

DEEP DIVE

Puberty and autism: An unexplored transition

BY SPECTRUM

24 MARCH 2021

Illustration by Jun Cen

Henry's early years in school had been rocky enough. The boy had been diagnosed with autism at age 7. He struggled to control his emotions and process sensory information in his Tennessee classroom. But by the time Henry was 10, his parents had figured out ways to ease these issues with therapy and medication.

Then puberty hit. Henry became moody and more sensitive. A perceived slight from a classmate could trigger an emotional outburst. "He couldn't bounce back," says his mother, Elisa. "He was upset for the rest of the day." (We withheld Henry and Elisa's last name to protect their privacy.)

Henry's outbursts became harder and harder to manage as the small boy shot up to nearly 6 feet tall. Last year at age 13, as he was adjusting to new medication, his irritability and compulsive behaviors got so bad that Elisa and her husband pulled Henry out of school for two weeks. "He was so sad," Elisa recalls. "It was awful." Adding to the pandemonium was Henry's burgeoning sexuality, complicated by his challenges with social skills. He would tell a raunchy joke, not intuiting that his parents would find it offensive. He might ask a girl he hardly knew to be his girlfriend. "I hope that we can just finish out this puberty ride," Elisa says. "Because it is a roller coaster."

Puberty can be an extra-fraught time for young people on the spectrum. The features that define autism — including sensory and emotional issues, **repetitive behaviors** and missing social nuance — can make it hard for them to cope as they mature sexually and become more interested in friendships and dating. Autistic girls may have a particularly tough time socially, as they struggle to fathom the intricacies of non-autistic girls' interactions. **Depression, anxiety** and **eating disorders** are unusually prevalent in autistic adolescents: One 2006 study showed that 72 percent of 109 autistic youth had depression, anxiety or another **mental health condition**. By comparison, a 2016 survey of more than 50,000 children and adolescents suggests that **less than 20 percent** have a mental health condition. Autistic teenagers are also at a heightened risk of seizures and cognitive setbacks.

Yet the scientific community has paid scant attention to this developmental turning point in the life of an autistic person and the dramatic biological changes that accompany it, says **Kathy Koenig**, associate research scientist at the Child Study Center at Yale University. It is unclear whether autistic youth enter puberty at the typical time, much less how puberty's onset affects their developing brains. "A lot of the literature has been, in the past, focused very much on the youngest children," Koenig says. Only 2 percent of U.S. autism research dollars in 2016, for instance, were directed toward research on the challenges **autistic young people** face as they transition to adulthood or later on, according to an Interagency Autism Coordinating Committee report.

As awareness of the knowledge gap grows, however, a few researchers have secured grants to study autistic adolescents during sexual development. They are exploring whether these young people experience elevated stress levels, and if so, what might be the physical and psychological toll. They are also delving into what happens in the brain, and early data suggest differences in the activity of key brain networks between autistic and non-autistic teenagers. "This critical point in life, when autistic kids are hitting puberty and going through adolescence, is really under-researched," says **Kevin Pelphrey**, a neuroscientist at the University of Virginia in Charlottesville.

Additional data could point to the best types of treatments and support for autistic teenagers as they make the transition to adulthood. Meanwhile, psychologists are parlaying what is known about these teenagers' experiences and the ways in which they learn into new sex and relationship education programs for autistic youth.

Second hit:

Puberty may be a roller coaster, but it is no quick ride. It occurs in phases and involves significant changes in **brain structure and function**. During this time, unused neuronal connections (**synapses**) produced in the brain during the first decade or so of life are trimmed away. The pruning starts before adolescence in the regions responsible for basic sensory and motor functions. Among the last areas to undergo this maturation process is the dorsolateral prefrontal cortex, which is involved in higher cognitive functions such as impulse control, decision-making, judgment, social skills and emotional regulation.

Meanwhile, adolescence brings faster long-distance signaling in the brain, as bundles of nerve fibers become wrapped in fatty insulation, effectively creating new neuronal highways. This brain remodeling typically results in greater cognitive skills, such as enhanced problem-solving, as well as emotional maturity and a stronger sense of identity. And although many young people on the spectrum show similar progress, a large subset does not.

Inklings of this discrepancy began to show up decades ago. In 1970, psychiatrists at Maudsley

Hospital in London, England found that about half of the autistic individuals who made the most progress during treatment did not develop key social and interpersonal skills during adolescence; they also noted that about a quarter of those teenagers developed epilepsy. In 1982, Swedish researchers described **five autistic teenagers** whose abilities declined or autism traits became more severe after the onset of puberty.

Two larger studies, published in 2011 and 2015, reported that older adolescents have more problems with **adaptive behavior** — **life skills** such as communication, bathing and dressing — than do younger children on the spectrum. And in a 2013 study, 185 autistic children showed only modest progress in **executive functions** such as short-term memory and self-control during adolescence, when these skills typically develop rapidly, affecting their ability to plan and to form close friendships. Such developmental setbacks can leave autistic people behind, as the skills people learn in adolescence predict their functioning in adulthood, says psychologist **Suzy Scherf** of Pennsylvania State University in University Park.

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Kathy Koenig

Neuroscientist **Lucina Uddin** has for years been wanting to clarify what puberty looks like in the autistic brain. At the University of Miami in Florida, Uddin explores brain connectivity — the extent to which brain regions co-activate — in autistic people, using imaging techniques. In a study published in 2015, she and her colleague **Jason Nomi** examined **brain connectivity** in 26 children, 28 adolescents and 18 adults on the spectrum, along with 72 non-autistic individuals of similar age and intelligence quotients. They looked at 18 neural networks in the brain — including the salience network, which determines which stimuli are deserving of our attention; and the default mode network, which processes emotions and thoughts when the brain is at rest. Across all of these networks, the researchers found that connectivity tends to be atypical in autistic children but becomes gradually more similar to that of their non-autistic peers as they age, with fewer discrepancies in autistic adolescents and still fewer in autistic adults.

The results piqued Uddin’s curiosity about what happens between childhood and adolescence, so she wrote a grant proposal to study how brain connectivity changes during puberty in autistic children. “It never got funded,” she says. One reason, she thinks, is that puberty is complicated; it occurs in stages, and individuals enter those stages at different times. Parent reports, self-reports or visual exams can provide clues to a person’s stage, though they are often inexact; measuring levels of puberty-related hormones is a better gauge, but **blood draws** are challenging for many people with autism. So ensuring she was comparing children at the same stage would be tricky.

Meanwhile, researchers who study autistic children were seeing more hints that adolescence may be a particularly vulnerable time for them. In 2015, Scherf and Pennsylvania State University postdoctoral fellow **Giorgia Picci** conceptualized this idea using a **two-hit model**. The first hit is disruption to neural development in the womb or in early childhood. The second hit comes during adolescence, when the neural circuitry fails to rewire in the way it does in most teenagers. This wiring difference may mean that the brain cannot adapt as the social and practical demands of the neurotypical world increase, Scherf says. As a result, autistic teenagers may respond inappropriately to social cues, be unable to perform skills needed for independence and be at an increased risk of mental health problems. Emerging genetic evidence supports this idea: A 2017 study assessed 5,551 children in the United Kingdom for **social-communication difficulties** at ages 8, 11, 14 and 17 and found that, from 11 to 17, a unique set of genetic variants that govern social skills comes into play in autistic teenagers.

A second hit may also help explain why many autistic teenagers develop **epilepsy**. Up to 13 percent of children with **autism have epilepsy**, but that proportion may jump to 26 percent during puberty. Seizures can appear suddenly and cause language difficulties, motor problems and regression. “We don’t know why this happens,” says Pelphrey, whose own autistic daughter developed seizures as she entered puberty.

Exactly how that second hit manifests in the brain is unclear, in part because there is a lack of funding for proposals like Uddin’s. Still, some clues have emerged from existing longitudinal studies in which researchers follow children through adolescence, though without trying to pick up puberty per se. In a 2019 study, for instance, researchers examined connectivity between the salience network, the default mode network and the central executive network — which is responsible for attention control — in 16 autistic teenagers and 22 non-autistic teenagers. They scanned the teenagers’ brains at two time points, three years apart, representing early-to-middle and late adolescence. In non-autistic teenagers, they found a **weakening of brain connectivity** between the executive and default networks in these three years, likely reflecting increased separation and specialization of these networks. That was not the case in autistic teenagers, pointing to one difference in brain development that could define the transition in autism.

Pelphrey is leading one of the few efforts to define the brain changes that characterize the **adolescent transition**. Since 2012, Pelphrey’s team has been following 620 autistic and non-autistic children aged 6 to 17 years, conducting annual clinical assessments and scanning their brains. The researchers also sequenced the children’s genomes and measured gene expression from blood samples. In 2017, the team won a five-year **Autism Centers of Excellence renewal grant** to use this cohort to investigate what happens at puberty.

Just as Uddin proposed, Pelphrey’s team is eyeing changes in brain systems associated with autism, including the salience, default mode and central executive networks, using magnetic resonance imaging and electroencephalography. The researchers are also tracking hormone levels to see how those interact with brain function, as sex hormones are known to help organize the

nervous system during adolescence. A study published in February, for example, suggests that **testosterone exposure** during puberty in young non-autistic men affects how the brain responds to social cues.

One of many questions Pelphrey says his work could answer is whether autistic adolescents experience a loss of brain connectivity during puberty and, if so, what the ramifications of that decline are as the scientists track those adolescents into adulthood. Pelphrey and his colleagues are also trying to predict who is at risk for seizures. They plan to feed resting-state brain scans into a computer and use a machine-learning algorithm to identify brain signatures of those adolescents who develop seizures. They then aim to test and refine the model using a large database of brain scans, such as the **Autism Brain Imaging Data Exchange**. “We’re hoping we’ll end up with images from thousands and thousands of people” on which to test the model, he says. If the study is successful, he says, its results could help provide advance warning for at least one curveball that puberty throws at many autistic teenagers and their families.

Danger zone:

Whatever its details, the remodeling of the brain during puberty also leads to an intensifying of emotions and rapid mood changes; teenagers seesaw from irritable to jubilant to anxious. This process appears to be exaggerated in autistic children, and the consequences more difficult to moderate, in part because autistic children may have trouble grasping what is happening. When 16-year-old Brendan Toh, who is autistic and minimally verbal, hit puberty at 12, he became **increasingly aggressive**, with an escalation of self-harming behaviors such as pinching and biting. “In a regular child, a young person, that’s quite a difficult transition,” says his mother, **May Ng**, a pediatric endocrinologist at the University of Liverpool in the U.K. For autistic teenagers who don’t understand what’s going on, it can be even more difficult to deal with, Ng says.

Other teenagers on the spectrum seem to suffer because they understand enough of what is going on to know what they are missing. At 14, **Amy Gravino**, now an autism sexuality advocate, longed for friends and was acutely aware that she did not fit in. No one at school wanted to hang out with her; her only friends were people she corresponded with in chat rooms dedicated the Backstreet Boys, a 1990s boy band she was obsessed with.

Gravino’s sense of being left out seems to be common among autistic girls. In a 2018 survey, parents of 40 autistic girls reported that their daughters had significant difficulty **socializing with other girls** and experienced rejection. “Girls have to develop pretty sophisticated ways of interacting with other girls to keep up as they get into fourth, fifth, sixth grade,” says Koenig, who led the study. “These are times when a lot of teasing happens, a lot of ostracism. There’s a lot of relational aggression.” For Gravino, the emotional pain was so sharp in her early teens that she

had suicidal thoughts, she says.

Feelings of not belonging contribute to the high prevalence of depression and anxiety among autistic adolescents. “Many have problems with social communication, and you’re setting the stage for potentially having a lot of possible psychological impact during adolescence,” says psychologist **Blythe Corbett** of Vanderbilt University in Nashville, Tennessee. In a 2020 study in Minnesota, researchers found that 1,104 autistic teenagers and young adults were nearly three times as likely to have depression, and more than three times as likely to have anxiety, by the age of 30 as their non-autistic peers. And tragically, one 2013 study suggested that autistic children are 28 times as likely to **plan or attempt suicide** as their non-autistic peers are.

“My mom came in the bathroom one day and was like, ‘Oh, you’re a woman now.’ I had no clue what was going on.” Amy Gravino

Disordered eating, which **rarely occurs before puberty**, also is likely to disproportionately affect autistic youth. A study of more than 5,000 adolescents found that the more autism traits a teenage girl has, the more frequent her **disordered eating behaviors**.

Some researchers are investigating another key question: Do autistic children reach puberty before other children do? If they do, they might feel even more out of place, exacerbating their social isolation and potentially contributing to mental health issues, Corbett says. The data on this timing are conflicting, however. A 2017 study of 3,454 non-autistic children and 94 autistic children aged 8 to 15 **showed no difference** between the two groups; signs of puberty were parent- or self-reported, and included menses, body hair development and a deepening voice. In a 2020 study of 239 children aged 10 to 13 years old, on the other hand, Corbett and her colleagues found that autistic girls **start their period 9.5 months earlier** than their non-autistic peers. (There was no difference in the start of puberty for boys.) If the findings are replicated, they could underscore the importance of providing autistic girls with tailored sex education at an earlier age to demystify puberty, and to prepare them for it, Corbett says.

Corbett and her colleagues are working on finding a way to identify children at risk for depression and anxiety during the pre-teen and teenage years. They are monitoring psychological stress in more than 100 children with autism and a similar number of controls. They assess each child’s stress levels starting at age 10 to 13 by measuring, at regular intervals over four years, salivary cortisol and arousal during two social tasks — a speech and a conversation with a peer. If clinicians can identify markers that indicate, say, which pre-teens are likely to have a difficult time later on, they can start interventions early. “We need to be ready,” Corbett says.

Life lessons:

Amid these emotional struggles, autistic adolescents are often woefully unprepared for the physical changes puberty brings. When Gravino first got her period, at age 12, the autistic tween was baffled. She went through five pairs of underwear before her mother realized what was happening. “My mom came in the bathroom one day and was like, ‘Oh, you’re a woman now,’” Gravino says. “I had no clue what was going on.”

Studies show that autistic young people are less likely than their non-autistic peers to receive any kind of **sex education**, at school or at home. “These kids have a lot of professionals in their lives, so for you to have never spoken to anyone about [sexual development] is kind of mind-blowing,” says **Laura Graham Holmes**, a clinical psychologist at Hunter College in New York City who is helping create an autism-specific healthy relationships curriculum. Data suggest that relationship training is also critical for this population. A survey of adolescents and adults with autism about their experiences with **sex and sexuality** suggests that many people with autism want a romantic relationship but do not feel equipped to find or develop one.

Not understanding sexual rules — often unspoken and infused with nuance — can result in faux pas, such as provocative talk and openly discussing sexuality. It can also lead to sexual offenses, involving **autistic people as perpetrator** or victim. Autistic teenagers might masturbate in public; text, phone or follow someone they are interested in to the point that it is considered stalking; or download illegal pornography. On the flip side, autistic people, especially girls, are at an **elevated risk of being abused** — sexually, physically and emotionally.

Traditional sex education can be wanting for autistic teenagers, who may need more of the details spelled out, and more social gaps filled in, than non-autistic students. The need for a different approach is especially evident among those who need a lot of support. For these individuals, repetition, visuals and rules are key teaching tools, experts say. Ng and her husband had long used the Picture Exchange Communication System, which involves cards showing various pictures, to help them communicate with Brendan — to explain what would happen at a doctor’s appointment, say, or how to ask for a favorite toy or snack. Ng employed a new suite of cards to explain puberty. Over many months, she used these cards to explain to and reassure Brendan that what he was experiencing was natural. The cards conveyed important lessons, such as that masturbating is fine, so long as he does it only in his bedroom with the door closed.

Researchers are devising and testing several types of new sex education and social programs for adolescents on the spectrum. Last year, the Organization for Autism Research launched a self-directed online guide called **Sex Ed for Self-Advocates**, which contains nine sections on topics such as puberty, sexual orientation and gender identity, sexual activity, and online relationships

and safety. “It’s got the pros of the internet as a delivery model, which is that people can do it privately. They can go at their own pace,” says **Jessica Penwell Barnett**, a sociologist at Wright State University in Dayton, Ohio, who wrote the sexual activity section. It cannot, however, incorporate in-person teaching techniques, such as role playing and corrective feedback, that help autistic teenagers build peer relationships.

Building those bonds is the aim of a program in New Haven, Connecticut, for autistic girls and women called **SELF (Socialize, Experience, Learn and have Fun)**. Koenig developed SELF to address the lack of therapies designed to help girls with autism overcome their unique social challenges. The girls sign up for activities such as yoga and art classes that give them an opportunity to meet other girls and have fun. They talk about music and movies, who they like, and interactions that they find confusing, such as why a boy kept making excuses for not giving out his phone number. “These kids really did develop relationships with each other,” says Koenig. “They accepted each other fully.”

A program called **Tackling Teenage Training** offers one-on-one sex and relationship lessons for autistic teenagers who have an intelligence quotient of at least 80. Over 18 sessions, a trainer uses visuals and role-playing, among other exercises, to teach a teenager about topics such as body changes, masturbation, friendship and boundary recognition. In a pilot project, 23 autistic boys and 7 autistic girls, 15 years old on average, performed significantly better on a test of various **aspects of sexual development** after the training than they had before it. A follow-up study with **189 participants** confirmed the findings. The program has been tested at sites around the world, and several teams are expanding it from a one-on-one to a group format.

In September 2019, Henry enrolled in the program, and through it gained a new understanding of relationships, communication and sexuality. At home, his parents were also teaching him about boundaries, such as proper texting etiquette. This education happened none too soon: After completing the training, Henry made an announcement: He had a girlfriend. “He was so proud,” Elisa says. “Everyone knew.”

Elisa hopes the concrete messages and rules Henry is learning stay with him as he gains independence. She knows he is not going to listen to his parents forever: “What 17-year-old says, ‘Good point, Mom and Dad, thanks for telling me that?’” Although Henry’s excitement over having a girlfriend was sweet, Elisa and her husband worried that he was too immature for such a relationship. Their concerns were short-lived: The couple broke up after about two weeks. Henry might not have been ready for a girlfriend. Not quite yet.

With reporting by Alisa Opar.

Cite this article: <https://doi.org/10.53053/DESD7673>