

A RESPONSE TO “*THOU SHALT NOT RATION JUSTICE*”: APPLIED BEHAVIOR ANALYSIS CAUSES HARM

Ariana Cernius*

In recent years, I have come to regret writing an Article published in the *Journal of Legislation* in 2018, “*Thou Shalt Not Ration Justice*”: *The Importance of Autism Insurance Reform for Military Autism Families, and the Economic and National Security Implications of Improving Access to ABA Therapy Under TRICARE*.¹ This piece analyzes TRICARE military insurance coverage of Applied Behavior Analysis (“ABA”) therapy for autism families, and my views on equity of access to health care services, the provision of consistent and strong support to military families, and the maintenance of appropriate reimbursement for healthcare professionals have not changed. However, my perspective on ABA therapy, and therefore on whether TRICARE should reimburse subscribers for ABA therapy (a proposition I answered affirmatively in “*Thou Shalt Not Ration Justice*”) has been transformed in recent years. A synopsis of my updated thoughts was recently published in the *Harvard Law and Policy Review*.²

In September 2021, the Autistic Self Advocacy Network (“ASAN”) released a white paper report on the ethics, evidence, and efficacy concerns regarding ABA.³ The paper states, in relevant part, “Autistic people (especially autistic people of color, autistic women, and non-binary people, autistic young people, autistic people from the Global South, nonspeaking autistic people, and autistic people with intellectual disabilities) have been systematically excluded from academia.”⁴ I agree with the authors from ASAN and regard their work as thoughtful, well-supported, and worthy of academic consideration. I encourage everyone to read and share it widely.

In the aftermath of retracting my prior written work on ABA, I have received outreach from autistic individuals from across the globe. I have felt honored to hear from this community and am thankful to those who have been in touch. I have also

* Anyone trying to get in touch to discuss may reach me at my publicly listed email on the State Bar of California website: <https://apps.calbar.ca.gov/attorney/Licensee/Detail/318296>. Thank you to the editors of the *Journal of Legislation* for working together with me on this Essay.

1. Ariana Cernius, “*Thou Shalt Not Ration Justice*”: *The Importance of Autism Insurance Reform for Military Autism Families, and the Economic and National Security Implications of Improving Access to ABA Therapy Under TRICARE*, 44 J. LEGIS. 201 (2017).

2. Ariana Cernius, *Statement of Retraction & Withdrawal: “No Imbecile At All”: How California Won the Autism Insurance Reform Battle, and Why Its Model Should be Replicated in Other States*, 10 HARV. L. & POL’Y REV. 661 (2022).

3. *For Whose Benefit?: Evidence, Ethics, and Effectiveness of Autism Interventions*, AUTISTIC SELF ADVOCACY NETWORK, <https://autisticadvocacy.org/wp-content/uploads/2021/12/ACWP-Ethics-of-Intervention.pdf> [<https://perma.cc/QJ4R-5NVR>].

4. *Id.* at 27.

received responses from other stakeholders in the community, including practitioners, parents, and researchers. I appreciate the level of engagement, and I have consolidated my thoughts in this more public forum rather than respond individually.

Several practitioners have reached out to suggest that autistic individuals harmed by ABA have experienced “bad,” outdated, or improperly delivered ABA. Others have offered the concept of “trauma-informed ABA” as a solution. I disagree. ABA is anecdotally linked to trauma-based syndromes in autistic people on a global scale;⁵ this is not a local, regional, national, or company-specific phenomenon. The breadth and consistency of the accounts of trauma experienced by ABA recipients indicates there is something inherently wrong with the practice itself rather than with the way it is being practiced or the quality of its oversight and regulation.

And practitioners’ willingness to assume those complaining about ABA have simply experienced low-quality ABA, and their use of this assumption as a basis to continue providing ABA without proper investigation, strikes me as reckless and dismissive, given the gravity of the complaints put forth.

Others who responded have raised the evidence-based nature of ABA in its defense. That the imbalance of peer-reviewed research currently favors ABA seems to reflect of a lack of funding behind research that meaningfully incorporates and respects autistic experiences, rather than a lack of truth.

Finally, in recent months, I have been directed by the autistic community to “Autistic Twitter” and similar online communities on other social media platforms.⁶ For those who are unfamiliar, as I was, with this collective, it is the autistic community’s attempt at answering the lack of services responsive to their needs given that the services space is currently monopolized by ABA.

As a human being, I feel the need to emphasize that these people have been so hurt by the current therapy construct that they believe neurotypical people (1)

5. Jennifer Jabut, “*You Can’t Train Autism Out of Me*”: *Identifying Themes from Autistic Adults’ Social Media Content About Applied Behavior Analysis* (2019) (M.A. thesis, University of Pittsburgh), <http://d-scholarship.pitt.edu/43217/1/Jabaut%2C%20Jennifer%20MPH%20Thesis%202022.pdf> [https://perma.cc/NY6N-9RNC]; see also Hanna Violet, Beep Beep Breakfast Momcast, *Nothing About Us Without Us: ABA Therapy from an Autistic Perspective*, SPOTIFY FOR PODCASTERS (June 23, 2022), <https://anchor.fm/hannavioletschwank/episodes/Nothing-about-us-without-us-ABA-Therapy-from-an-Autistic-Perspective-e1kdc0>; Interview: JayJay Mudridge, NEURODIVERSITY NEWS (Nov. 11, 2020), <https://neurodiversitynews.net/interview-jayjay-mudridge/> [https://perma.cc/WHM4-TB73]; *Results and Analysis of the Autistic Not Weird 2022 Autism Survey*, AUTISTIC NOT WEIRD (Mar. 23, 2022), <https://autisticnotweird.com/autismsurvey/> [https://perma.cc/7V4X-G2HG].

6. See, e.g., @autisticats, TWITTER, <https://twitter.com/autisticats> (last visited Mar. 24, 2023); #NeurotypicalAwareness (illustration), in TheNTWife, FACEBOOK (Apr. 11, 2018), <https://www.facebook.com/theNTwife/posts/pfbid0sG5GEaucHuXRiNchLechi5rIpovtWTasHnsVdbPugHLkaarKPkKxR3zF6LqjWM8il> [https://perma.cc/A79E-PLU7]; *Cure Neurotypicality Now* (illustration), in ManicMolotov, *Meme from @wellmeaningneurotypicals on Instagram*, REDDIT (Nov. 16, 2022), https://www.reddit.com/r/autism/comments/ywkv4f/meme_from_wellmeaningneurotypicals_on_instagram/ [https://perma.cc/L43A-KDDS]; *I Love Someone with Neurotypicalness—The Autism Meme Leaving Many in Tears (Of Laughter)*, LIVING ON THE SPECTRUM (Feb. 17, 2023), <https://www.livingonthespectrum.com/current-events/i-love-someone-with-neurotypicalness-the-viral-autism-meme/> [https://perma.cc/6B72-U3BL].

experience the need to self-stimulate, or “stim,” but instead suppress their stims or turn to more socially acceptable ones for the sake of appearances; (2) care deeply about eye contact and force it upon others; (3) do not like them and are seeking to get rid of them; and (4) cannot or will not productively listen to their experiences with ABA.

They have found every system so nonresponsive when they attempt to report this state of affairs that they have organized themselves into comfort groups on Twitter to brainstorm and develop their own framework and services.

I understand and empathize with the behavioral and respite needs within autism families that must be addressed, and that many families are dependent, for a variety of reasons, on ABA.⁷ I also understand that many of these reasons, especially within black, indigenous, and people-of-color communities, have to do with safety in connection with other institutionalized harms experienced on a daily basis that I, as a white woman, cannot directly relate to. I further understand, as someone who previously expressed support for ABA, the reluctance to abandon something that has been framed as the gold standard in favor of an uncertain services model.

However, I have yet to encounter an autistic person who does not tell the truth to a fault, and do believe we can do better to meet the diverse needs of the community than compliance therapy and Twitter. There is strong evidence emerging that the former is harmful,⁸ and the latter is not a service provider.

The medical community’s original recommendation regarding behavior modification for autistic people was that it would be ineffective.⁹ This instinct has now been proven out by the overwhelming majority of accounts of autistic individuals who have undergone ABA, which are strongly supported by several recent studies. Such studies include the Department of Defense’s findings in its 2020 “Comprehensive Autism Care Demonstration Annual Report” that engaged 3,794 participants and found that “ABA services are not working.”¹⁰ The report also raised concern within the department “about these results, and whether the current design of this demonstration, as well as ABA services specifically, is providing the most appropriate and/or effective services to our beneficiaries diagnosed with ASD.”¹¹

7. *Respite*, DEP’T OF DEVELOPMENTAL SERVS., <https://www.dds.ca.gov/services/crisis-safety-net-services/respite/> [https://perma.cc/D2D6-N3BW].

8. Faye Fahrenheit, *An Open Letter to the NYT: Acknowledge the Controversy Surrounding the ABA*, NEUROCLASTIC (June 11, 2020), <https://neuroclastic.com/an-open-letter-to-the-nyt-acknowledge-the-controversy-surrounding-aba/> [https://perma.cc/5QYG-AQUF]; see Aileen Herlinda et al., *How Much Compliance Is Too Much Compliance: Is Long-term ABA Therapy Abuse?*, COGENT PSYC. (July 10, 2019), <https://www.tandfonline.com/doi/full/10.1080/23311908.2019.1641258> [https://perma.cc/596S-9GJY].

9. *Autism: Present Challenges, Future Needs—Why the Increased Rates?: Hearing Before the H.R. Comm. on Gov’t Reform*, 106th Cong. 327–477(2000) (statement of Bernard Rimland).

10. Barry R. Nathan, *ABA Is Not Effective: So Says the Latest Report from the Department of Defense*, THERAPIST NEURODIVERSITY COLLECTIVE, <https://therapistndc.org/aba-is-not-effective-so-says-the-latest-report-from-the-department-of-defense/> [https://perma.cc/8NH2-24UR].

11. *Id.*

The original promise of nonmaleficence of the Hippocratic oath places an ethical duty on the medical community to step in, self-regulate, and re-assess when harm is being done. The medical community, along with government and other agencies that have supported ABA, should direct financial backing to studying ABA's impact on the autistic community and work collaboratively with its members to assemble a services package that is more responsive to patient needs.

I regret that I am not able to offer more immediate relief to this community.