

## IDEAS

# My son is profoundly autistic. Please don't say he's merely 'neurodiverse.'

Advocates are fighting to eliminate terminology that accurately describes my son and thousands of other people like him — who can't speak up for themselves.

**By Whitney Ellenby** Updated May 23, 2024, 3:00 a.m.



ADOBE PHOTO ILLUSTRATION

**I**t was pure coincidence that I happened upon the bloody site. Hoping to surprise my son, I drove to his favorite walking trail, along a lakefront, where I caught sight of police officers in a tense confrontation. Three officers stood side by side in an impenetrable wall while instructing someone splayed out and writhing on the ground. *I hope Zack doesn't get distracted by this scene, I thought.*

As I neared the trail, I saw Zack's aide, slouched inside her car, fully absorbed in texting. She was supposed to remain beside him at all times, but he was not with her. I called out to her, "Where's Zack?" as my throat tightened with the realization he was nowhere in sight. I began sprinting toward the police officers — only to discover with mounting horror that Zack *was* the scene they were dealing with.

He was ravaging his forearms with deep, mutilating bites, thrashing angrily on the ground, and then rising to charge at the officers, who patiently but sternly reminded him to "stay seated" and repeated "Don't panic, you're not in trouble." Breaking into the scene, I began a frantic avalanche of contrition. "I'm so sorry, I don't know what triggered this —" But I was abruptly cut off by an officer who stated calmly, "Yes, we understand who he is and that he's petrified."

Somewhere during his sojourn along the lake, Zack, who was 20 years old at the time, had abruptly sat down too close to a woman seated on a bench, who gingerly told him to put on a COVID mask — and Zack bit her on the shoulder for what he perceived as a reprimand. The woman immediately summoned the police, not in anger but in compassion, realizing this young man was seriously disabled and apparently unattended.

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“He’s not in trouble, the woman’s not pressing charges,” the officer assured me. “We’ve been trying to get him to recount a phone number of someone we could contact —” He halted, spying a robust purple bruise on my calf and deep bite marks encrusted with dried blood along my arms. His tone turned solemn. “I can only imagine what you’ve been through. I do understand.”

I stood in stunned silence. *I was not prepared for them to be prepared.* It had been 45 minutes since they first gathered around Zack with no identifying information, 45 minutes during which his very safety hinged not only on the instincts of a benevolent stranger whom he assaulted but on a shared understanding by all involved of his clinical identity — that Zack is profoundly autistic.



Zack in 2023. COURTESY OF WHITNEY ELLENBY

What's remarkable about Zack's behavior is how unremarkable it is. Autism has been on an inexplicable rise with no signs of a plateau. The Centers for Disease Control and Prevention estimates that 1 in every 36 children born today has autism, and 1 in every 4 of those will have "profound autism," a clinical distinction for those with much higher needs than the more verbally and intellectually able people who also have an autism

diagnosis. Individuals like Zack with profound autism have minimal or no expressive language and require round-the-clock care to assist with daily living activities and safeguard them from extreme behaviors such as self-injury, the destruction of property, and “elopement” — the term for running or wandering away from caregivers or secure locations.

But while parents like me struggle to manage our children's dangerous impulses, a powerful cultural movement has taken hold that forbids open discussion of profound autism and its manifestations. Advocates for “neurodiversity” are seeking to eliminate the term “profound autism” — on the grounds, they say, that it makes it seem as if autism is always an affliction. And now they are bullying doctors, researchers, lawmakers, and the rest of society into ignoring truths about Zack's disorder that define his life.

Sanitizing Zack's diagnosis and intense needs is dangerous. That day out on the lakefront trail, my son's safety turned on the officers' ability to decode from his conspicuous behaviors that he has profound autism in particular. They told me they realized that Zack's refusal to identify himself to them despite repeated requests stemmed from an inability to articulate salient information in a moment of acute stress. They employed a measured response to his rage by speaking in succinct, assertive phrases, repeating reassurances, and maintaining a physical distance. If they hadn't had [such precise training](#), which depends on recognizing precise clinical criteria rather than employing general descriptors such as "neurodiverse," the scenario could have gone very differently — with his arrest, forcible restraint, and even suffocation and death.

## The intimidation campaign

I embrace many of neurodiversity's fundamental tenets, especially the idea that people with intellectual disabilities

should be broadly accepted and included in society.

I've staked my career on this principle — I used to work in the US Department of Justice as a disability rights attorney. I witnessed firsthand the exclusion of people with physical and cognitive disabilities from the rituals of daily life most other people take for granted. And I believe parents and professionals must aspire to discern a child's authentic needs rather than superimpose our own preferences on them or force them into compliant molds of "normal." Our children do not need to be "typical" to thrive in a society designed for its vast majority, nor is that an attainable goal.

But the concept of neurodiversity is going into dangerous territory if diagnostic distinctions across the spectrum are now considered archaic and bigoted.

In 2021, the medical journal The Lancet published a report from [a commission of](#) worldwide medical experts who recognized the need for "profound autism" as a

discrete diagnostic category. The backlash was swift and mighty.

Autistic self-advocates launched a virulent campaign to quash the term, arguing that it had arisen, [in the words of self-advocate Julia Bascom](#), “because some parents . . . see their kids as needing different kinds of support and different levels of restriction. But they are wrong on all counts.” The Global Autistic Task Force on Autism Research, an advocacy group, [responded to The Lancet commission by saying](#): “For more than 30 years, autistic people have resisted functioning labels as misleading and offensive.”

As neurodiversity advocates denounce any framing of autism as a disability that requires medical intervention, they demand more support systems for people with autism, such as independent living “that honors authentic forms of human diversity.” Groups like the Autistic Self-Advocacy Network, people who identify on social media as

#ActuallyAutistic, and parent activists insist that there is no such thing as a “normal” brain, only relative differences that render all humans “differently abled.”

To them, frank discussions about profound autism give a distorted image of people like Zack as unpredictable, cognitively limited, and presenting more behavioral challenges than the general population. Except the image is not distorted. While it's painful to accept, these descriptors are accurate. Over the course of a single day, Zack, who is now 23, might furiously pummel his head in rage, slam his body into a wall, and bite me hard enough to draw blood.

The neurodiversity advocates — whose members are distinguished precisely by their ability to advocate for themselves, as Zack cannot — are not illuminating the complexity of autism; they are castigating into submission anyone who dares to deviate from their accepted language.

Intolerance for the term “profound autism” is leaching into medical journals and doctors’ practices. Doctors who’ve devoted their careers to treating children who compulsively ravage their flesh and slam their skulls into the ground are now verbally castrated on social media and “canceled” from lectures so regularly that preserving their livelihood requires stifling crucial medical data. It’s become common for autism self-advocates to “shout down” researchers imparting medical data at conferences or to call the researchers out on social media for online hazing and threats by neurodiverse mobs.

Today, both experienced and newer autism researchers contemplate leaving the field because, as one University of California scientist, David Amaral, observed, “People are getting reluctant to give public presentations or to be too vocal about what they’re finding,” despite the fact that “science is supposed to be about communication.” Top research institutions like the National Institutes of Health (NIH), tasked with conducting clinical trials to illuminate

the disorder, face vitriolic accusations of being “ableist” and uncomprehending of the very people they are trying to help.

After the The Lancet’s commission recognized “profound autism” in 2021, the journal [published an article](#) by a doctor who wrote: “Generally, physicians think that disability is medical, and that if a patient’s condition interferes with their daily life, they are disabled. This traditional, medical model of disability does not address societal factors that influence disability, nor does it recognize disability as a cultural identity. Viewing disability as an issue stemming from an impaired body can encourage physicians to view disabled patients’ quality of life negatively . . . and to offer treatments aiming to fix the patient.”

This is absurd. I know of no person with profound autism who proudly identifies self-mutilating or violent impulses

as core to their “cultural” identity. There is nothing bigoted about striving to ameliorate dangerous behaviors.

More critically, it is not the role of medical researchers to kowtow to trending cultural demands at the expense of addressing medically life-threatening conditions. Erasing diagnostic distinctions will make it impossible to perform research into the behaviors that are associated with profound autism — research that could lead to drugs that could benefit people across the entire autism spectrum. Although about 27 percent of all people with autism have profound autism, the condition is already underrepresented in clinical trials, which typically exclude those with an IQ lower than 70.

Two years ago, my son was abruptly ensnared in a cycle of self-injury, physical assaults, and chronic insomnia that within days catapulted him into a dangerously manic state — during which he risked seizures and seriously injuring anyone in proximity to him. Introducing anti-psychotic

medicine delivered the jolt of serotonin to Zack's brain that allowed him to reclaim his stability. Might other medicines become available that would work better? A movement that vilifies any medical mention of "risk," "limitations," or extreme behaviors has the power to thwart the development of such urgently needed drugs.

## I hope Congress hears parents like me

The Autism CARES Act, which allocates NIH-funded research and services, sunsets on Sept. 30. Fierce debates are already underway about what Congress should do when it reauthorizes this funding. On one side stand autistic self-advocates who rally against any research not explicitly approved by them. On the other are parents who are desperate for clinical advancements but are so engulfed in the daily ordeal of managing their profoundly autistic children's aggression and property destruction that they are largely incapable of organizing. The few dedicated parents calling for NIH to set aside funding to specifically address "profound autism" are vastly

outnumbered by neurodiverse advocates who seek to block the act from passing if such “stigmatizing” language is included.

The loudest voices seek to abolish *all* spending on autism medical research and replace it with select services, such as workforce initiatives, that assist only those with milder autism. It's here that the idea of neurodiversity poses the greatest threat — a movement that celebrates autism in all its forms, and depicts even the most severe afflictions as “merely a difference,” vehemently opposes any investigation into autism's causes as ableist.

The truth is that we still don't know what explains the steep rise in autism — perhaps it's the product of widespread environmental contaminants altering our children's brains — and this increase needs urgent attention. As these children age, state programs already strained by the deluge of adults needing lifelong services threaten to collapse entirely. Capitulating to self-

advocates' demands amid a global proliferation of one of the gravest disorders of our time is not only morally incoherent but medical malpractice.

In the natural course of events, every profoundly autistic child will eventually be orphaned by the most qualified and dedicated caretakers he's ever known — his parents. Absent meticulous advance planning and abundant resources, that child will be automatically transitioned by the state to placement in a residential living arrangement. For that child to be placed appropriately depends entirely upon having accurate clinical information about the intensity of his needs, taking into account the possibility of physical aggression, self-injury, elopement, property destruction, seizures, and other overlapping medical needs. I'm confident that if a person facing homelessness and a precariously uncertain future were asked whether he values a safe residential arrangement over semantics that obscure his diagnosis, he would choose the former.

For the record, any language that contorts or constricts the full scope of Zack's identity is something I find deeply offensive. Zack has struggled with innumerable obstacles and heartbreak in navigating a world that does not come naturally to him, and his competence is strengthening to this day. Blurring his identity under the indistinct banner of "neurodiverse" erases Zack's lived history — all that he has endured and overcome to get here.

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