

ANNALS OF MEDICINE

# THE ARGUMENT OVER A LONG-STANDING AUTISM INTERVENTION

*Applied Behavior Analysis therapy has a troubling history, and even many supporters say it was used too widely in the past. But has criticism of the practice gone too far?*

**By Jessica Winter**

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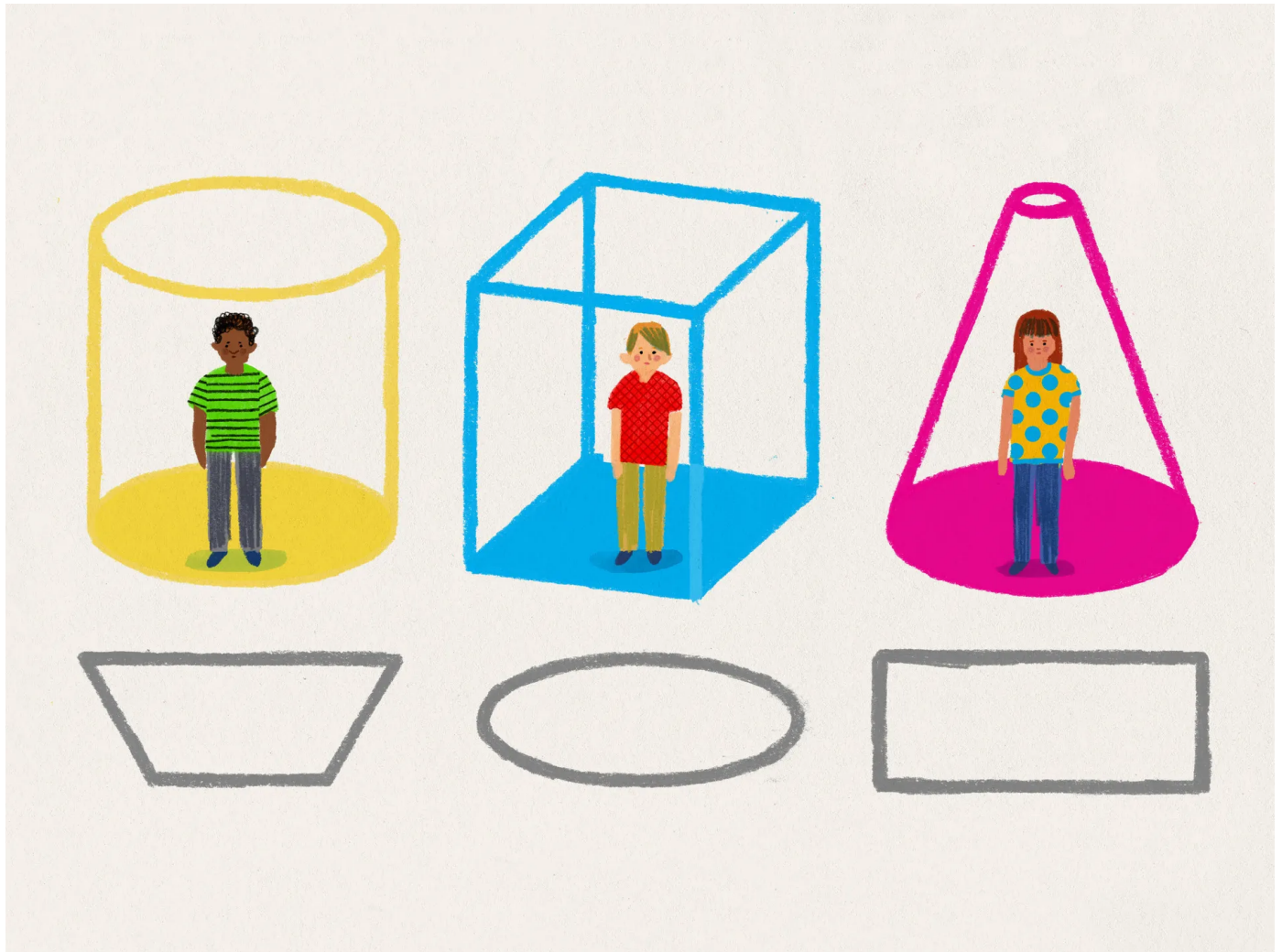
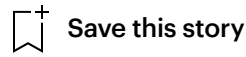


Illustration by Keith Negley



When Tiffany Hammond was growing up in Texas, in the nineteen-nineties, other children teased her for how she spoke: she talked too softly, she talked in a monotone, she paused too long between words, she didn't talk enough, she talked to herself. "Something's wrong with her head," kids would say. She was always fidgeting with pens or Troll dolls. She tried to connect with her peers by taking on their interests as her own—the Goosebumps series of scary novels, the N.B.A.—but the attempts backfired, as when she printed out an N.B.A. schedule, laminated and color-coded it, and brought it to school as a conversation piece. She kept a notebook on "how to be human," which included tips such as remembering to staple your worksheets at the top-left corner and acquiring a pair of the correct Filas. Nothing worked. "I wondered why I didn't have friends, or if I even deserved friends," Hammond said. She dreaded school so much that, on a few mornings, when she was supposed to be walking there, she instead tried to make it to her great-grandparents' house, some twenty-five miles away.

When Hammond was twelve, she took an overdose of Tylenol. She told me that she's not sure if she intended to attempt suicide; she just wanted the noise and negativity in her head to stop. Her mother brought her to doctors who gave Hammond a prescription for Paxil and a diagnosis of Asperger's syndrome, which, at the time, was recognized as an autism-related disorder that affects communication and social-emotional skills. She began going to a clinic for therapy twice a week, and continued for two years. "It was, 'You have to sit right in the chair, you can't cross your legs this way, you have to enunciate, no fidgeting,'" Hammond said. She might be asked to practice speaking clearly by reading the same paragraph from "Charlotte's Web" out loud, over and over, and then do it again the next session. The work was tedious and difficult. "As a kid, you think,

Why am I like this? Why can't I *get* it?" Hammond said. "And then you have those times when you're, like, Why can't they just let me sit the way I want to sit?"

It was not until she was in her late twenties that Hammond, an autistic advocate who is the author of the best-selling picture book "A Day with No Words," realized that her childhood therapist was practicing something called Applied Behavior Analysis. A.B.A. therapy aims to build skills and habits that many autistic people do not have by breaking tasks down into small steps and reinforcing desired behaviors through repetition and rewards, which, with little kids, could take the form of candy or extra time with a favorite toy. Hammond had aged out of such incentives by the time she was enrolled in A.B.A., but earning praise from her therapists was reinforcement enough. "I wanted to please these adults. I wanted people to feel good being around me," she said.

A.B.A. is the only autism intervention that is approved by insurers and Medicaid in all fifty states. The practice is widely recommended for autistic kids who exhibit dangerous behaviors, such as self-injury or aggression toward others, or who need to acquire basic skills, such as dressing themselves or going to the bathroom. The mother of a boy with severe autism in New York City told me that her son's current goals in A.B.A. include tolerating the shower for incrementally longer intervals, redirecting the urge to pull on other people's hair, and using a speech tablet to say no. Another kid might be working on more complex language skills by drilling with flash cards or honing his ability to focus on academic work. Often, A.B.A. targets autistic traits that may be socially stigmatizing but are harmless unto themselves, such as fidgeting, avoiding eye contact, or stereotypic behaviors commonly known as stimming—rocking, hand-flapping, and so forth.

Hammond is now the mother of two autistic sons. Her older son, Aidan, who is sixteen, is nonverbal and needs round-the-clock care. When he was young, he attended a traditional school, but teachers, Hammond said, "were literally calling me every single day: 'Can you please come here and sit with him? Can you please pick him up?'" Hammond tried physical, occupational, and speech-language

therapy for Aidan, but he was “kicked out of every single one,” she said. Therapists “felt that his behaviors were interfering with his learning, and that he needed to be in A.B.A.” A.B.A. clinicians, she added, “were at least willing to look at my son.”

She drove him to A.B.A. appointments at a clinic about an hour from their home in southwest Texas, but stopped treatment after just a few sessions. This was partly due to the commute and the co-pay, but also to a discomfort with the approach, which required Aidan to spend long periods, over multiple sessions, solving a puzzle in which he matched shapes to the right-sized holes. “He’s having to do this over and over and over again,” Hammond recalled, “and, when he picked the right thing, it’s, like, Ooh, here’s a Skittle! Like he’s a puppy.”

In recent years, A.B.A. has come under increasingly vehement criticism from members of the neurodiversity movement, who believe that it cruelly pathologizes autistic behavior. They say that its rewards for compliance are dehumanizing; some compare A.B.A. to conversion therapy. Social-media posts condemning the practice often carry the hashtag #ABAIsAbuse. The message that A.B.A. sends is that “your instinctual way of being is incorrect,” Zoe Gross, the director of advocacy at the nonprofit Autistic Self Advocacy Network, told me. “The goals of A.B.A. therapy—from its inception, but still through today—tend to focus on teaching autistic people to behave like non-autistic people.” But others say this criticism obscures the good work that A.B.A. can do. Alicia Allgood, a board-certified behavior analyst who co-runs an A.B.A. agency in New York City, and who is herself autistic, told me, “The autistic community is up in arms. There is a very vocal part of the autistic population that is saying that A.B.A. is harmful or aversive or has potentially caused trauma.”

Until recently, the American Medical Association officially endorsed “evidence-based treatment of Autism Spectrum Disorder including, but not limited to, Applied Behavior Analysis Therapy.” Last summer, the medical students’ body of the association proposed that the organization withdraw its support for A.B.A., citing objections by autistic self-advocates. The association did not adopt the

resolution as submitted, but its house of delegates eventually approved an amendment removing any explicit reference to A.B.A., and autistic activists spread the word that A.B.A. no longer appeared to have the outright endorsement of the nation's largest medical society.

Alison Singer, who is the president and co-founder of the Autism Science Foundation, believes that criticism of A.B.A. has gone too far. She told me that her daughter, Jodie, now in her twenties, acquired essential language skills in A.B.A., such as naming the parts of her body. “If she had a toothache, she could say, ‘Tooth hurts,’ rather than screaming or tantruming, with me having no idea that she needed to go to the dentist,” Singer said. Jodie used to have hours-long meltdowns during transitions. “A lot of kids with autism are not able to wait their turn,” Singer told me. “In A.B.A., she learned, over time, that *first* we will do this, and *then* we will do this”—for example, first, we’ll practice some new words, and then we can have some free time on the iPad. The intervals between “first” and “then” might begin at just ten seconds, then build up to thirty seconds, then one minute, and so on.

A generation ago, Singer said, “everyone who was diagnosed with autism got A.B.A. That type of one-size-fits-all treatment never really made sense for a child who had intact language or a high I.Q.” Now those children have grown up. “They’re talking about A.B.A. and how negative it was for them. But that doesn’t mean that we should eliminate it for the people who need it.” Singer’s position is, in part, a pragmatic one, but the debate over A.B.A. goes beyond practicalities. It is not simply a matter of whether a particular treatment works but what it means to be autistic, and what all autistic people do, or do not, have in common.

**T**he origins of A.B.A. are undeniably disturbing. The person most closely associated with A.B.A.’s genesis is O. Ivar Lovaas, a clinical psychologist at U.C.L.A. who worked with severely autistic children. Beginning in the nineteen-sixties, Lovaas sometimes used “aversives”—shouting, slaps, and even electric

shocks—to punish tantrums, stimming, and inattention in his child subjects. (Today, the Judge Rotenberg Center, in central Massachusetts, is believed to be the last institution in the U.S. that still administers electric shocks as part of A.B.A. therapy.) Some of the children in Lovaas’s care were not served regular meals, only receiving spoonfuls of food, such as sherbet, as rewards for complying with commands. And Lovaas openly shared appalling views of the autistic children he treated, once telling an interviewer that “they are not people in the psychological sense.”

In 1987, Lovaas authored a seminal study of sixty autistic children. In it, nearly half of the kids who were treated with an A.B.A. technique known as discrete trial training became, in Lovaas’s words, “indistinguishable from their normal friends.” “We would argue that that’s not a good goal in the first place,” Zoe Gross noted, dryly, “but, even for what it purports to do, which is to reduce the quote-unquote symptoms of autism, A.B.A. has not been rigorously proven to be good at that.” There is ample research, collected over decades, supporting the efficacy of A.B.A., but much of it is based on small studies and what are known as single-subject designs, in which subjects effectively serve as their own control group. Weighing the data also becomes more complex owing to the proliferation of A.B.A. subgenres, which tend to be more play-based and less repetitive than old-school A.B.A.

An idiosyncrasy of A.B.A. is that, often, the highly credentialled analyst is not the person directly providing service to the client; rather, the analyst supervises groups of lower-skilled behavior technicians. “The logic was that anybody could do A.B.A., and it can be cheap, because these are basic principles of behavior that you can use with a rat,” Catherine Lord, a professor at U.C.L.A. who studied under Lovaas as an undergraduate, told me. (“It’s not true,” she added.)

In recent years, private equity has taken a voracious interest in A.B.A. services, partly because they are perceived as inexpensive. Private-equity firms have

consolidated many small clinics into larger chains, where providers are often saddled with unrealistic billing quotas and cut-and-paste treatment plans. Last year, the Center for Economic and Policy Research published a startling report on the subject, which included an account of how Blackstone effectively bankrupted a successful A.B.A. provider and shut down more than a hundred of its treatment sites. Private-equity-owned A.B.A. chains have been accused of fraudulent billing and wage theft; message boards for A.B.A. providers overflow with horror stories about low pay, churn, and burnout. High rates of turnover are acutely damaging to a specialty that relies on familiarity between provider and client. “The idea that we could just franchise A.B.A. providers and anyone could do the work—that was misinformed,” Singer, of the Autism Science Foundation, said.

Some autistic people are trying to change the field from within. Armando Bernal, who is autistic and runs an independent A.B.A. clinic outside Houston, doesn’t work on helping clients make eye contact—in fact, he tends to avoid it himself. He also flaps his hands when he gets excited. (If a parent is concerned about their own child’s stimming, Bernal tries to put them at ease by telling them that his hand-flapping is how his fiancée knows that she’s got him the perfect Christmas or birthday gift.) He’ll work on stereotypic behaviors only if he’s convinced that they’re disruptive—for example, if a child is stimming in certain school settings. “I don’t agree that it forces people to be less autistic to focus on these behaviors,” he said. “It allows these children to be successful and independent while being able to manage themselves in a space with neurotypical individuals.”

Allgood, another autistic A.B.A. provider, spent the early months of the pandemic speaking with people who oppose A.B.A., then hired autistic self-advocates to tutor her staff. Her clinic does not use food rewards, partly owing to concerns that they can contribute to eating disorders. “Eye contact, I really don’t care,” she told me. “I have met so many doctors who don’t look at me.” Her agency has also moved away from a technique known as extinction, in which unwanted behaviors are simply ignored; the hypothesis is that if, for example, a child’s meltdowns are denied the oxygen of attention, they will cease to exist. But, Allgood said, “I’ve

come to learn how damaging extinction can be,” because it doesn’t address challenges native to autism—such as sensory triggers or underlying executive-function issues—that may be causing the meltdowns in the first place. “It is the last moment that we should be turning our backs on you,” she said.

“Autistic people are not the sum of their behaviors,” Paige Layle, a neurodiversity activist in Ontario, told me. “If you change the behavior, the autistic person still has all those same feelings and all the same reactions.” Layle has nearly three million followers on TikTok and is the author of the forthcoming memoir “But Everyone Feels This Way.” After she was diagnosed with autism, at the age of fifteen, Layle underwent A.B.A. therapy that focussed on socializing: how to read social cues, how to avoid making blunt or hurtful comments, and so forth. “I was like, I’m sorry that I offend people so much, and I would love people to like me, but that’s not my main problem—like, *I want to like me*,” Layle, who is now twenty-three, said. “I want to learn how I can emotionally regulate myself so I don’t get angry, so I’m not having panic attacks, so life isn’t so hard.” Sometimes her therapist, noticing that she was becoming frustrated, would suggest a short break, and walk away. The message, Layle said, was “that when I’m upset, people will go away, and I have to be happy for people to pay attention to me.”

Layle expressed support for autistic therapists who are working to reform A.B.A., but other self-advocates are more dubious. “The people who claim that they’re neurodiversity-affirming, I think you’re going to find that those people are not doing A.B.A., but labelling it that for insurance purposes,” Gross, of the Autistic Self Advocacy Network, said. This work-around, she went on, may at times seem “like a parent’s best option. Technically, it’s also insurance fraud. It’s not a policy solution.”

**A** B.A.’s strongest detractors and supporters often seem to be describing two completely different phenomena. The autistic self-advocates describe a coercive practice that forces kids to smother who they are for the comfort of those



around them. The parents of kids with high support needs describe a life-altering intervention that has taught their child how to put on her shoes, or how to communicate a need or desire in ways that don't involve banging her head against a wall or hours of screaming.

This schism is a microcosm of a larger, equally contentious debate over how to define autism itself. In 2013, the *DSM-V* retired several autism-related diagnoses, including Asperger's syndrome, and created a new, single category: autism-spectrum disorder. "When the *DSM-V* lumped everyone together, it did a disservice," Singer said. She advocates for the *DSM-VI*, whenever it may arrive, to break off a new diagnosis from the spectrum, called profound autism, to describe a person who requires constant supervision and has limited cognitive and verbal ability. "The umbrella term 'autism-spectrum disorder' provides absolutely no information about a person's functional level or their needs," she said.

A new category is also necessary, Singer told me, because some neurodiversity advocates "intentionally advocate against recognizing the suffering and acute needs wrought by profound autism." She went on, "The truth is that, for some people, autism may be a gift, while the simultaneous truth is that for other people autism symptoms are a tremendous burden, a lifelong disorder, for which society should seek understanding, prevention, and medical intervention."

The Autistic Self Advocacy Network and other like-minded organizations largely reject the concept of profound autism. "It's an attempt to make autism into these two monolithic categories, whereas autism is one heterogeneous spectrum," Gross said. She is concerned that an official designation of profound autism might be used by health insurers and social-service agencies as a pretext to limit services to those who lack the diagnosis, and that it risks segregating certain autistic people from their communities. "We think that it's important that everyone has access to community living and to integrated education, and to be supported to have a job in the community if that's what they want," Gross said.

This line of thinking seems to take for granted that all autistic people can successfully communicate what they want. Tiffany Hammond has come to question whether it genuinely accounts for the challenges that many autistic people face. “There are really loud voices in the community that almost make autism seem like it’s a personality quirk, and that society is the only thing that disables us,” she told me. “They’re not leaving space for my son’s experience.” Although Hammond ultimately pulled Aidan from A.B.A. therapy, she believes that some strains of the anti-A.B.A. movement have become divorced from reality. “Advocates say, ‘There’s better ways than A.B.A.,’ and I’m, like, ‘Where are the better ways?’ They don’t know the systems that we have to navigate. They just kind of *talk*.” Hammond now homeschools her sons; she knows many single and working parents who don’t have that option. “But they can enroll their child in an all-day A.B.A. center that is more than willing to accept their child, even if it’s not perfect,” she said. “I hate that that would be the only option. But, if they’re not in that, they’re in nothing.” She has heard from parents who have sustained multiple concussions owing to their autistic children’s behavior. “They don’t know where to turn for help.”

Hammond and her sons are Black, and she likened some of A.B.A.’s lessons to the masking and code-switching that Black people have to do all the time. “You learn to be different people, because you have to get a job and put a roof over your head, and all you have to do is be a muted version of yourself for  $x$  hours a day.” A.B.A. may emphasize conformity and compliance, but, then again, Hammond said, “we live in a compliance-based society.”

For Hammond’s family, the question of compliance might have terrifyingly high stakes. More than once, she said, when she is with Aidan in public, people have called the police or security. “My kid does not know how to mask, he doesn’t know how to rein it in, he’s loud, he’s animated, he’s all over the place, and he doesn’t speak. When the cops come, he might be running in circles, he might be reaching for his iPad, and they’re reaching for their firearms. Are you going to try to change

the cops, or are you going to try to change my son?” She added, “A.B.A. is just a symptom. It’s a leaf of a tree with rotted roots.” ♦

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