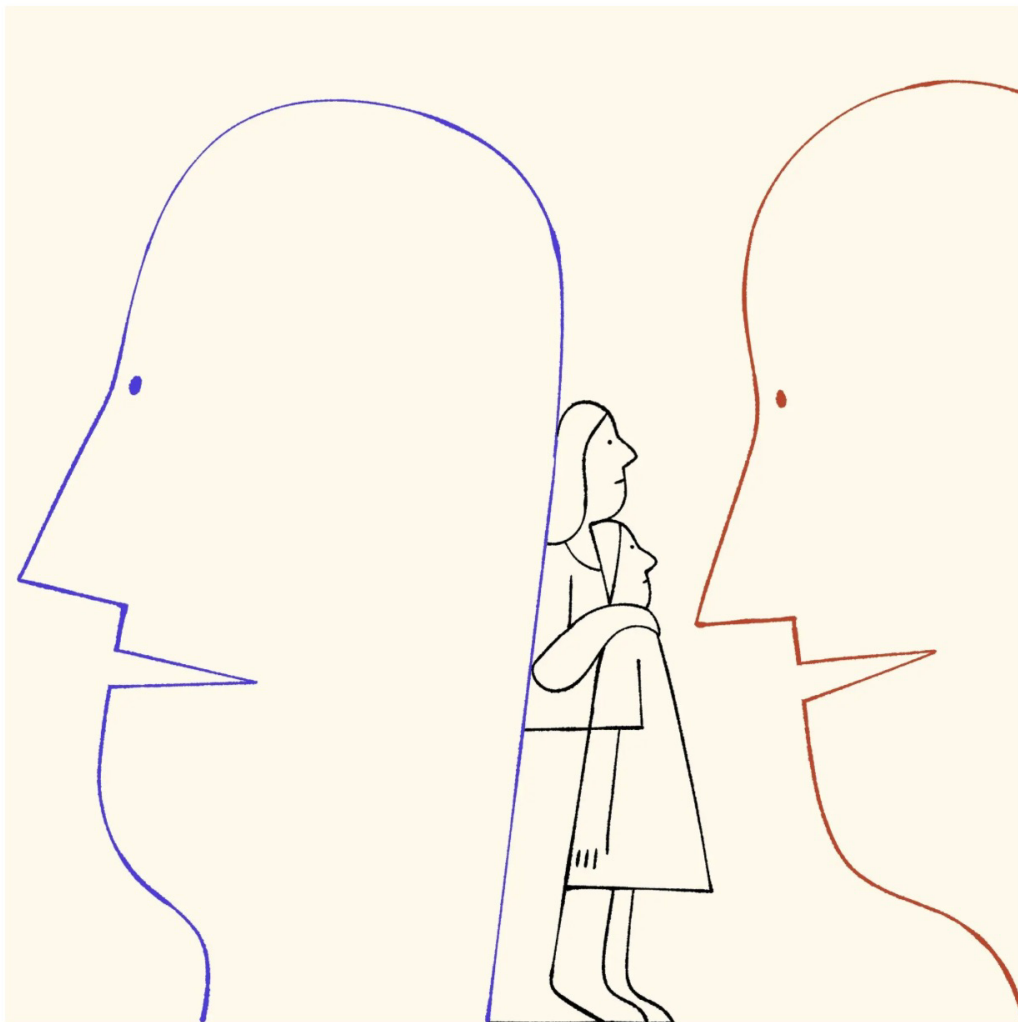



Kennedy Described My Daughter's Reality

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By Emily May

Ms. May is a writer and the mother of a child with autism.

My daughter hasn't spoken in five years. She never had many words, but they all disappeared just before she turned 2. She used to clap her hands along to music, respond to her name and once tried to feed her baby doll Cheerios. Those skills vanished quickly — it felt like trying to keep water cupped in your hands. Several months later, in October 2020, we received a diagnosis: Level 3 autism, the most severe form. I asked the child psychiatrist, who was very kind, if she knew why regressions like this happen. She said that she didn't, but that it wasn't uncommon — about one in three kids she diagnosed with autism had similar trajectories.

When Robert F. Kennedy Jr. said in a recent press briefing that autistic children will “never pay taxes,” “never hold a job,” “never play baseball,” many people in the autism community reacted angrily. And yet I was transported back to the psychiatrist's office and her bleak prognosis that my child might never speak again. I found myself nodding along as Mr. Kennedy spoke about the grim realities of profound autism.

It's not a position I expected to be in. I have never voted for Donald Trump. I vaccinated my children. I consider myself squarely left of center. I want Medicaid expansion, increased special education funding, support for caregivers and investment in research — all things this administration seems intent on gutting. I have no interest in defending Mr. Kennedy, whose shaky science and conspiracy theories will do nothing to benefit those with autism and their families.

And yet, I think his remarks echo the reality and pain of a subset of parents of children with autism who feel left out of much of the conversation around the condition. Many advocacy groups focus so much on acceptance, inclusion and celebrating neurodiversity that it can feel as if they are avoiding uncomfortable truths about children like mine. Parents are encouraged not to use words like “severe,” “profound,” or even “Level 3” to describe our child's autism — we're told those terms are stigmatizing and we should instead speak of “high support needs.” A Harvard-affiliated research center [halted a panel](#) on autism awareness in 2022, after students claimed that the panel's language about treating autism was “toxic.” A student petition circulated on Change.org said that autism “is not an illness or disease and, most importantly, it is not inherently negative.”

This advocacy reflects the huge shift our culture has gone through in how we think and talk about disability. We have moved from viewing disability through

a purely medical lens — as something broken to be fixed — to a social lens that puts the onus on society to accommodate it. Autism has become an identity, a different way of thinking and existing. Through this lens, autism itself isn't the problem; it's the lack of support and the lack of understanding. Much good has come from those changes. We don't live in an era of mass institutionalization anymore. Children with autism have a right to an appropriate education, to accommodations, changes in the classroom to help them succeed; we have sensory-friendly days at the zoo.

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There are limits, however. It's one thing to teach children how to engage with a classmate who struggles with social cues, but my daughter can't say her name. She struggles to interact at all. These are the hard realities for families like ours — families whose children are “too severe” even for spaces designed to be inclusive. And yet it feels like our needs are often unacknowledged.

Part of the issue is that autism now encompasses both children who will need lifelong care and, say, a teenage girl who does well academically but has panic attacks about going to school. We have TV shows like “The Good Doctor,” but I can't imagine a network willing to touch my child's reality with a 10-foot pole. It feels incredibly condescending to be told by people whose experience with autism still allowed them to be students at Harvard that our children, who cannot communicate if they have a stomachache and might instead bang their head in distress, are not having a negative experience. It concerns me that children like my daughter who have profound autism — including intellectual disability and little or no verbal communication — have become [increasingly less likely](#) to be included in autism research, despite making up about a quarter of autism cases. Many parents feel that there should be a separate diagnostic category for such children to help tailor research, policy and services more effectively.

I understand why Mr. Kennedy is such a polarizing figure. I did not support his cabinet appointment, and I don't believe his platform will materially help families like mine. I think his policies are likely to harm. I don't think he was the right person to make those comments. But I was struck by his willingness to speak frankly about the painful parts of my child's life. I don't care if my child ever pays taxes — but I do care that she may never have the opportunity

to work or live independently. She did not destroy my family, but I live in constant fear for her safety. I care deeply about her quality of life, and the limited options ahead. I appreciated his acknowledgment, because most of the time, families like mine are invisible.

There's a resistance to parents who wish their children were less disabled — as if it's an indictment of our love, rather than a testament to our pain. The parents who say they want to eradicate autism because they feel as if it's a disorder that is separate from their children's being are often accused of being eugenicists who wish their children didn't exist. There's a pressure to say that we wouldn't change a thing about our children, that we wouldn't want a cure. That autism has given us gifts.

But I don't want my child to hurt herself. I want her to enjoy a vacation with her siblings. I don't want pity, stigma or fear-mongering, but I want to know why regressive autism happens. I want to know if there are treatments that could be done to make my child's life easier. I want her to receive an education that makes sense for her, for families to have support. I want to not have a panic attack when I think about what will happen to her when she no longer has parents. I want the government to ensure that our children have access to good care, that they aren't waiting a decade or more for a Medicaid waiver that will help pay for therapy or bankrupting themselves paying for supports their child desperately needs.

My daughter turns 7 next month. I've long accepted that I may never hear her call me mom. I have grieved a million tiny deaths of the things I once assumed would be. And yet she is the most beautiful child I have ever laid eyes on. She is pure magic. I live in terror of the day she outgrows cute, and I worry constantly that as she grows bigger, her world grows smaller.

Emily May is a writer and the mother of a child with autism.

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