

HEALTH & SCIENCE

A medical condition or just a difference? The question roils autism community.

By Alisa Opar

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This year, London's Southwark Playhouse announced the cast of a new play, "All in a Row." It was instantly clear this would not be a typical family drama. The play unfolds the night before social services separates a boy named Laurence from his family. Unlike the other three characters, Laurence, a nonverbal autistic and sometimes aggressive 11-year-old, would be portrayed by a child-size puppet.

When the play opened, a reviewer for the Guardian newspaper awarded it four stars, saying it had "warmth and truth." On Twitter and beyond, theatergoers also offered praise.

"It was utterly believable. Raw. Honest," Sarah Ziegel, mother of four autistic boys and author of "[A Parent's Guide to Coping With Autism](#)," wrote on her blog. The puppet was an effective stand-in for a role that would have been too challenging for any child actor, Ziegel wrote.

Elsewhere, however, people were outraged.

Before opening night, more than 12,000 people signed a petition calling for the theater to cancel the show. They argued that using a puppet to portray Laurence "dehumanizes autistic children" and promotes the harmful "common misconceptions that we lack feelings and empathy." They also slammed the play for focusing on the parents' experience over Laurence's perspective. These critics adopted the hashtag "#puppetgate" to spread the word on Twitter; many included another hashtag, #ActuallyAutistic, widely used by people on the spectrum. For several weeks, barbed tweets flew back and forth.

The backlash took playwright Alex Oates by surprise. He wrote the script based on his years of experience as a care worker for a severely autistic child. He sought input from people on the spectrum and the parents of the child who had inspired the story. As for the puppet, it seemed more sensitive to him to use a "creative medium" than to ask an actor to mimic the condition. "I am genuinely sorry for the hurt that anyone felt," he told Spectrum. "I'm particularly sorry if this play added to a divide between autistic people and neurotypical people with severely autistic children."

The controversy over Oates's play is just one example of a deep divide in the autism community: On one side are parents of autistic children with severe traits — including intellectual disability, limited language ability and self-harm — who say autism is a medical condition that needs often-intense treatment.

On the other side are supporters of “neurodiversity,” who maintain that the condition represents a neurological difference and a disability — one that society should accept and accommodate rather than try to prevent or cure.

“While I would gladly cure my anxiety, I don't want to cure my autism because I believe it's an important part of who I am and something worth celebrating,” says Lilo, an autistic college student who uses gender-neutral pronouns and asked to be identified by this name for safety reasons.

This fight between the two camps has at times gotten ugly, with the former camp calling neurodiversity advocates privileged and naive, and the latter saying the parents are “ableist” and failing their autistic children. Over the past two decades, as the autism spectrum has broadened to include those with milder traits, this fight has flared into an all-out war that plays out online and in person.

Both sides make good points, say many experts who are frustrated by the situation, but the animosity does only harm.

“I see many positives in the neurodiversity movement, including fighting for what parents of autistic children want: to get society's acceptance of them and to get accommodations for them,” says Manuel Casanova, professor of biomedical sciences at the University of South Carolina. But the loudest voices in the neurodiversity camp are causing an “upheaval” by insisting on a strict interpretation of autism and what autistic people need, he says. If these opinions ultimately sway public opinion, “It might end up hurting research, and hurting the delivery of services to those people who most need them.”

'These attitudes harm us'

Many people trace the beginning of the neurodiversity movement to an open letter read at the 1993 International Conference on Autism by Jim Sinclair, who was diagnosed with autism as a child. “It is not possible to separate the person from the autism,” he said, addressing the desire by many parents for a cure and the impact it can have on their child. “Therefore, when parents say, ‘I wish my child did not have autism,’ what they're really saying is, ‘I wish the autistic child I have did not exist, and I had a different (non-autistic) child instead.’”

At the time, there were escalating calls for an autism cure, as the prevalence of autism in the United States had jumped more than tenfold from the 1980s to the 1990s. This rapid increase was in part because of expanding definitions of the condition. But the media nevertheless portrayed autism as an epidemic, and scores of parents took up advocacy work for their autistic children.

Then those children grew up — and they didn't necessarily agree with their parents' views of autism, says Ari Ne'eman, who co-founded the nonprofit Autistic Self Advocacy Network in 2006. "When the organization was formed, there was an unprecedented amount of public discussion about autism but no representation of autistic people in that conversation," he says.

These autistic adults amplified the neurodiversity movement, and won greater recognition of the differences between autistic and neurotypical people: Many companies, for example, are now dedicated to hiring autistic employees.

But some parents say that as autistic self-advocates have become more vocal, their perspective is drowning out the voices of autistic people who cannot speak for themselves. In January, some of these parents banded together to form the National Council on Severe Autism, the first advocacy organization to focus exclusively on the needs of autistic people who require high levels of support.

"There's a wide abyss between someone who is very mildly impaired and someone who is really severely impaired with intellectual disability and all the different kinds of comorbid conditions that tend to cluster at that end of the spectrum," says Amy Lutz, a founding member of the organization and mother of Jonah, 20, who has severe autism and is prone to aggression and self-harm. "There's no one speaking directly for these families and about this severe end of the spectrum."

Many self-advocates have responded with anger to the organization's creation. "NCSA lifts up and advances depictions of autism, which paint autistic people as burdens, as toxic and as catastrophes," says Julia Bascom, executive director of the Autistic Self Advocacy Network. "These attitudes harm us, increase stigma and misunderstanding, and make life harder for everyone, including our families."

Family members can be important allies, Bascom wrote in an email to Spectrum, but "it's about advocating with, as opposed to advocating for."

'Autism is a living hell'

The controversy over the NCSA gets at a central point of contention in the autism wars: Is autism a difference, diagnosis, disorder, disease or disability? These are the "D-words" that really matter in the autism community, says Simon Baron-Cohen, professor of developmental psychopathology at the University of Cambridge.

Those in the neurodiversity camp see autism primarily as the first D-word: difference. Viewing autism as a disease is harmful, Ne'eman says. "In lots of cases, the way that you make an autistic person successful and happy and as independent as possible for them to be, is by leaning into the autism, not trying to correct it," he says. Those who describe autism as a disease, he and others say, are reflecting back society's intolerance of difference.

Supporters of the NCSA and others argue that the “difference” from neurotypicals looks vastly different across the spectrum and cannot be so easily recapitulated. For some autistic people, repetitive behaviors may serve to calm them or offer a means to express great discomfort, or even great joy — and need only acceptance, not treatment. But that’s not always the case, Casanova says. “It’s not a blessing to have headbanging, eye-gouging or self-biting,” he says. “Those people need to be treated.”

Thomas Clements, 30, a mildly autistic man whose brother is severely autistic, says he is dismayed by what he sees as neurodiversity advocates casting autism as a benign neurological quirk.

“It denies the very medical nature of autism and the need for research into ways of alleviating the most distressing symptoms of the condition,” he says. Benjamin Alexander, a nonverbal autistic man who graduated in 2018 from Tulane University in New Orleans, goes even further: “Autism is a living hell,” he wrote in an email. “I don’t want to be accepted for the way I am; I want to be cured just like a cancer patient wants to be free of disease.”

Julie Greenan, who has five autistic children spanning the spectrum, sees three D-words — difference, disorder and disability — in her children: Her oldest is in college, two are in mainstream schools, one attends a school for autistic children and 17-year-old Sam is nonverbal, has intellectual disability and harms himself and others. She says she wouldn’t speak for her son in college, but that Sam is not intellectually capable of advocating for himself.

“For some people it is just a difference; it’s not a disability,” she says. “For others this is a complete, severe disability.”

She says she is frustrated by what she sees as the public’s acceptance of autistic people who need little support as the face of the condition. “Where is the publicity of my child who’s suffering every day?” she says.

Subgroups on the spectrum

Which word someone uses to define autism is more than an intellectual exercise. It affects how the public views people on the spectrum and their quality of life, as well as access to job placement programs, housing and health care.

Parents in the “disorder” camp wonder who will look after their adult children after they die, and what happens if they are left out of those decisions. If you asked Sam where he wants to live, “He would go into the bathtub,” Greenan says. “We can’t let him make that decision himself.”

But many neurodiversity advocates also fear the consequences if autistic people lose input. They point to the dark history of abuse at institutions.

Ivanova Smith, who is autistic, uses gender-neutral pronouns and has intellectual disability, spent the first five years of life in an institutional orphanage in the former Soviet Union.

Today, Smith lives with their husband and daughter and works as a disability-rights activist. “I’ve seen so many in the autism community left behind,” Smith says, with regard to choice over where they live and what care they receive. “We don’t want anybody to be left out — all means all.”

The battle over services spills into arguments about research funding. Bascom and others say they worry that a focus on genetics research could lead to eugenics, in the form of selective abortions or even genetic engineering to “correct” mutations that lead to autism.

Those fears are not unfounded, says Baron-Cohen, but defining biological subtypes of autism — and their corresponding needs for support and accommodation — could help ease the conflicts between parents and self-advocates. Ideally, “We’ll be able to target different kinds of interventions or support to different subgroups on the spectrum.”

Any kind of truce in the autism wars will probably require both sides to take a perspective that encompasses all of the spectrum — where the fight is for the happiness and well-being of all autistic people rather than over who is right.

Oates, the playwright, isn’t sure if he will ever stage “All in a Row” again. But he has another suggestion: “My aim and great wish was to help these parents and therefore their children,” he says about the play. “If there was a way for those autistic voices to turn their outrage into advice for the parents, I’d love that.”

Alisa Opar is a California-based science writer and the articles editor at Audubon magazine. This story first appeared in longer form on [Spectrum](#), a news site focused on autism research.