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INTRODUCTION

In 2015, as a second-year law student, I authored a research paper entitled, “‘No Imbecile At All’: How California Won the Autism Insurance Reform Battle, and Why Its Model Should be Replicated in Other States.” The piece, which explored the health insurance landscape with respect to services for autism, and argued for wider access to what has become known as the main form of “treatment” for autistic individuals—Applied Behavior Analysis (“ABA”) therapy—is one that I would now like to withdraw. This statement and letter of explanation comprise my formal retraction of this work. Thank you to the Harvard Law & Policy Review for accepting my withdrawal request and affording me this space to discuss my change in perspective, in the hopes that those who have read my work, cited it, or come across it in the future, will step with me into greater enlightenment about autism.

I. AUTHOR’S REASONS FOR RETRACTION

This is a topic concerning a community I care a great deal about. My decision to retract this piece stems from my love for my brother and years of inner turmoil over wanting to support both autistic individuals and their parents and caregivers, and growing up in an era and within a community that framed ABA as a positive tool for the autistic population that they had been wrongfully denied. That, in recent years, has been followed by the slow realization and resolution of cognitive dissonance in light of recent studies and literature reviews on the impact of ABA on people with autism and the individual testimonials of autistic adults on the trauma ABA caused them—that real harm is being done to these individuals by ABA. ABA has been in my family’s life for decades, since my brother was diagnosed in the 1990s,


and though I am aware this retraction may not be well-received in our community of origin, I have seen enough for myself to be convinced that ABA is the autistic community’s analog to the LGBTQ community’s conversion therapy.

I thank the autistic individuals who have spoken out for their willingness and bravery to share their experiences publicly, which lent clarity to internal feelings of unease about people with autism’s experiences with ABA that had not yet resolved themselves into convictions, and helped provide a path to see this clearly. I apologize to them for the role my actions have played in perpetuating these practices, and I urge others to take a hard look as well.

Although this was just a paper I wrote in law school, it has had real world effects for autistic individuals and families like my own. While I did not argue in the paper that people with autism should have ABA, I did make a case for expanding access to ABA throughout the United States, which given current research and new knowledge, would contribute to the damage being done. Moreover, I feel that maintaining this article without a formal and thorough retraction on a well-respected platform like HLPR’s would itself be a statement contributing to the continued acceptance of ABA as a legitimate form of intervention for autism. These facts, along with the confluence of evidence and experiences described below, are what compel me now to reverse myself and state that I can no longer in good conscience support ABA.

A. Experience with ABA and the Medical Model of Autism

I held different views at the time this article was written—views that were shaped by the medical model of autism, which is the approach that dominated the era when my brother was diagnosed, and which came to dominate our lived experience with him. Back then, autism was framed as a tragedy, and “treatment” was recommended. Autism was so rare at the time that the smattering of physicians involved in my brother’s diagnosis had to think back to their medical residency training years to convey the meaning of the word to my family. The 1994 DSM-IV definition of autism, the criteria

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2 See R. E. B. v. Hawai‘i Dep’t of Educ., 870 F.3d 1025 (9th Cir. 2017).
which directed diagnosis, was translated to us as a lack of empathy disorder by the medical community. ABA was recommended as one of the few things that could help him learn to socialize, thrive, eliminate "harmful" behaviors, earn societal acceptance, and avoid the fate of being “other.”

In those days there were few centers offering ABA, no standards, no billing procedures, no licensing levels, and very few trained therapists. ABA was a theory based on behavioral science, and as a practice was nascent. My parents put out an advertisement through the local university and hired a handful of college-aged students who were willing to learn ABA and paid them to deliver the therapy to my brother, who was about four at the time. One of the core tenets of ABA is family involvement and consistency—in order for an ABA program to be effective for the child, the family must globally and consistently reinforce the child's behavioral program.

Family integration was something that occurred in my family around my brother. From the start of his program to the present day, his ABA therapists would actively incorporate my parents, our other siblings, and me into my brother's program. From a young age, I remember his therapists would walk him over to me as I practiced the piano, and prompt him to ask me a question so he could work on developing social interaction skills. In practice it looked something like this: “Ask Ariana,” they would say. “Ask Ariana,” he would echo back, standing in front of me, and quickly follow up with the predetermined question, which varied: “How are you?” / “How was school?” / “What are you doing?” My siblings and parents experienced and participated in similar encounters. If my brother was excited to see us and jumped up and down on his tip-toes, his therapists would prompt us to tell him “no” to stop that behavioral response and instead to use his words to convey his excitement, as his therapy plan dictated. If my brother was frustrated and closed his eyes and flapped his hands because something in the environment irritated him, my family members and I would be prompted to redirect him to express this feeling in a more normal way—with words.

As ABA became more standardized (ways to implement it on a person, train professionals in it, charge families for it, and set up business structures around it) and drew together the worlds of psychology, medicine, and business, my brother's program became more regimented and supervised. It also cost more, and had more steps and parties involved. Licensing boards emerged, charging fees to train those interested in becoming ABA practi-


tioners\(^8\); lawyers passed legislation forcing insurance companies to cover ABA as a medical treatment; and companies were created, which would hire teams of therapists to deliver ABA on a more robust level, to a wider number of clients.\(^9\)

As my brother’s 40-hour per week therapy schedule was implemented our collective lives assumed a new normal. ABA utilized most of the hours on the weekdays and half of the day Saturday to provide therapy at the appropriate intensity recommended for someone like him—with “severe” autism—by the medical community’s consensus and prescription. When we would wake up in the morning, my brother’s therapists would be there getting ready to work with him, prepping the binder that tracked the discrete trials that had been worked on the previous day by the other therapists on the team. When my siblings and I came home from tennis practice, my brother’s therapists would be there working with him, and would prompt him to make eye contact and ask us questions about our activities so that he would know how to interact with us. When my family hosted a high school AP test review session in our home for my teacher and classmates, and my brother, listening to a YouTube video, danced diagonally across the neighboring room and into the kitchen, singing along with joy, his therapists followed and made sure to help him calm down and “take the volume down to a 1.” When my brother was overstimulated and would say video talk from a familiar Disney movie to calm himself down and I would repeat it back to him to help him laugh and know that someone heard him, my parents and his therapists would let me know that I was holding him back in his program because that was behavior that had been extinguished or “put on extinction.” When I went away to college and visited over the holidays, bringing back two sand-filled stress pillows with my college’s name on them to help my brother understand where I had been, his therapists were there to help him learn how to play with the pillows properly, and put them on his bed. And when I took the California Bar Exam and passed, and came home to hug my brother, his therapists were there working with him, and explained to us that we could have some more substantive time together once his therapy was done that day.

Ever since we were young—both before his diagnosis and after it—everywhere we go, my brother is the light. Gradually I have watched that light, which emanates from the natural exercise of being authentically oneself, go out because it has been and continues to be put out by ABA, which is, essentially, compliance therapy. My brother has developed anxiety, increasingly worsening OCD-like behaviors, and intensifying self-harm tendencies, and I have seen the same effects in many of my clients over the years who have received ABA.


I share these personal experiences with my brother, which are supported and supplemented by the results of recent research and statements of the adult autistic community not as an accusation, but to lend credence, from a non-autistic individual’s firsthand lifelong witnessing of ABA and its effects, to what these individuals are recounting in their declarations that ABA is harmful. As autistic individuals have grown up and information sharing mechanisms have improved and proliferated compared to what was available in the 1990s, these individuals are speaking out and trying to raise society’s awareness as to what is going on.\textsuperscript{10} Many have Post-Traumatic Stress Syndrome (PTSS), anxiety, depression, and other trauma-based conditions as a direct result of ABA.\textsuperscript{11} While several in the community have heard their cries and responded productively with scientific investigations which have yielded credible evidence to support these claims, as well as reports to human rights commissions,\textsuperscript{12} a great many have responded in the opposite way: doubling down on ABA and/or silencing individuals who speak out. In the author’s view, this response is abhorrent and utterly wrong. It is my intent, with this letter, to course-correct those professionals, parents, and other family members and caregivers of people with autism who continue to use ABA as an intervention for autism. The autistic adults speaking out are not misinterpreting, exaggerating, or complaining. They are seeing reality correctly, and telling the truth as it is. It is my sincerest hope that people will open their minds and hearts and listen.

\textbf{B. New Research, Evidence, and Testimonials Available}

In the years since this paper was published, new and comprehensive research has been conducted offering credible insight into the documentable harm caused by ABA to autistic individuals. ABA is abusive, according to these studies, because it ignores the structure of the autistic brain and the overstimulation of the autistic experience, focuses on measurable behavior at the expense of internal processes, ignores the complex nature of human psychology, and promotes dependence rather than independence. It is not just


\textsuperscript{12} “Violations of the right to dignity granted in the UN Convention on the Rights of Persons with Disabilities include victimization by care providers (University of Cambridge 2017), being excluded from public places due to their behaviors, and exposure to treatments that can cause harm, especially Applied Behavior Analysis (one of the only treatments thought to be effective in teaching children social interaction). Applied Behavioral Analysis is inspired by training for animals and in its original form includes both positive rewards for behavioral changes—being more like neurotypical people—as well as negative sanctions for neurodiverse behavior (Silberman 2016).” Keri E. Iyall Smith, Understanding and Promoting the Human Rights of Autistic People, 15.1 Societies Without Borders 3 (2021).
“old ABA,” (which involved negative reinforcement) that is abusive, but even “new ABA,” (exclusively based on positive reinforcement) because it is ABA itself that is fundamentally abusive to the autistic person. It promotes the idea that autistic children must change to fit in. As excerpted from Sandoval-Norton, Shkedy, and Shkedy (2021):13

- “ABA is concerned with outward manifestations of behavior and the treatment of those manifestations.”
- “Wilkenfeld and McCarthy (2020) demonstrated that ABA is unethical from a bioethics perspective because ABA violates autonomy insofar as it coercively closes off certain paths of identity formation. It also violates autonomy by coercively modifying children’s patterns of behaviors to be misaligned with their preferences, passions, and pursuits.”
- “We have moved away from old science and the primitive understanding of human beings as merely a bundle of behaviors and moved towards more developed and more scientifically supported models which incorporate cognitions, internal processes, neuroscience, genetic predispositions, multiculturalism, etc. There would be no need for various psychological orientations if all human beings were a mere bundle of behaviors who could be rewarded, punished, or conditioned into achieving anything.”
- “Furthermore, Shkedy (2019) demonstrated there is a plethora of research showing the oversensitivity of the autistic brain has to do with external stimuli with some of them actually causing physical pain.”
- “While the behaviors may be viewed as abnormal, they help to soothe and calm the autistic person. Yet the practice of large scale extinguishing of all forms of undesired behavior, whether harmful or not, largely continues and persists within ABA circles. The fact that it’s claimed that there are hundreds of studies that effectively reduce self-stimulatory behaviors that are deemed problematic by consumers, parents, and families only serves as further evidence of abuse.”
- “It has been “demonstrated that self-injurious behaviors in non-verbal children with autism are a cry for help due to their lack of communication skills; ABA therapists overwhelmingly predominantly denote these behaviors as task avoidance.”
- “Moreover, one treatment that ABA uses for negative attention is called extinction, where the reinforcement for the behavior is discontinued in order to attempt to decrease the incidence of the behavior. The literature on ABA lists possible side effects of extinction, one of which is depression (Powell et al., 2016). ABA therapists are not trained to recognize depression and therefore will

continue this treatment while unknowingly causing psychological harm.”

- “Rather than live up to the promise of supporting independence, ABA forces compliance and ignores the child’s true feelings, methods of coping, and development in favor of external behavior that is pleasing to allistic, neurotypical members of society.”
- “Research indicates prompt dependency is a very prevalent problem, even in ‘higher functioning’ individuals.”
- “Providing a treatment that causes pain in exchange for no benefit, even if unknowingly, is tantamount to torture and violates the most basic requirement of any therapy, to do no harm. As ABA focuses solely on a behavior itself as opposed to internal constructs (e.g., thoughts, emotions, pain), Sandoval-Norton and Shkedy (2019) illustrated and cited research demonstrating how this can lead to psychological and physical abuse and violates the ethical obligation to ‘do no harm.’”

This study along with the studies cited within are corroborated by the narratives autistic adults who have received ABA during childhood are recounting. For example, C.L. Lynch, an autistic woman and blogging contributor to Neuroclastic, Inc., describes ABA:14

- In general: “But ABA has changed,’ people argue. ‘My ABA therapist never uses punishment. It’s all positive and reward-based.’ That is very true for many people. Most ABA therapists don’t set out to hurt children. And yet, despite making ABA therapy fun and positive, the underlying goals of ABA have not changed. And it is these goals that, like gay conversion therapy, do long-term damage to the human psyche. The reason parents and ABA therapists can’t see it as abusive is because they can’t see it from an autistic point of view.”
- Regarding a recorded ABA session, used as an example: “While they do not address it in the voice-over, if you watched it again you would notice how often the therapists take the children’s hands and fold them into the children’s lap. You would also notice how often the child’s feelings are ignored . . . In the video with the girl in the supermarket, an autistic person can spot that she was getting over-stimulated, exhausted, and was increasingly desperate to escape this environment . . . She isn’t happier. She’s just accepted that her feelings don’t matter and the fastest way to escape the situation is by complying . . . [y]ou can see that ABA therapists deliberately ignore

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attempts to communicate or produce behaviors that have not been demanded by the therapist . . . The problem with ABA is that it addresses the child's behaviors, not the child's needs . . . You can go to any ABA website and read what they say and you'll see that there will be no discussion of the child's emotional welfare or happiness, only behaviors. To ABA, behavior is the only thing that matters. ABA considers autistic children as unbalanced kids who need to be balanced out, and if you balance their behavior, they are fixed.”

- On stimming and sensory needs: “Stimming isn't like doodling when you're bored or throwing a basketball. Stimming is a comforting self-soothing behavior which helps us reduce stress, feel more comfortable in uncomfortable environments, and regulate our emotions. Grabbing my hands when I stim the way ABA recommends would not help my day go better. It would be an excellent way to piss me off and make me feel frustrated and anxious, though . . . The parents say the ABA really helped their daughter. Does it really help the child, or the parents? The grocery store isn't any less noisy or bright or overwhelming. And the child obviously still finds it difficult to go in. Instead, she has learned to keep her feelings to herself, to try and focus on pleasing her family, and bottle up her stress inside until she can't take it anymore. That's a healthy thing to teach a child, right? With time she may become excellent at this. She may be able to go to the store, put items in the cart, and go home without a meltdown. But the meltdown WILL come. It will come over something minor, some silly thing that seems like nothing and pushes her over the edge where she was already teetering. And they will wonder where it came from. They'll talk about how unpredictable her meltdowns can be. It isn't unpredictable to us . . . We can see that her autism hasn't been treated to improve her life so much as to improve her family's life. And while that is important too, wouldn't it be better to find a solution that works for everyone? . . . I know that ear defenders [e.g. earmuffs or noise-canceling headphones] are not part of standard ABA protocols. Instead of teaching them to understand their sensory needs and self-advocate for having their needs met, they are taught to ignore them.”

- On the recommended 40-hour per week program: “Now understand that sessions like this are not a couple of hours a week. ABA therapists recommend that small children between 2 and 5 go through 40 hours a week of this type of learning . . . My allistic eight year old doesn't do 40 hours a week of school. He goes to school from nine to three and gets a half hour recess and a half hour lunch. That's 5 hours a day five days a week. 25 hours of active learning . . .

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16 This term describes a nonautistic person.
Imagine asking double that for a preschooler . . . 40 hours a week is too much for me so I can’t imagine how a small child manages it.”

- On the gaslighting and abusive nature of ABA: “I know that ABA aims to be positive and rewarding for the child, but doesn’t allow the child to tap out whenever they need to. I know that ABA considers vital emotional regulation tools to be problems that must be extinguished. I know that neurotypical pre-schoolers are not usually expected to learn for 40 hours a week. I know that neurotypical children are encouraged to express their emotions, not smother them. I know that ABA believes in removing a child's language tool like the iPad when they are naughty.17 Whenever autistic people protest ABA, we are told that we don’t understand, that we don’t know how hard autistic children are to live with. They talk about improving the child’s independence and argue that it isn’t cruel to teach a child to write or play with toys. They don’t see how weird it is to try to systematically shape a child’s behavior to teach them to play with a toy the “right” way . . . They don’t see how dangerous it is to teach a child to do whatever they are ordered to do, no questions asked, and to never object or say ‘no.’”

C. Unethical Practices, Conflicts of Interest, Cognitive Dissonance, and Bad Incentives Around ABA and Organizations that Support It

While ABA has been in my brother’s life for decades, it is only in recent history that I have gained experience within this space in a professional capacity, and over the past few years, have had access to leadership in several ABA proponent organizations. What that experience has shown me is that there are many people in the world of ABA and autism therapy who are operating from the ego and not from a genuine desire to improve things for this population, and aside from them, many others who do want to help but have not yet awakened to the several critical flaws inherent to the business of ABA.18 In the years since writing the original article, I have obtained both a J.D. and an M.B.A., which has enabled me to better see the misguided structures and incentives involved.

First, “ABA therapists are not required to take even a single class on autism, brain function, or child development,” and they do not understand why the child is doing what they are doing, but they understand how to change the child’s external behavior.19 “We are unaware of other professions

17 Ms. Cernius supports this author’s assertion, as Ms. Cernius’s family members have been trained to withhold her brother’s iPhone and iPad to motivate him to comply.
or circumstances where it’s considered ethical to not study anything about the manifestation or circumstances of a condition and then attempt to treat it.”

This has essentially transformed into a situation where ABA therapists “have no training, knowledge, or expertise on the behaviors they are treating within the context of the autistic brain,” but at the same time, ABA therapists and associations present themselves to the government and to the public as scientific experts on treating autism. “Representing oneself as an expert in a subject area one has no knowledge of is usually considered fraud, at least once revealed. At its very core, it is the epitome of unethical action.”

Furthermore, under ABA’s model, the dignity of the child is not taken into account. “The aspects of the child have been neglected likely because the people entrusted to help these children specifically have no training on how to study, understand, and treat this population, and so, they must wholly rely on the observations of parents instead of on a theoretically based, structurally sound model.”

Additionally, ABA is imposed with little scientific validation. “There have been limited, if any, scientifically validated studies on the use of ABA on nonverbal children with ASD. Still, this population is forced to engage in these same interventions, perhaps more often than the non-severe population, despite these studies occurring without them as a primary participant. Many of them have ABA imposed on them over nearly their entire lifetime, despite the dearth of any studies focused on determining the efficacy of ABA on the severe autism population specifically.”

Cognitive dissonance is the psychological stress experienced from holding two conflicting beliefs, values, or attitudes. The inconsistency between what people believe and how they behave motivates people to engage in actions that will help minimize feelings of discomfort. People attempt to relieve this tension in different ways, such as by rejecting, explaining away, or avoiding new information. It is my belief and experience that much of the autism community is trapped in cognitive dissonance surrounding ABA and the notion of “treating” or “curing” autism. The pro-ABA community wants to help people with autism, but persists in the provision of ABA despite the plethora of accounts of autistic adults who received ABA as children describing the ways the therapy abused them; the pro-ABA community insists that ABA leads to increased independence for people with autism, despite the...
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fact that ABA cultivates a mindset of self-quieting and compliance\(^\text{27}\); ABA suppliers represent themselves as experts in autism despite the factual situation that training in autism, brain function, and child development is not required to become an ABA practitioner; the pro-ABA community denies that ABA is ableist despite the eugenist views expressed by its founder, Ole Ivar Lovaas (discussed further in Section D); and the pro-ABA community recommends ABA for children with nonverbal or “severe” autism, blind to the fact that studies do not exist that validate ABA’s efficacy for this group.

As it stands, the business of ABA is poised to reach a market value of $2.45 billion by 2025.\(^\text{28}\) The growth of the neurodiversity movement in autism is a direct result of the practice of ABA on the autism population—they are fighting back against a billion-dollar industry of pseudoscience professionals who are profiting off of institutional child abuse.

D. Ableist\(^\text{29}\) History, Eugenics, and Comparison to Conversion Therapy

The history of ABA has been sanitized to appeal to caregivers. I know this because I reiterated much of it in my original paper. Ole Ivar Lovaas, who is widely considered the father of ABA, was an involved pioneer in conversion therapy and a supporter of eugenics, and the history and development of ABA largely parallels that of conversion therapy.\(^\text{30}\)

II. OTHER POINTS OF CORRECTION AND CLARITY

I would also like to correct a few additional assertions, associations, and terminology referenced and cited throughout the paper:


\(^{29}\) Abelism is defined as discrimination or social prejudice against people with disabilities based on the belief that typical abilities are superior. It can manifest as an attitude, stereotype, or an outright offensive comment or behavior. See Rakshitha Arni Ravishankar, Why You Need to Stop Using These Words and Phrases, H ARVARD B USINESS R EVIEW (Dec. 15, 2020), https://hbr.org/2020/12/why-you-need-to-stop-using-these-words-and-phrases [perma.cc/BK4B-29DL].

“Special Needs”: the use of this term to describe people with disabilities is outdated and tone-deaf.31

“Treatment”: the author regrets the suggestion in the paper that people with autism need treatment.

“Severity, mild”: the author regrets alluding to the medical model of autism throughout the paper through the usage of outdated autism spectrum terminology.

The author supports the use of other services, such as speech therapy, occupational therapy, communication devices, sensory integration therapy, etc., to assist individuals with autism.

Contemporaneously with the publication of this retraction, the author has notified the courts, representatives, and other authors who have cited her work of this retraction, and has made similar efforts to retract other writings on ABA with other journals as well.

CONCLUSION

It pains me deeply that I was ever involved in furthering ABA, and I hope this retraction will be a productive step in undoing the harm that has been done to the autistic community. I've had my arm around my brother for our entire lives together, and my love for him is such that I would put aside my own discomfort at the dynamics of ABA in order to prioritize his needs, which, due to the circumstances of our childhood, were framed to me as being intensive ABA therapy. With greater education, knowledge stemming from the increasing visibility of autistic voices, and personal and professional experiences within this community over the past few years, I am convinced that the opposite is true. While this letter is a thorough explanation of many of my thoughts on ABA, it is not exhaustive, the discussion is long from over, and there is much more to be uncovered and said. The story of autism up until now has been told by the voices of everyone but autistic individuals, who have a right to be heard and respected where their wellbeing is concerned. I will do my best to support them as the discussion gains momentum and takes shape.

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