

Autism Is an Identity, Not a Disease: Inside the Neurodiversity Movement

Activists argue that rather than trying to ‘cure’ or treat the neurodivergent, society should learn to accept, appreciate, and accommodate their needs



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At first glance, the Autistic Self Advocacy Network (ASAN) annual gala in November looked like many a Washington, D.C., nonprofit fundraiser. Approaching the swank ballroom of a downtown hotel, I saw the standard check-in table by the door, and coat check nearby.

But with my drink ticket, I received an unusual packet: a set of color-coded communication badges to display like a name tag. Green signifies “actively seeking communication and happy to be approached for a conversation.” Yellow means “I only want to talk to people I know.” Red indicates “I don’t want to talk to anyone.”

I clipped a green badge on my jacket, and proceeded into the event. At the tables, each place setting sported a colorful stim toy — a small object to fidget with in order to self-soothe — and a list of potential table conversation topics, including “If you could eliminate any societal unwritten rule, what would it be?” and “Should small talk be illegal or just discouraged?” a nod to the discomfort many autistic people* feel when making conversation with strangers. Since clapping can cause a sensory overload for some people, the audience used flapplause — flapping hands in the air above our heads — to signal enthusiasm as speakers took the stage. Some attendees rocked in their seats, or played with their phones or stim toys, or took breaks in the nearby quiet room.

Moderator John Marble apologized for forgetting his glasses, with a little joke. “Please bear with me if I look sometimes at these notes, but if you can’t be awkward at an autistic event, where can you be awkward?”

This is autistic culture. And this event was a living example of neurodiversity, a concept that emerged in the late 1990s to describe variation in brain wiring, which

can include autism, depression, attention-deficit hyperactivity disorder, intellectual and developmental disabilities, dyslexia, epilepsy, and more.

The keynote speaker, #CripTheVote co-founder Alice Wong, gave a presentation via robot, since her disabilities keep her from traveling. A person-height robot on wheels with a screen showing Wong's face allowed her to present from the podium and interact with guests before and after the main event. "It is so nice to be at an autistic event, to have a robot that's not trying to teach us social skills," Marble said, to laughter.

The wide variety of norms and accommodations on display here could, one day, become standard for all professional circles and public spaces. This could be a vision of our neurodivergent future. At least, that's what activists are calling for — and they're becoming increasingly visible and vocal. Neurodivergent characters have emerged in television shows such as *The Big Bang Theory*, *Criminal Minds*, *House*, and *Atypical*. Scholars and journalists have written about the importance of acceptance and inclusion for neurodivergent people. Employers including Freddie Mac, Microsoft, SAP, and Specialisterne started recognizing some of the most obvious strengths of autistic people, like attention to detail and pattern recognition, and started recruiting them for well-suited jobs. And 16-year old autistic climate activist Greta Thunberg created a stir in 2019 by eloquently chiding the UN for inaction on global warming.

As the Americans with Disabilities Act (ADA) celebrates its 30-year anniversary this month, neurodivergent activists are seeking control of the policy agenda for brain-based disabilities, (those around learning, attention, mood, social interaction, self-control, and other functions). They have a powerful constituency: Nearly half the population (46%) qualifies as neurodivergent, having either a mood, impulse-control, anxiety, or other disorder, according to a Harvard Medical School study. To be sure, many of those people don't think of themselves as part of a marginalized community — but a growing number do. Studies of autism put the prevalence between 1% and 2% of the population, about as large as the Muslim or Jewish population in the U.S., respectively. No matter how you count, there are tens of millions of neurodivergent people in this country, at varying stages of awareness of their identity, rights, and broader community.

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Activists are demanding that neurodivergent people be treated as decision-makers in the medical community, rather than just the subjects of “expert” decisions. They criticize prevailing disability therapies as designed to make people appear non-disabled, rather than supporting disabled people’s priorities. They’re clamoring for greater representation within government bodies that oversee research, funding, and policy. They’re advocating for policy change and seeking leadership roles in government, academia, and business. In Pennsylvania, community organizer Jessica Benham recently won the Democratic nomination for House District 36, in her bid to become the first openly autistic woman elected to the state legislature, on a platform of infrastructure and accountability to voters, especially the most marginalized. “Autistic people can be leaders,” Benham told me over coffee in the South Side Flats section of Pittsburgh late last year. “And I’m saying that not just with my words but with my actions.”

But activists are slamming into the massive, well-funded establishment of scientific researchers, policymakers, and health care providers who show no eagerness to release the reins of control. This growing conflict revolves around truly consequential issues, such as the distribution of tens of billions of dollars in research funding, support services, and charitable dollars — and which treatments should be deployed.

If you’ve never met an openly autistic person, most likely your strongest association with autism is the nonprofit [Autism Speaks](#), which was founded in 2005 by the late former NBC and GE Capital president and CEO Robert Wright and his late wife Suzanne Wright. Their grandchild is autistic, and the family had struggled to find support and information for meeting his needs.

For many autistic adults, Autism Speaks is the enemy, and represents the goal of eliminating autism rather than embracing autistic people as part of human diversity.

Since then, Autism Speaks has become a juggernaut in the autism community, pulling in \$60 million in annual revenue. (Compare that to ASAN's annual budget of \$1.1 million.) Every April, the nonprofit lights up landmarks around the country, such as New York City's Empire State Building and the CN Tower, as part of an awareness-building campaign. Its blue puzzle-piece logo is arguably the most visible symbol of autism since Dustin Hoffman's 1998 portrayal of Raymond Babbitt in *Rain Man*.

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The organization was founded with a stated goal to find a cure for autism, much in the way nonprofits seek a cure for breast cancer or lymphoma. But for many autistic people, autism forms part of their identity; it's not a disease to be cured. This split between autistic adults and Autism Speaks came to a head in 2009 over an Autism Speaks video called "I Am Autism." Featuring horror-movie cinematography and narration, the video depicts autism coming to steal parents' children, destroy marriages, bankrupt families, and destroy their sleep.

Even though Autism Speaks removed the word "cure" from its public goals in 2016, autistic activists still criticize the organization for focusing primarily on scientific research into the causes of autism with a focus on prevention, and for supporting interventions that seek to make neurodivergent people seem neurotypical.

"They're still promoting therapies that autistic people describe as really traumatic and unhelpful," said ASAN executive director Julia Bascom, such as insisting on eye contact or suppressing rocking, stimming, and other self-regulating activities. Bascom says that Autism Speaks and other advocacy groups led by parents of neurodivergent children lack the authenticity of a group led by autistic individuals,

who can draw on their lived experience. “Advocacy about disability isn’t complete or legitimate if it’s done without us. It doesn’t have to just be us, but we have to be there and we have to have a real role,” she said.

Autism Speaks responds that self-advocates are included as part of the organization and its outreach. “We want the most diverse autism community possible,” said Stuart Spielman, senior vice president for advocacy. “We want to hear from a mom who has a newly diagnosed child. We want to hear from the recent college grad who’s on the spectrum, who’s excited about his first job. We want to hear and include the speech therapist who has worked with children and adults with autism.”



Jessica Benham recently won the Democratic nomination for Pennsylvania House District 36. If she wins in the November general election, she’d be the first openly autistic woman elected to the state legislature.

A similar schism is emerging across mental disability communities: scientists and psychiatric providers who focus on research, treatment, and control on one side; neurodivergent activists, many of whom have experienced involuntary commitment and coercive treatments on another. The former view conditions such as depression, schizophrenia, and bipolar disorder as medical problems to be solved,

with the latter often claiming “madness” as part of their identity while still seeking relief and support in managing the negative aspects. (Opinions vary, of course; many people don’t view their mental disability as part of their identity.)

Margaret Price, PhD, an Ohio State University professor who experiences post-traumatic stress disorder and wrote the book *Mad at School*, about mental disability in higher education, put it this way: “Many things that make PTSD painful and difficult have to do with the way I’m not accommodated at my workplace or out in the world... I don’t like having panic attacks, [but] it’s part of my history and part of who I am as a person. Disability is what made my life what it is today.”

Price pushes back on the notion that disabilities or neurodivergence are inherently negative. “Disability culture is so full of joy. We dance together; we support each other; we share pictures; we make families together,” she told me. “These are things we wouldn’t have if we didn’t identify as disabled. It would be odd to think about removing any part of your life that causes you to have a community.”

A movement that originated in Canada and the U.K., Mad Pride reclaims the words “mad” and “crazy” in a similar way that the LGBTQ+ movement reclaimed the term “queer,” which was once exclusively used as a slur. The self-advocates are articulating a social model of disability, in contrast to a medical model. So much of their suffering, they say, stems from the way neurotypical society fails to accommodate a variety of needs, often broken into sensory, movement, executive function, language, and social interaction. Many societal norms are based on assumptions around these domains: the expectation that everyone can network in a loud, fluorescent lit-ballroom at the beginning of a conference, or can comfortably make eye contact during conversation, or can keep their body completely still.

Mad Pride and activists like Price are calling for a radical realignment of norms, both interpersonal and structural. “A lot of things we take for granted now started as accommodations: plastic straws, zippers, light switches,” said Bascom, who needs to move her body or use a fidget toy to self-regulate during meetings. “At a lot of meetings that I go to now, the policy folks have gotten used to the way I move. Someone will bring her knitting because it helps her focus. She figures if Julia can do it, she can do it too.”

The same day I spoke with ASAN’s Bascom, she had met with a children’s hospital to discuss how to make blood draws less traumatic for autistic children. Working

together, ASAN and the hospital developed a set of pictures that laid out the procedure for autistic and non-speaking children in a calming, readily understood manner. Once nurses and technicians receive training on the method, neurotypical children will benefit from a more reassuring process as well.

Two weeks before the ASAN gala, I traveled to Pittsburgh, where I witnessed a vivid example of the split between neurodivergent advocates and researchers at the [ASSETS conference](#), a gathering of academics, technologists, scientists, and policymakers to share research on technology and disability.

Over the course of two hours, researchers gave presentations on how to use technology to influence disabled children's behavior, train schizophrenic individuals in common social situations, and teach social skills to intellectually disabled young adults. In one video, adults moved the limbs of autistic children when they failed to respond to cues.

I watched as neurodivergent conference attendees' shoulders tightened with each new paper presenting a technology aimed at getting them to conform and comply. "This research dehumanizes me and my children," tweeted one attendee.

At the very back of the ballroom, Lydia X.Z. Brown, policy counsel at the Center for Democracy & Technology and a blogger known as Autistic Hoya, took a handheld microphone. "We've just heard a series of presentations that all sound to me like... we are treating disabled people's existence as needing to be therapized, to be individually fixed or remediated," said Brown, an Asian American with short hair and a crisp blue pantsuit, standing with their torso angled forward, as is their habit.

Activists argue that rather than disabled people trying to conform and pass unnoticed among the general population, the world needs to change to accept, appreciate, and accommodate the needs of millions of Americans.

“I’m developmentally disabled and I’m psych disabled... That’s not something that needs to be approached with the intent of trying to fix me... I’d like to ask, how are you engaging with people who have these disabilities? What are our priorities in not being medicalized and therapized?”

A Boston native with an Italian mother (the combination of which they credit with their tendency for fast talking), Brown shares their opinions freely, on everything from the best Ethiopian restaurants in the country to the danger of blaming gun violence on mental illness. From our previous conversations, even before they took the mic, I could tell they were feeling something between annoyance and rage—and so were some of the other attendees in the room. A flurry of thank-yous to Brown appeared on Twitter, from a small but vocal group of conference attendees.

The speaker responded briefly to Brown’s complaint by saying designers should reflect on the concern, and the moderator moved on to the next presenter.

A century ago, neurodivergent people weren’t clamoring for policy control or pushing accommodations boundaries. That’s because they were either undiagnosed and hidden, or locked up in state hospitals, clinics, and other

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By the 1940s and ’50s, parents of intellectually and developmentally disabled (I/DD) children started challenging doctors’ recommendations. Instead of housing their children in institutions, they devoted hours of one-on-one care to teach them basic life skills, reading, writing, and the other tools they’d need to thrive in the world. Children who previously would have suffered through isolation, abuse, and traumatic practices such as lobotomy and forced sterilization thrived, and some even grew up to become nationally known scholars and activists.

With more parents of disabled children refusing institutionalization and seeking education, organizations emerged like The Arc, a disability rights organization that lobbied for services supporting people with I/DD and exposed the horrific conditions and abuses in mental institutions. The 1960s and 1970s saw deinstitutionalization and the growth of disability income supports and required

public education for disabled children. In 1990, after rallies and protests including a mass crawl up the U.S. Capitol steps by physically disabled demonstrators, President George H.W. Bush signed into law the Americans with Disabilities Act, forming the basis for a whole body of legislation giving disabled people a right to equal access to housing, education, employment, and public spaces.

As more neurodivergent people earned college degrees and gained power to speak for themselves, they formed self-advocacy organizations, notably Autism Network International in 1992, the Autistic Self Advocacy Network in 2006, and the Autistic Women and Nonbinary Network in 2009.

Despite the three decades of ADA-supported laws and rules, the pace of progress for neurodivergent individuals has been slow. Employment for disabled people lags at less than one-third the level of non-disabled people, and punishment-oriented institutions continue to house people with brain-based disabilities. In March, the Food and Drug Administration (FDA) banned electric shock devices that the Rotenberg Center in Canton, Mass. was still using to manage disabled residents' behavior, despite exposés and protests. People in prison are three times more likely to have disabilities than the general public, with cognitive disabilities being among the most common conditions.



Margaret Price, PhD, an Ohio State University professor who experiences post-traumatic stress disorder and wrote the book *Mad at School*, about mental disability in higher education.

Activists argue that rather than disabled people trying to conform and pass unnoticed among the general population, the world needs to change to accept, appreciate, and accommodate the needs of millions of Americans. They condemn the widespread use of coercive “therapy” to force children to appear neurotypical, such as making eye contact and controlling their natural body movements.

Take applied behavioral analysis, the most long-standing therapy for autistic children, and the one most likely to be reimbursed under health insurance plans. ABA therapists create an individualized plan for each person, aimed at rewarding desired behaviors and discouraging unwanted behaviors. Depending on the situation, the goal of a plan could be to increase eye contact, keeping quiet hands on the table, or refraining from flapping their hands to self-stimulate, known as stimming. Young children might have up to 40 hours a week of ABA therapy. Many autistic adults describe their experience with ABA as traumatic, and say stimming can be a useful strategy to relieve anxiety, manage stress, increase focus, or orient oneself in the world.

“A lot of the interventions and ‘cures’ that are considered evidence-based or best practices were not designed with disabled people in mind. Therefore they’re designed to make us appear non-disabled,” said Morénike Giwa Onaiwu, an autistic college professor in Houston, Texas, and the mother of five children from elementary to high school age, two of whom are also autistic. Like Price, Onaiwu values some of her traits and qualities associated with autism, and seeks interventions to mediate other aspects of disability. “I would be glad to have a greater grasp on executive function and ways to mitigate anxiety. I would like to keep my ability to persevere and out-of-the-box thinking. We want supports, but we want supports that we choose.”

As a Black woman, Giwa Onaiwu said, she’s surprised to see mainstream society tout multiculturalism, racial diversity, and queer acceptance while still blatantly discriminating against brain-based differences, notably nonspeaking autism and schizophrenia.

“Nobody would dare say I should bleach my skin or straighten my hair or have a name that’s more Eurocentric,” she said. And yet, most early childhood autism intervention programs focus on multiple hours a day of controlling practices aimed at forcing neurodivergent children to conform to neurotypical standards.

“People don’t see disability as an identity; it’s a condition to be cured. No, we do not want a cure for a part of our neurology that’s a part of who we are, just like there’s no cure for Blackness.”

Debates about who sets priorities for neurodivergent individuals can have very real — and very expensive — implications. The Interagency Autism Coordinating Committee coordinates autism efforts across the country, reviews research and advises the U.S. Health and Human Services Department on policy, and oversees nearly \$300 million the federal government spends on autism research each year, representing over 80% of the total funding. Autistic activists have fought for representation on the body, winning two seats out of 30 in 2015. But conflict continues over the question of who represents the needs and voices of nonspeaking autistic people with high support needs. The group — often called low-functioning, a term many autistic people consider offensive — comprises as much as half of the autistic population.

Parents and care providers argue that they’re best positioned to understand the challenges, because these autistic adults can’t verbally communicate, have multiple medical needs, and often exhibit self-injurious behavior.

Activists respond that clinicians lack any way to distinguish between autistic children who will remain nonspeaking and those who merely have a delay in speech, or between those whose intellectual disabilities will impair their cognition for life and those who will master assistive and adaptive technologies to communicate, attend school, and work. Those autistic adults who fall in the latter group understand the needs of both groups best, they say.

Under the surface of the discussion lie thorny questions: Who tells the story of autism? How does that story set priorities, and determine the flow of funding? Who should have decision-making power? Can I/DD adults make their own decisions about housing, romantic relationships, money, employment, and the like? Does the majority culture have to adapt to include disabled people? What does self-advocacy look like? And even, what does it mean to be human?

There seems to be a notable drive to control mentally disabled people to a greater degree than there is with physically disabled people. Something about brain-based disabilities seems to be perceived as so threatening and dangerous, that it prompts people to make decisions on behalf of neurodivergent people. When we see someone on the street muttering to themselves, it can seem scary. Many parents of autistic teens and young adults say they need control to keep their child from self-injuring, running away, or even harming others.

During a break in the ASSETS conference in October 2019, I met up with Cori Frazer, executive director of the Pittsburgh Center for Autistic Advocacy, at their office in a co-working suite. Frazer pointed out that statistically, disabled children and adults are more likely to be victims than to commit violence. “When we teach compliance, we teach people how to be better victims,” they said. “We want our young people to be able to speak up and say, ‘You know, no, this isn’t okay. I have rules and boundaries.’”

Brown worries about the habit in the media and politics of linking episodes of gun violence to mental illness. We shouldn’t demonize mentally ill people, they argue. “When I was in high school, I was falsely accused of planning a school shooting,” Brown said, explaining that they’d been talking to a classmate about a novel-in-progress that dealt with violent themes. “Somebody else overheard part of our conversation decided to report it as a threat. And I was brought into the principal’s office and confronted about whether I was planning a shooting and why I was supposedly so obsessed with weapons and violence. And I was very lucky because I did not end up being criminally charged out of that.”

In spring 2015, I drove to Williamsburg, Virginia to speak with John Elder Robison, neurodiversity scholar-in-residence at the College of William & Mary. An engineer, entrepreneur, and author of *Look Me in the Eye*, a memoir of growing up with undiagnosed autism, Robison is a tall, white man with glasses and a fondness for check-patterned dress shirts. As we ate lunch under the hand-stamped tin ceiling of the Blue Talon Inn, we discussed the underdiagnosis of autistic girls and the relative lack of stigma around ADHD when his cell phone rang.

“Hello,” he said, bending his graying head toward his shoulder to hear better over the restaurant chatter. “Yep. What’s up?”

In his memoir, Robison writes that he repeatedly found himself in trouble at school. Eventually, he dropped out to teach himself electrical engineering, going on to design guitars for the rock band KISS and electronic games for Milton Bradley. Finally, at 40, a therapist suggested he might be autistic, a discovery that catapulted him into autism advocacy and advising on research and policy.

After a lengthy silence, Robison responded to the person on the other end of the phone. “Tell them I’ll come meet them.... I’ll head for Blow Hall right now. Yup. Bye bye.”

“Autism emergency?” I asked, as he put down the phone.

“I guess so,” he replied.

We paid the bill quickly and set off on a speed walk across the brick-and-grass quads that make up William & Mary’s campus. At Blow Memorial Hall, Robison found a couple whose 23-year old autistic son was living at home and attending Christopher Newport University, but might benefit from the neurodiversity community at William & Mary. Over the course of the next 35 minutes, Robison explained how William & Mary was leading the way in neurodiversity and community building. He encouraged the family to consider a transfer or graduate program so their son could connect with the student group. “He would see that there was a community that was his own kind, that was welcoming,” Robison said. “That’s very different and it’s a much stronger proposition than having someone to talk to at the counseling center.”

The previous day, I’d accompanied him as he’d worked tirelessly, hand-carrying the gospel of neurodiversity through the campus and community, converting people in one’s and two’s at a time. First, we attended a meeting of the neurodiversity working group, a combination of administrators and faculty, with one student representative, the aptly named Haley Outlaw, a sophomore with shoulder-length brown hair and librarian glasses. Robison spoke at two different classes and presented over lunch with the counseling office, to raise awareness of neurodivergent students’ needs.

Robison also brought me to the neurodiversity student group, where I met Outlaw’s co-leader, Joel Carver, also a sophomore. The student conversation sounded like a

typical college discussion: grouching about early-morning classes, gently teasing each other about personal foibles, brainstorming upcoming events. The group thought it would be fun to have an ice cream anti-social, where people could attend, eat ice cream, and be awkward, maybe even have a bouncy castle. Free pizza at every class where Robison presents, to draw a crowd. They explained to me that they've adopted War Pug as their symbol.

On the topic of neurodiversity, their passion rose. "Worth shouldn't be determined by conformity," Carver said. They shuddered over the story of an autistic child killed by a parent. "Nobody cares about the dead kid," one student said. "It's all about the put-upon parents." They grew particularly heated talking about advocacy groups espousing a cure approach. "They're like racist grandparents on the porch," Carver said. "They believe autism should be cured, [that] we should be removed from the gene pool."

The conversations and activism happening in this college common room are being mirrored around the country and world, as the first generation of self-identified neurodivergent college students come of age. Unlike Robison, who received his autism diagnosis as an adult, these young people learn about their neurodivergence in their late teens, early 20s, or even earlier, when their identity is still forming. As a result, they're pushing the boundaries of what defines a student or a scholar, and expanding the picture of who deserves to be at college.

Take DJ Savarese, a nonspeaking autistic man who communicates through a tablet or computer. His parents initially taught him to communicate with a speaking partner holding the tablet and stabilizing his arm, then helped him communicate more independently over time, as depicted in Deej, a documentary about his transition to Oberlin College, where he graduated Phi Beta Kappa in 2017.

And in the years since I first met Outlaw at the beginning of her advocacy work, she graduated from William & Mary in 2017. Now, she works for the Autistic Self Advocacy Network, training neurodivergent college students from across the continent in a one-week summer session, and supporting them from afar as they return to their campuses. She herself attended the training in 2015, "one of the best weeks of my life," she said, when I caught up with her on a recent afternoon. She described the groundbreaking feeling of creating new programs, resources, or events to support disabled people, that didn't exist before.

“People in my generation grew up with rights that previous generations of disabled people didn’t have. It’s because of the work of previous generations of disabled people that I grew up with those rights,” she said. “I want to work hard to make things better for the next generations, the ones after me. So that every generation grows up with more rights and less barriers.”

There’s certainly been progress, Outlaw said, but she regularly hears about professors refusing accommodations to disabled students and about systemic ableism and oppression on college campuses. So she wants to arm neurodivergent students with knowledge of their rights and tools to fight to claim them. She’d like colleges and universities to abolish attendance policies, which she considers ableist, and stop requiring documentation of a diagnosis for accommodations, since a diagnosis is more available to wealthy, white students with educated parents.

“It really means recognizing that discrimination is systemic. It’s not one student who is not getting an accommodation because her professor doesn’t respect accommodations. It’s not one student who leaves because the school forces them out because of mental illness,” she said. “Hundreds if not thousands of students are all experiencing that.”

Editor’s note: Most people interviewed for this story prefer identity-first language. We are honoring their preferences here.

Update: This story has been updated to reflect that Jessica Benham is the first openly autistic woman elected to the Pennsylvania state legislature, not the first openly autistic woman elected to state legislature.

Autism

Neurodiversity

Advocacy

Activism

