FEATURES

Divisions over ABA

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Tensions are high in the applied behavior analysis (ABA) field. ABA is the default suggestion from the medical community for parents of newly diagnosed autistic children, and in some corners it has a track record of improving communication skills. The therapy is accepted by insurers across the United States now, thanks to lobbying.

But legions of autistic people and neurodiversity advocates are dead set against it. ASAN's public stance, for instance, is that ABA and similar therapies can "hurt" autistic people, and "don't teach us the skills we actually need to navigate the world." Online, there are scores of people — autistic or otherwise — calling ABA traumatic, torture, bigoted, a "shitshow."

Much of their dislike is tied to precedence. Up until the 1990s, ABA used "aversives" to stop aggressive or harmful behavior, including loud sounds, slaps or even electric shocks (the Judge Rotenberg Center in Canton, Massachusetts, still uses shocks). Yet in online autism groups, members sometimes pass around memes as if they are facts, or say that ABA tries to "convert autistic people into neurotypical." It can feel impossible to productively discuss this topic, as many Facebook autism groups run by neurodiversity advocates prevent dialogue on ABA by banning positive comments in their forums. "Autism Inclusivity" has more than 145,000 members and has a "no pro ABA" post guideline; the groups "Sounds autistic, I'm in" and "Autistic Adults with ADHD" have similar guidelines.

Battling against misinformation and the ranks of people who disapprove of the therapy has sapped the strength of some ABA practitioners. Yev Veverka, a board-certified behavior analyst (BCBA) who has a daughter with autism, said "a lot" of her colleagues "have left, or are talking about leaving." The reason the rest have stayed "is because we have these meetings" and look around and "are like, 'What if we all go? Then what?' So it's like this sense of obligation, almost, to the field."

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Armando Bernal, a BCBA with autism, is also struggling with the rigidity of the anti-ABA community, because he knows its principles can be effective. When Bernal was diagnosed with autism at age 3, the doctor told his mother to focus on teaching him sign language, because he would never speak. This was in the 1990s, when there was no mandated insurance coverage for ABA, and Bernal "didn't grow up with a lot of money," he said, so his mother went to the public library and checked out books on autism to craft her own strategies for helping her son.

Armando started in a special-education preschool, but he eventually tested into general public schools and went on to higher education — first college and then an online course that earned him certification as a special-education teacher.

Still, he felt he could do more. When he learned about ABA, the science reminded him of the techniques his mother had used to help him blossom. He went to graduate school and in August 2019 became a BCBA. He's now clinical director of an ABA program, consults with parents and speaks at colleges, and is associated with Vanderbilt University's TRIAD Institute, where he encourages self-advocacy in people with autism.

He considers himself an "interesting bridge" between communities. Half the people he meets (mostly non-autistic) tell him he's an inspiration. The other half, often autistic, ask him, "How could you ever be a part of that?"

Bernal fully understands the doubters. He knows the history of hitting, and electric shocks that were used as deterrents. But he also knows the application of the science has changed, and he knows that it helped him. And it bothers him that there does not seem to be room for discussion.

"Don't get me wrong," he said, if ABA detractors "are saying that they have gone through some sort of traumatic experience, they need to be honored and respected. But for you to shut down a whole science? I feel that is difficult." What the field needs, he said, is "an open dialogue."

When Bernal was young, he was sometimes ridiculed for his autism, and he became ashamed of it. He knows there is less stigma attached to being neurodivergent now. He recently interviewed a man in his 60s, newly diagnosed as autistic. The man had been considered strange his entire life, he told Bernal, and had lived like an outsider. Talking to him, Bernal had a moment of realization. Given his own socioeconomic status as a boy, if Bernal had been of the same era as this man, he would have remained undiagnosed and dismissed as unreachable, he said. It's likely he would have ended up "in an institution or a jail or on the streets if my family couldn't take care of me."

So Bernal knows there has been progress. Yet the current state of dialogue on the autism field has him worried. If the varying factions in autism cannot communicate in a "professional way," he said, then things "will plateau and stop."

"We're in this limbo," he said. "We're not moving forward or backward; we're just butting heads."

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