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What Autistic Girls Are Made Of

By EMILY BAZELON

Caitlyn & Marguerite sat knee to knee in a sunny room at the Hawks Camp in Park City, Utah. On one wall was a white board with these questions: What's your favorite vacation and why? What's your favorite thing about yourself? If you could have any superpower, what would it be?

Caitlyn, who is 13, and Marguerite, who is 16 (I've used only their first names to protect their privacy), held yellow sheets of paper on which they had written their answers. It was the third day of the weeklong camp, late for icebreakers. But the Hawks are kids with autistic disorders accompanied by a normal or high I.Q. And so the main goal of the camp, run on a 26-acre ranch by a Utah nonprofit organization called the National Ability Center, is to nudge them toward the sort of back and forth — “What's your favorite video game?” — that comes easily to most kids.

Along with Caitlyn and Marguerite, there were nine boys in the camp between the ages of 10 and 18. They also sat across from one another in pairs, with the exception of one 18-year-old who was arguing with a counselor. “All I require is a purple marker,” the boy said over and over again, refusing to write with the black marker he had been given. A few feet away, an 11-year-old was yipping and grunting while his partner read his answers in a monotone, eyes trained on his yellow paper. Another counselor hurried over to them.

Marguerite was also reading her answers without eye contact or inflection. “My favorite vacations were to India and Thailand my favorite thing about myself is that I'm nice to people if I could choose any superpower I'd be invisible,” she said in an unbroken stream. She looked up from her paper and past Caitlyn, smoothing her turquoise halter top over the waist of a pair of baggy cotton pants. Caitlyn was also staring into the middle distance. She has gold-streaked hair, which was bunched on top, and wore a black T-shirt with a sunburst on the front and canvas sneakers with skulls on the tops. The girls didn't look uncomfortable, just unplugged.

A counselor noticed their marooned silence and prodded Caitlyn to take her turn. At first, she ran quickly through her answers, too. But Caitlyn loves fantasy — she is an avid writer of “fan fiction,” spinning new story lines for familiar characters from “Pokémon” and “[Harry Potter](#)” — and the superpower question grabbed her. She looked at Marguerite. “If I could have any power, I'd want to be able to transform into an animal like a tiger,” she said, smiling and putting her hands in front of her face, fingers tensed as if they were claws. Marguerite smiled and tentatively mirrored the claw gesture. Caitlyn smiled back. “I like tigers,” she said, her eyes bright behind her glasses. “Do you?”

It was a small, casual encounter and also an exceedingly rare one — a taste of teenage patter shared by two autistic girls.

Autism is often thought of as a boys' affliction. Boys are three or four times as likely as girls to have classic autism (autism with [mental retardation](#), which is now often referred to as cognitive impairment). The sex ratio is even more imbalanced for diagnoses that include normal intelligence along with the features of autism — social and communication impairments and restricted interests; this is called Asperger's syndrome (when there is no speech delay) or high-functioning autism or, more generally, being "on the autistic spectrum." Among kids in this category, referral rates are in the range of 10 boys for every girl.

According to the [Centers for Disease Control](#), there are about 560,000 people under the age of 21 with autism in the United States. (Adults aren't included because there is no good data on their numbers.) If 1 in 4 are female, the girls number about 140,000. The C.D.C. estimates that about 42 percent of them are of normal intelligence, putting their total at roughly 58,000 (with the caveat that these numbers are, at best, estimates).

Because there are so many fewer females with autism, they are "research orphans," as Ami Klin, a psychology and psychiatry professor who directs [Yale's](#) autism program, puts it. Scientists have tended to cull girls from studies because it is difficult to find sufficiently large numbers of them. Some of the drugs, for example, commonly used to treat symptoms of autism like anxiety and hyperactivity have rarely been tested on autistic girls.

The scant data make it impossible to draw firm conclusions about why their numbers are small and how autistic girls and boys with normal intelligence may differ. But a few researchers are trying to establish whether and how the disorder may vary by sex. This research and the observations of some clinicians who work with autistic girls suggest that because of biology and experience, and the interaction between the two, autism may express itself differently in girls. And that may have implications for their well-being.

The typical image of the autistic child is a boy who is lost in his own world and indifferent to other people. It is hard to generalize about autistic kids, boys or girls, but some clinicians who work with high-functioning autistic children say they often see girls who care a great deal about what their peers think. These girls want to connect with people outside their families, says Janet Lainhart, a professor of psychiatry and [pediatrics](#) at the [University of Utah](#) who treats Caitlyn and Marguerite. But often they can't. Lainhart says that this thwarted desire may trigger severe anxiety and depression.

Other specialists are not sure that girls struggle more in these ways. "This is a profile of both boys and girls," Klin says of the wish to connect that some people with autism have. But he agrees with Lainhart that it is easier for Asperger's boys to find other boys — either on or off the autistic spectrum — who want to spend hours on their Game Boys or in a realm of Internet fantasy. Klin and Lainhart also say they think that the world is a more forgiving place for boys with the quirks of Asperger's because, like it or not, awkwardness is a more acceptable male trait.

This gender dynamic doesn't necessarily affect girls with Asperger's when they are very young; if anything, they often fare better than boys at an early age because they tend to be less disruptive. In 1993, Catherine Lord, a veteran autism researcher, published a study of 21 boys and 21 girls. She found that when the children were between the ages of 3 and 5, parents more frequently described the girls as imitating typical kids and seeking out social contacts. Yet by age 10, none of the girls had reciprocal friendships while some of the boys did. "The girls often have the potential to really develop relationships," says Lord, a psychology and

psychiatry professor and director of the Autism and Communication Disorders Center at the [University of Michigan](#). “But by middle school, a subset of them is literally dumbstruck by anxiety. They do things like bursting into tears or lashing out in school, which make them very conspicuous. Their behavior really doesn’t jibe with what’s expected of girls. And that makes their lives very hard.”

No doubt part of the problem for autistic girls is the rising level of social interaction that comes in middle school. Girls’ networks become intricate and demanding, and friendships often hinge on attention to feelings and lots of rapid and nuanced communication — in person, by cellphone or Instant Messenger. No matter how much they want to connect, autistic girls are not good at empathy and conversation, and they find themselves locked out, seemingly even more than boys do. At the [University of Texas](#) Medical School, Katherine Loveland, a psychiatry professor, recently compared 700 autistic boys and 300 autistic girls and found that while the boys’ “abnormal communications” decreased as I.Q. scores rose, the girls’ did not. “Girls will have more trouble with social networks if they’re having greater difficulty with communication and language,” she says.

And so girls with autism and normal intelligence may end up at a particular disadvantage. In a new study published in May, a group of German researchers compared 23 high-functioning autistic girls with 23 high-functioning boys between the ages of 5 and 20, matching them for age, I.Q. and autism diagnosis. Parents reported more problems for girls involving peer relations, maturity, social independence and attention.

The difficulty may continue into adulthood. While some men with Asperger’s marry and have families, women almost never do, psychiatrists observe. A 2004 study by two prominent British researchers, Michael Rutter and Patricia Howlin, followed 68 high-functioning autistics over more than two decades. The group included only seven women, too small a sample to reach solid conclusions about gender differences, Rutter and Howlin caution. But 15 men — 22 percent of the sample — rated “good” or “very good” for educational attainment, employment, relationships and independent living, while no women did. Two women rated “fair,” compared with 11 men, and the other five women were counted as “poor” or “very poor.” None had gone to college. None reported having friends or living on their own. Only one had a job. Undermined by anxiety and depression, women with autism appear to be more often confined to the small world of their families.

When Caitlyn started kindergarten and didn’t play normally with other kids, her mother, Juli, thought it was because she hadn’t gone to preschool. The first warning of real trouble came from the first-grade gym teacher, who told Juli that Caitlyn exposed herself to the class. Caitlyn is overweight, and she has always been private about her body. Juli couldn’t imagine her daughter taking off her clothes in public, and when she asked what had happened, Caitlyn said another girl had pulled down her pants. “Caitlyn stood there mortified,” Juli says. “But she couldn’t express that to the teacher.”

Caitlyn lives with her mother, her older sister, the girls’ great-grandparents and a pair of poodles in Farmington, outside of Salt Lake City. (Her father died before she was 2.) Until second grade, Caitlyn had a neighborhood friend with whom she went to school. Other than that, she was often alone in class. Her teachers were frequently frustrated with her inability to work and play in groups. But she connected with a few adults — in fifth grade, one class aide took her horseback riding, and the school [librarian](#) gave Caitlyn her own copy of “Spindle’s End,” a retelling of “Sleeping Beauty,” “because she said I helped her so much,”

Caitlyn remembers.

Contrary to the Asperger's stereotype, Caitlyn struggles in math but tests in the highly gifted range in reading and writing. This is another sex difference that Lord sees among her patients. "I don't have any real data, but a lot of high-functioning girls are real readers — not great on subtleties, but they like fantasies and the 'Baby-Sitters' series," she says. "The boys are much less so."

In elementary school, Caitlyn went to special-education classes for math and social skills. At 11, as other girls began to slip out of reach, Asperger's was diagnosed. The shift a year later to junior high for seventh grade was a jolt. By the second week of school, a few boys were mocking Caitlyn's weight and calling her weird while other kids laughed. "No one would sit by me at lunch," Caitlyn says. Girls told her that they didn't want her to be in their reading group. Caitlyn did her homework, but she was too anxious to walk to the front of the room to turn it in. At home, her neighborhood friend no longer came out to play.

In the winter, Caitlyn switched from a special-education math class into a mainstream one, and the kids in her new class made her miserable. For days she refused to go to school. She told Lainhart: "No one likes me at lunch. I'm very sad." (With Juli's and Caitlyn's permission, I read Lainhart's notes on Caitlyn's treatment.) After a huge outburst of anger at home, Caitlyn told her mother that she wanted to die. At her next appointment with Lainhart, she said: "I listen to people's conversations during free time in science. They talk about live games, R-rated movies, outfits. I feel left out." Caitlyn told Lainhart about two dreams. In one, her school had a bridge running through it, and she kept falling off. In the second, she was in the lunchroom throwing a party; no one came. Lainhart says that while boys are aware of rejection and bullying, in her experience they are not hurt by it to the extent that some girls are. "I have rarely had a male patient with autism become suicidal or express such intense emotional pain," she says.

Caitlyn has never hit another child. But at school, her retorts to her peers — "I yelled at a . . . little bimbo. They yelled at me," she told Lainhart during one appointment — pushed them further away. With Lainhart's help, Juli persuaded the school to let her daughter eat lunch in a classroom rather than in the cafeteria. Still, Caitlyn's grades dropped from A's and B's to D's and F's. Her anxiety level spiked, and her sadness bloomed into depression.

Lainhart has seen the same blend of anxiety and depression in other female patients. Like Caitlyn, Marguerite's serious problems date from middle school. In sixth grade, she moved to Salt Lake City and away from a couple of strong friendships, and she couldn't replace them. "She found it increasingly difficult to do the things necessary to maintain friendships with 'normal' kids," her father says. Last fall, at 15, she withdrew further. An olive-skinned girl with thick brown hair — she was adopted from Guatemala as a baby — Marguerite has always liked to go shopping and wear pretty things (not a typical trait for a girl with autism, though not unique either). But she stopped dressing herself, washing her hair and going to school. For months, Marguerite spiraled into one of the worst bouts of depression Lainhart has ever seen.

Since 1990, when she was recruited to work with autistic children by Susan Folstein, a prominent Johns Hopkins researcher, Lainhart has been interested in the relationship between autism and depression. In a 1994 paper, Lainhart and Folstein pointed out that despite the 4-to-1 male-female ratio for autism, females made up half the autistic patients with mood disorders described in the medical literature. The case reports may not represent the population as a whole; still, the overrepresentation is suggestive. Lainhart is

currently looking at the relationship between autism and depression in boys and girls and the potential link to depression in their parents and siblings. “We know that anxiety and depression are co-morbid,” meaning that they occur together, Lainhart says. “And we know that depression is worse for women in the general population. But what’s the link to autism? And is it worse for girls?”

Social anxiety affects Lainhart’s female patients into adulthood. Liz Lee, who is 43, is studying for her master’s degree in electrical engineering, yet she cannot cope with going to lunch with the other graduate students at the lab where she works. Ash Baxter, who is 22, spends hours making art, sewing dolls with wild yarn hair and macramé-edged suits; she created an extraordinary blue-and-gold octopus mask out of a three-foot gourd she found in the garage. She is talented and would like to attend art school, but Baxter can’t master her anxiety well enough to learn to drive or live in a dorm, so college art classes remain out of reach. Another patient, Charlotte (she asked that I not use her last name) is 23 and goes to a social-skills class that Lainhart runs for her patients in their late teens and early 20s. Because of the dearth of females, the class is mostly male, and Charlotte often leaves in the middle saying she’s “stressed out.” “She can only take so much,” her mother told me. Lainhart says, “You see these incredible areas of anxiety in Liz and Charlotte and Marguerite that don’t seem to have a parallel in the boys and men.”

There is preliminary evidence that girls and women also vary from the male Asperger’s profile in terms of their interests, as Catherine Lord suggests. David Skuse, a psychiatry professor at the Institute of Child Health at University College London, has analyzed data from 1,000 children, 700 of them on the autistic spectrum. “Girls with autism are rarely fascinated with numbers and rarely have stores of arcane knowledge, and this is reflected in the interests of females in the general population,” Skuse explains. “The girls are strikingly different from the boys in this respect.”

With her high aptitude for reading and writing and her difficulties with math, Caitlyn fits Skuse’s model. Even as she was failing school last year, she kept up her fan fiction, posting stories she had written on the Web site Gaia Online. On the 40-mile drive home from camp, she told me about her plan to write an original eight-book fantasy series about a werewolf, to be called “Midnight Wind.”

One of the best-known theorists on sex difference and autism, Simon Baron-Cohen, comes at these questions from another angle. A psychology professor and director of the Autism Research Centre at [Cambridge University](#), Baron-Cohen has characterized autism as a condition of the “extreme male brain.” His research shows that in the general population men are more likely than women to score low on a test of empathy and high on a test of recognizing rules and patterns, or “systemizing.” High systemizing together with low empathy correlates with social and communication deficits and, at the extreme end of the scale, with autism. Baron-Cohen is currently studying whether elevated levels of fetal [testosterone](#) — a prime driver of masculinity — are linked to autistic traits.

Baron-Cohen says that he believes that autistic girls are strong systemizers. That quality may manifest itself in letters rather than numbers. But in his view, the thought processes for Asperger’s girls mirror those of boys. He explains, “These females often feel more compatibility with typical males simply because typical males may be more willing to adhere to the linear, step-by-step form of thinking and conversation — more like debating or playing chess or doing logic.”

To Lainhart, Baron-Cohen’s extreme-male-brain theory is an apt description for a subset of her female

patients, for example Liz Lee, who in pursuing electrical engineering is training for a classic Asperger's profession. Lee is socially aloof: she usually sits on the floor with her back to Lainhart during their sessions, twirling the propeller of a toy helicopter. Eye contact makes Lee angry, and she says she would like to live alone in the desert.

But based on their clinical experience, Lainhart and also Skuse see autism as a heterogeneous disorder. Its profile may change and expand as more is understood about girls, whose autism, they worry, often goes undiagnosed. That is partly, Skuse posits, because girls' general aptitude for communication and their social competence helps some Asperger's girls "pass" — they pick up on their difference and carefully mask it by mimicking other girls' speech and manner and dress. In a sense, their femaleness allows some girls to seem less autistic. It is as if they start off with a social advantage — Skuse sees this as a 20-point bonus on a scale of 100 — that helps counter the disorder. This idea isn't necessarily at odds with the findings that show girls to be more seriously affected by autism, Skuse says, because the girls who succeed in masking their deficit wouldn't be included in studies. And so they are missing from the picture. "There is no doubt in my mind that the way we have defined autism currently biases our assessments strongly in the direction of identifying a male stereotype," he says. The C.D.C. agrees and says that as a result the estimate for the number of girls with autism and normal intelligence may be low.

Why would autism express itself differently depending on sex? The short answer is that no one knows. Genetic researchers, however, have just begun to hint at possibilities. In the last two years, new data-pooling efforts have yielded two major genetic-linkage studies — attempts to link autism to specific chromosomes — that suggest that some of the genes underlying autism may be different in males and females. By isolating sex as a variable, scientists are seeing potential genetic hot spots for autism. "By comparing males and females, we will have a much better chance of discovering the causes of autism," says Geraldine Dawson, a psychology professor and director of the [University of Washington](#) Autism Center, who was a co-author of one of the studies.

Studies that use the latest brain-scanning tools — magnetic resonance imaging and diffusion tensor imaging — generally focus on boys. But a single study of M.R.I.'s of both boys and girls found differences in their brain anatomy. Published in April in *The Journal of the American Academy of Child and Adolescent Psychiatry*, the study compared nine girls and 27 boys who were matched for age, I.Q. and severity of autism. Other research has established some correlation between abnormally large brain size and autism; the April paper reported that the brain volume of the autistic girls deviated from the norm more than the volume of the autistic boys. Lainhart, who is a member of the University of Utah's Brain Institute, has measured head circumference as a proxy for brain volume. (The two are linked.) In a 1997 paper, she reported that the mean head circumference of eight autistic girls at birth was significantly greater than the norm, whereas the mean head size of 37 autistic boys was not.

These are small and preliminary studies, but their findings may relate to a puzzle of autism: while overall, there are more mentally retarded autistic boys than girls, a greater proportion of autistic girls are retarded — 58 percent compared with 42 percent for boys, according to the C.D.C. As for Asperger's girls, Lainhart, who continues to conduct brain research, says she hopes eventually to shed light on the deficits of girls like Caitlyn and Marguerite and suggest new treatments for them. "In children with [dyslexia](#), scientists identified where the basic cognitive deficits were," she says. "Then they intervened to go after those

deficits, and they saw the brain change in those areas.”

In the meantime, girls with autism and normal I.Q.’s pose a particular challenge for schools. Though mainstreaming has its benefits, autistic kids risk becoming outcasts in a regular classroom. Yet if girls go to a special-education program or a separate school, they are often swimming in a sea of boys. Lord pointed to this as a factor in girls’ lack of friendships in her 1993 study. When the girls in her sample were shifted to specialized programs, “their opportunities to meet girls and women with some common interests were even more limited than those of the boys and men,” she wrote.

The Harbour School in Baltimore has tried to address this predicament. The school has 120 students, all with learning disabilities, speech impairments, attention-deficit disorders and autistic-spectrum disorders. Only 19 of them are girls, which leaves one or two in each class from first to 12th grade. (More boys than girls are also diagnosed with the hyperactive form of A.D.D. and some learning disabilities.) Along with the playful Baltimore street scenes that decorate the walls of the hallways at Harbour, the predominance of gangly male bodies and loud voices was the first thing I noticed on a recent visit. The school felt like a haven — for boys.

And so I wondered whether the girls would feel overwhelmed, as Charlotte often is at her mostly male social-skills class. In the school auditorium at about 9 a.m., there were 13 sixth graders — 12 boys and a single girl, Krissy, whose clinical designation is pervasive developmental disorder on the autistic spectrum. She was sitting on the floor playing Connect Four with one of the boys. She won her game, smiled without looking at her opponent, then got up and walked across the room to another of her classmates.

“Hi, Michael,” she said. He didn’t look up. Krissy sat down next to him and watched him play on his Game Boy. They talked quietly about his progress; she knew the game. A few minutes later, she found her Connect Four partner again, and they decided to play Operation. They talked about the rules, but when Krissy tripped the buzzer, he let her finish taking out the body parts she was maneuvering. Krissy declared victory and moved on again, this time to lie on the floor next to a boy who was building with metal rods and blue glass balls.

“Do you need help?” she asked him.

“No,” he answered.

“Can I at least play with you?” Krissy persisted. The boy grunted. Without talking more, they each built a structure.

Krissy has been at Harbour since first grade, and the small size of her class means that she knows the boys well. Her teachers say she is at ease with them because she shares their Game Boy enthusiasm and watches the same movies. But sometimes Krissy’s interests seem entirely girlish. She was excited about straightening her hair and then styling it into corkscrew curls for her interview with me and showed off pictures she had drawn of princesses, covered with hearts.

Harbour makes a concerted effort to give its girls the chance to develop relationships with one another. The girls’ lunch periods coincide to give them time together. A social worker, Kelli Rimmel, runs a regular “girls club” for a group of about half a dozen. “There are some things the girls don’t want to discuss in front of

their male peers,” she says. “It’s a chance for them to talk about boys, how to handle hormonal changes, other girls, their bodies, dating.”

Krissy seems to be getting the social opportunities and support that Lord and Lainhart want for the girls they treat. Salt Lake City has good schools for kids with Asperger’s, Lainhart says, but the catch is money. School districts in Maryland, Washington and Virginia pay Harbour’s tuition for more than 95 percent of the students. But districts in many parts of the country — including Utah — don’t pay for private-school placements for kids with Asperger’s. Caitlyn doesn’t go to a school like Harbour because her family can’t afford it; her experience, not Krissy’s, is typical.

Lord and Lainhart try to help by setting up social-skills groups for their patients. But families must pay for the classes out of pocket because medical insurers generally don’t pay for treatment and services that focus on autism — a terrible problem for her patients, Lainhart says. So the groups tend to meet only a couple of times a month for a few hours. Charlotte doesn’t know the boys in her group the way Krissy knows her classmates. At the University of Michigan, Lord runs co-ed groups for younger children and then tries to put together groups of older girls that mix autistic and nonautistic kids. As the girls get older, it is harder to find normally developing girls who want to participate. Twenty years ago, as a clinical psychologist in Canada, Lord started a group of four Asperger’s girls who stayed in touch into adulthood. They called themselves the highest-functioning autistic women in Canada, she remembers, and treasured their solidarity. “It’s striking how much girls with autism can care about each other and other people and develop friendships that are really a source of joy for them,” Lord says. “But when I think of the teenage girls I know, many of them have no shot at forming those relationships.”

At the Hawks Camp in Utah, Caitlyn and Marguerite didn’t become friends. A week earlier, Marguerite and Lainhart had made a list of conversation starters, but Marguerite didn’t really use them. Caitlyn didn’t try to talk to her much, either. The camp lasted only a week; for these girls, not long enough for bonding. Still, Caitlyn said it was the best week of her year. One day after lunch, the Hawks campers drove in two minivans to a nearby lakefront to go tubing and Jet Skiing. Caitlyn changed into her bathing suit, then wrapped herself in a towel despite the strong hot sun. “Do I look O.K.?” she asked a counselor. “It’s just that there are so many people.”

But the other kids were paying Caitlyn no mind. This wasn’t a group that Caitlyn had to fear. She balled her hands into fists, visibly holding her anxiety at bay. “Sometimes I feel like I’m weird and ugly,” she said, “but I’m not going to today. I’m confident!” She strode out to Jet Ski and later returned with a description that she planned to use in a future story: “It was like riding a dragon through the storm.”

Back at camp, the Hawks poured onto the playground. During the school year, Caitlyn had been excused from gym class because she was so nervous about changing her clothes and running around in front of her classmates. As she sat on a swing and watched kids play tag, a counselor named Claire came over. As she and Caitlyn talked, Caitlyn did all the tiny things that people do to engage one another, smiling, laughing, gesturing, looking Claire in the eye. Claire urged her to join the game and called out, “Caitlyn’s playing!” Caitlyn protested. But Claire persisted, and finally Caitlyn yelled, “O.K., where’s the base?” A teenage boy pointed to the monkey bars, and Caitlyn ran for it. Her glasses slipped off her nose, and her shorts slipped a bit, too. She hiked them up and kept running, surrounded by other kids. Sweating and laughing, she yelled,

“Safe!”

Emily Bazelon is an editor of the online publication Slate. Her last article for the magazine was about the grass-roots pro-life movement.

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