

DEEP DIVE

In search of truce in the autism wars

BY ALISA OPAR

24 APRIL 2019



Illustration by Matt Chinworth

Earlier 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, theater-goers 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. She applauded the playwright, **Alex Oates**, for addressing **severe autism**: “It is not pretty and it is certainly not fashionable in these days of neurodiversity where everyone is supposed to accept autism as a difference and not a disability.”

Elsewhere, however, people were outraged. Even 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. One side dismissed #puppetgate, insisting that autistic people face more **pressing concerns**, such as a **shortage of programs and services** for adults and **potentially deadly encounters** with law enforcement; the other said that view perpetuates the false notion of autism as a tragedy that **destroys families**.

The backlash took Oates by surprise. He had written the script based on his years of experience as a care worker for a severely autistic child. He had also sought input from people on the spectrum, and the parents of the child who had inspired the story. In his view, supporting parents and encouraging conversation is the best way to support severely autistic children. As for the puppet, it had 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.”

Oates’ play, for all the controversy it generated, is just one example of this deep divide in the autism community: Battles like this one rage on every day on Twitter and other social media. 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 treatment. Julie Greenan, who lives in New York and has five autistic children spanning the spectrum, says she is frustrated by what she sees as the public’s embrace 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. “I just really think that there’s a population of people that are not being represented by the neurodiversity movement.”

On the other side are the supporters of ‘neurodiversity,’ who maintain that the condition represents neurological difference — 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 naïve, and the latter saying the parents are ‘able-ist’ and are failing their autistic children. Over the past two decades, as the spectrum has broadened to include those with milder traits, this fight has flared into an all-out war that plays out on social media, on the internet and at community meetings.

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

“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.

“They see the world in black and white, and either you are with them or against them,” Casanova says. And 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.”

Neurodiversity rising:

Many people trace the beginning of the neurodiversity movement to a presentation at the 1993 International Conference on Autism by Jim Sinclair, who had been diagnosed with autism as a child. Sinclair read an **open letter** to parents, addressing the impact their desire for a cure can have on their children. “Autism is a way of being,” he said. “It is not possible to separate the person from the autism. 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 number of new cases seemed to

be rising exponentially. The **prevalence** of autism in the United States had **jumped more than 10-fold** from the 1980s to the 1990s. This rapid increase was in part due to expanding definitions of the condition, but the media nevertheless declared autism an epidemic. While that notion prevailed, 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.

Some of these autistic adults amplified the neurodiversity movement, calling for greater recognition of the differences between autistic and neurotypical people. Over the past decade, books such as Steve Silberman's "**NeuroTribes**" and TV shows such as "**The Good Doctor**" have helped raise awareness of those differences. Autistic people have also become more open about their diagnosis, Ne'eman says: "When I first got started, it was a very radical, revolutionary thing to be openly autistic." But over the past year, for example, autistic Swedish teenager Greta Thunberg has inspired students all over the world to fight against government inaction on climate change. "Asperger is not a disease, it's a gift," Thunberg **wrote on Facebook** in February.

Autistic self-advocates have also made strides toward changing U.S. policy on autism. They testify before state legislatures and Congress, for instance, and sit on the **National Council on Disability** and the **Interagency Autism Coordinating Committee**. And from 2009 to 2012, they lobbied scientists who were drafting the most recent diagnostic criteria for autism to remove a 'severity scale' from the criteria — which they say wrongly focuses on the severity of **repetitive movements** and restricted interests. They did not succeed but say they were influential in reframing the scale to focus on the level of support an autistic person may need.

"While I would gladly cure my anxiety, I don't want to cure my autism." Lilo

Many autistic self-advocates interviewed for this story noted that how well they function varies day to day, whereas the support they need remains constant. As a result of the change to the criteria, an autistic person in the 'low severity' category no longer risks losing services.

"We instated language that the scale is not to be used for eligibility for, or provision of, services," **Steven Kapp**, an autistic research fellow in autism and neurodiversity at the University of Exeter in the United Kingdom, wrote via direct messaging.

As a result of the efforts of neurodiversity advocates, autistic behaviors are gaining wider acceptance, and people recognize that autistic individuals also have unique strengths: Many

companies are now **dedicated to hiring autistic employees.**

Still, even small changes can sometimes draw fire.

After scientific presentations at last year's meeting of the **International Society for Autism Research** (INSAR), for example, attendees were asked to respond to presentations not with applause but with 'flappause' — by silently moving their hands in the air. The gesture resembles the hand-flapping some autistic people find calming and is gentler than loud clapping for anyone with **sensory sensitivities.**

The request caused **consternation among some scientists**, who make up the bulk of the meeting's attendees. They noted that the volume of applause helps them evaluate their peers' response to a scientific presentation. This year, the conference organizers plan to ask audience members to respond in whichever way they prefer.

As self-advocates have become more vocal, some parent advocates say that the neurodiversity perspective is too dominant and 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. **An estimated 30 percent** of autistic people fit this description.

"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. "There's no one speaking directly for these families and about this severe end of the spectrum."

The group's Facebook page features stories about **residential facilities**, the **harm** people with severe autism sometimes inflict on themselves or their family members, **laws related to autism** and more. As of 18 April, the group had more than 4,500 followers. "It's time to improve awareness and acceptance across the entire autism spectrum," Rita Whitney, mother of a son with severe autism, **commented on the page** in March. "It's good for my soul to read that other parents share our journey! So glad I found NCSA."

Many self-advocates, however, **responded with anger** to the organization's creation, declaring it unnecessary and even harmful. "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*."

D is for ... :

The controversy over the NCSA gets at a central point of contention in the autism wars: Is autism a difference, a diagnosis, a disorder, a disease or a disability? These are the ‘D-words’ that really matter in the autism community, according to academics such as healthcare ethicist **Kenneth A. Richman** and researcher **Simon Baron-Cohen**.

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, for example, 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 head-banging, eye-gouging or self-biting; those have serious side effects, including retinal detachment, cauliflower ears, they can get brain trauma, contusions,” he says. “Those people need to be treated.”

Thomas Clements, 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 from Tulane University in New Orleans, Louisiana, in 2018, 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.”

Greenan sees three D-words — difference, disorder and disability — in her five autistic 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. The Greenans moved Sam to a residential facility in 2016 after he was kicked out of a school for special-needs children for harming others, and they no longer felt they could safely keep him at home. “For some people it is just a difference; it’s not a disability,” she says. “For others this is a complete, severe disability.”

Battling over services:

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**. It also influences access to services, including **job placement programs, housing** and **healthcare**. 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.” Sam has lived in a group home since he was 14, and Greenan expects that he’ll move to another residential facility when he reaches adulthood. “I’m not really sure how that’s going to work,” Greenan says.

In the U.S., federal rules set aside funding only for homes with no more than a few autistic people and which are not isolated from the community. The NCSA supports **federal funds to build gated communities** that house more than six autistic adults. “As far as I’m concerned, if my mom can live in a gated retirement community, there’s no reason why Jonah can’t live with his peers in some gated community,” Lutz says. Jonah sometimes ‘elopes,’ or wanders off, so Lutz’s house has code locks on every door. He has still managed to get out a couple of times, and in each instance Lutz found him walking in the middle of a busy road, focused on his iPad, with traffic stalled in both directions. Living in a gated community with trained staff would provide a rich environment with plenty of activities and support for Jonah and others like him, Lutz says. “It would just mean they can move safely in this community without having to worry about elopement.”

Many neurodiversity advocates oppose gated communities, pointing 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 their life in an institutional orphanage in the former Soviet Union. Smith learned to speak while living with the Washington family that adopted them, and received services in public school. 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 autistic people live, how they spend their time and what care they receive “We don’t want anybody to be left out — all means all. But they’re pushing policies that would limit the rights of autistic people.”

The battle over services spills into arguments about research funding. The bulk of research funding in the U.S., U.K. and elsewhere goes to studies of biological mechanisms and genetics. In 2016, for example, 59 percent of the funds in the U.S. went toward **understanding the biology** or causes of autism or preventing certain aspects of it. By contrast, studies into co-occurring conditions, services and support garnered 23 percent — and yet this is the more pressing need for

people on the spectrum, neurodiversity advocates say.

“There’s a wide abyss between someone who is mildly impaired and someone who is severely impaired.” Amy Lutz

Bascom and others say they worry the focus on genetics 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. He points to Hitler’s eugenics campaign and to compulsory sterilization programs for disabled people in the U.S. up until the 1970s. “There’s no way that we can ever say that a future political leader or a scientist won’t use the research for eugenics,” Baron-Cohen says. “I think responsible scientists can speak out against that and say, ‘These are the positive reasons for doing [genetics research].’”

Studying autism’s biology might help explain how autistic people differ from one another, Baron-Cohen says. There might be subtle differences between, say, children who go on to develop epilepsy and those who do not, or those who are slow to develop language but then catch up versus those who stay nonverbal. Defining these subtypes of autism — and their corresponding needs for support and accommodation — could help ease the conflicts between parents and self-advocates, he says. Ideally, “we’ll be able to target different kinds of interventions or support to different subgroups on the spectrum.”

Baron-Cohen says he would like to see a survey that assesses how pervasive the neurodiversity view is within the autism community. “We don’t know what proportion of the autism community is pro- or anti- neurodiversity,” he says. “When you see criticism on Twitter, for example, you don’t know if it’s just a small number of individuals generating all of the buzz about neurodiversity.” A survey might clarify which people take certain stances and why — an important step toward reconciliation.

Richman, the ethicist, sees other routes to reconciliation by way of larger conversations around the D-words — and by eliminating the expectation that autistic people should, for example, try to fit in by making eye contact and not stimming in public. “Having a diagnosis [of autism] doesn’t tell us all of the things that we need to know about an individual. Just because someone has a diagnosis or is different doesn’t mean action is necessary,” he says.

Any kind of truce is likely to 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."