviors,” she said, adding that “teen girls will shut you down if you do anything that’s different.”

Leironica Hawkins, an artist who has created a comic book about Asperger’s, also has to contend with social cues about race. “It’s not just because I’m a woman on the spectrum. I’m a black woman on the spectrum, and I have to deal with social cues that [other] people can afford to ignore,” she said. She added that she thought women “are probably punished more for not behaving the way we should. I’ve always heard women are socially aware to the needs of others, and that’s not me, most of the time... I feel like I get pressured to be that way.”

Because of these expectations, there is less tolerance for unusual behavior—and not just in high school. Many of the women report having difficulty keeping—but not getting—jobs, despite excellent qualifications. “You can see that in a faculty meeting even at the high-level academic departments,” Yale’s Pelphey says. “The guys still get away with much, much more.”

As awareness of autism grows, women and girls are already increasingly likely to be diagnosed; this generation clearly has significant advantages over those past. But much more research will need to be done to design better and more gender-appropriate diagnostic tools. Perhaps in the interim, the experiences of women with autism should teach us to be more tolerant of socially inept behavior in women—or less tolerant of it in men. Either way, it is clear that a greater understanding of autism in girls is needed to recognize this condition. And in the process it could illuminate new facets of typical behavior and the way that gender shapes the social world. **M**

MORE TO EXPLORE

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- **The Lost Girls.** Apoorva Mandavilli in Spectrum. Published online October 19, 2015. <https://spectrumnews.org/features/deep-dive/the-lost-girls>

From Our Archives

- **Taking Early Aim at Autism.** Luciana Gravotta; January/February 2014.
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