AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 706

(A-23)

Introduced by: Medical Student Section

Subject: Revision of H-185.921, Removal of AMA Support for Applied Behavior

Analysis

Referred to: Reference Committee G

Whereas, A 2018 study from the Centers for Disease Control and Prevention (CDC) estimated the prevalence of autism spectrum disorder (ASD) among adults aged 8 years to be 1 in 44¹; and

Whereas, Applied Behavioral Analysis (ABA) is currently the most widely available and commonly used state-funded form of autism therapy in Canada and the United States^{2,3}; and

Whereas, Autism treatment represents a fragmented industry that consists of a mixture of for-profit and nonprofit organizations, with the top nine for-profit chains estimated to have a combined revenue of \$547 million and a market value close to \$2 billion with future growth expected⁴; and

Whereas, An ABA software company reports over 3 billion in claims processed annually for about 1,300 practices highlighting the prevalence of ABA use as an intervention for individuals with autism⁵; and

Whereas, Autism Speaks lists 3,194 centers across the United States who offer ABA therapy as of 2022⁶; and

Whereas, ABA was conceived in 1961 by Dr. Ole Ivar Lovaas to condition neurotypical behaviors in children he viewed as "incomplete humans" 7–10; and

Whereas, Desired behavior is often defined by the adult or behaviorist without input or requirement of consent from the child and may include non-harmful stimming or coping behaviors^{2,3,8,11,12}; and

Whereas, ABA uses behavior modification techniques to eliminate behaviors deemed undesirable^{2,8,11–14}; and

Whereas, ABA practices are historically based in abuse such as holding autistic children's communication hostage through the use of their devices as leverage, and denying basic rights such as food and toileting privileges^{2,3,8,11,14–18}; and

Whereas, Modern ABA still abides by the founding principle of making a child appear "normal" or "indistinguishable from one's peers", which serves to separate the humanity of the individual with autism from desired behaviors^{2,8,15}; and

Whereas, A 2018 study found that Adults with autism who have received ABA are more prone to suicide¹⁹; and

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Whereas, ABA has been repeatedly linked to Post Traumatic Stress Disorder (PTSD), with 1 2 46% of 460 ABA participants meeting the diagnostic threshold for PTSD in an online 3 survev²⁰: and 4 5 Whereas, Adults with autism have been continuously outspoken about the trauma incurred 6 by ABA practices experienced in their childhood^{2,14,16–18}; and 7 8 Whereas, A 2012 literature review found the evidence base for services for adults with an 9 ASD to be underdeveloped²¹; and 10 11 Whereas, A 2018 Cochrane review recommend further research after reporting very weak 12 evidence in support of ABA²²; and 13 14 Whereas, A 2022 informal online community survey found that 71% of adults with autism 15 responded "disagree" or "strongly disagree" to the statement "Generally speaking. I support 16 ABA therapy for autistic children"23; and 17 18 Whereas, A 2020 Department of Defense report demonstrated a lack of correlation between 19 improvement in symptoms and hours of direct ABA services, found that the improvements 20 recorded were due to reasons other than ABA services, and ABA services did not meet the 21 TRICARE hierarchy of evidence standard for medical and proven care²⁴; and 22 23 Whereas, A 2021 study on conflicts of interest (COIs) in autism early intervention research found COIs to be prevalent and under-reported, with 70% of studies containing a conflict of 24 25 interest and less than 6% declaring them as such²⁵; and 26 27 Whereas, Current research supports alternatives to ABA such as the Developmental, 28 Individual Differences, and Relationship-based (DIRTM) program, the PLAY Project, 29 individualized Early Social Interaction (ESI) and, Social Communication, Emotional 30 Regulation, and Transactional Support (SCERTSTM)^{24,26–29}; and 31 32 Whereas, Current AMA policy supports the use of ABA through its advocation of coverage of 33 ABA and the evidence-based treatment for autism and fails to recognize its harms or 34 controversial nature within the community at large; therefore be it 35 36 RESOLVED. That our American Medical Association support research towards the evaluation and the development of interventions and programs for autistic individuals (New 37 38 HOD Policy); and be it further 39 40 RESOLVED, That our AMA work with relevant stakeholders to advocate for a comprehensive spectrum of primary and specialty care that recognizes the diversity and personhood of 41 42 individuals who are neurodivergent, including people with autism (Directive to Take Action); 43 and be it further

RESOLVED, That our AMA amend Policy H-185.921 "Standardizing Coverage of Applied

Behavioral Analysis Therapy for Persons with Autism Spectrum Disorder" by addition and

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deletion as follows:

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Standardizing Coverage of Applied Behavioural Analysts
Therapy for Persons with Autism Spectrum Disorder, H 185.921

4 Our AMA supports coverage and reimbursement for evidence-

- 5 based treatment of services for Autism Spectrum Disorder
- 6 including, but not limited to, Applied Behavior Analysis Therapy.
- 7 (Modify Current HOD Policy)

Fiscal Note: TBD

Received: 4/3/23

REFERENCES

- Maenner MJ. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018. MMWR Surveill Summ. 2021;70. doi:10.15585/mmwr.ss7011a1
- 2. Wilkenfeld DA, McCarthy AM. Ethical Concerns with Applied Behavior Analysis for Autism Spectrum "Disorder." *Kennedy Inst Ethics J.* 2020;30(1):31-69. doi:10.1353/ken.2020.0000
- Gruson-Wood JF. I'm a Juggling Robot: An Ethnography of the Organization and Culture of Autism-Based Applied Behaviour Therapies in Ontario, Canada. Published online August 24, 2018. Accessed March 12, 2022. https://yorkspace.library.yorku.ca/xmlui/handle/10315/35587
- John LaRosa. \$2 Billion Ú.S. Autism Treatment Market Is Poised for Growth Next Year. MarketResearch.com. Published December 16, 2020. Accessed April 15, 2022. https://blog.marketresearch.com/2-billion-u.s.-autism-treatment-market-is-poised-for-growth-next-year
- CentralReach. ABA and Behavioral Health Software. Published 2022. Accessed April 15, 2022. https://centralreach.com/
- Autism Speaks. Resource Guide | Autism Speaks. Published 2022. Accessed April 15, 2022. https://www.autismspeaks.org/resource-guide
- 7. Rubino S. The man behind ex-gay "conversion therapy" started out trying to make autistic children "normal." LGBTQ Nation. Published March 17, 2021. Accessed March 12, 2022. https://www.lgbtqnation.com/2021/03/man-behind-ex-gay-conversion-therapy-started-trying-make-autistic-children-normal/
- 8. Pyne J. "Building a Person": Legal and Clinical Personhood for Autistic and Trans Children in Ontario. Can J Law Soc Rev Can Droit Société. 2020;35(2):341-365. doi:10.1017/cls.2020.8
- Rekers GA, Lovaas Ol. Behavioral Treatment of Deviant Sex-Role Behaviors in a Male Child1. J Appl Behav Anal. 1974;7(2):173-190. doi:10.1901/jaba.1974.7-173
- 10. Gibson MF, Douglas P. Disturbing Behaviours: Ole Ivar Lovaas and the Queer History of Autism Science. *Catal Fem Theory Technoscience*. 2018;4(2):1-28. doi:10.28968/cftt.v4i2.29579
- Sandoval-Norton AH, Shkedy G. How much compliance is too much compliance: Is long-term ABA therapy abuse? Rushby JA, ed. Cogent Psychol. 2019;6(1):1641258. doi:10.1080/23311908.2019.1641258
- Enright J. The "Gold Standard" for Autistic Children. Fourth Wave. Published February 14, 2022. Accessed March 12, 2022. https://medium.com/fourth-wave/the-gold-standard-for-autistic-children-e815e9e7316a
- 13. Silberman S. Neurotribes: The Legacy of Autism and the Future of Neurodiversity. Penguin; 2015.
- Carol Millman. Is ABA Really "Dog Training for Children"? A Professional Dog Trainer Weighs In. NeuroClastic. Published March 27, 2019. Accessed March 12, 2022. https://neuroclastic.com/is-aba-really-dog-training-for-children-a-professional-dog-trainer-weighs-in/
- Faye Fahrenheit. An Open Letter to the NYT: Acknowledge the Controversy Surrounding ABA. NeuroClastic. Published January 12, 2020. Accessed March 12, 2022. https://neuroclastic.com/an-open-letter-to-the-nyt-acknowledge-the-controversy-surrounding-aba/
- ABA Horror Stories Are Far Too Common. NeuroClastic. Published August 17, 2021. Accessed March 12, 2022. https://neuroclastic.com/aba-horror-stories-are-far-too-common/
- 17. The Great Big ABA Opposition Resource List. Stop ABA, Support Autistics. Published August 11, 2019. Accessed March 12, 2022. https://stopabasupportautistics.home.blog/2019/08/11/the-great-big-aba-opposition-resource-list/
- Finn Gardiner. First-Hand-Perspectives-on-Behavioral-Interventions-for-Autistic-People-and-People-with-other-Developmental-Disabilities.pdf. Published online 2017. Accessed April 15, 2022. https://autisticadvocacy.org/wp-content/uploads/2017/07/First-Hand-Perspectives-on-Behavioral-Interventions-for-Autistic-People-and-People-with-other-Developmental-Disabilities.pdf
- 19. Cassidy S, Bradley L, Shaw R, Baron-Cohen S. Risk markers for suicidality in autistic adults. *Mol Autism*. 2018;9(1):42. doi:10.1186/s13229-018-0226-4
- 20. Kupferstein H. Evidence of increased PTSD symptoms in autistics exposed to applied behavior analysis. *Adv Autism*. 2018;4(1):19-29. doi:10.1108/AIA-08-2017-0016
- 21. Shattuck PT, Roux AM, Hudson LE, Taylor JL, Maenner MJ, Trani JF. Services for Adults With an Autism Spectrum Disorder. *Can J Psychiatry Rev Can Psychiatr*. 2012;57(5):284-291.
- Reichow B, Hume K, Barton EE, Boyd BA. Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD). Cochrane Database Syst Rev. 2018;5:CD009260. doi:10.1002/14651858.CD009260.pub3

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- 23. Chris Bonnello. 11,521 people answered this autism survey. Warning: the results may challenge you. Autistic Not Weird. Autistic not Weird. Published October 1, 2018. Accessed April 15, 2022. https://autisticnotweird.com/2018survey/
- 24. The Department of Defense. The Department of Defense Comprehensive Autism Care Demonstration Annual Report. The Department of Defense; 2020:35. Accessed April 15, 2022. https://iacc.hhs.gov/news/2020/annual_autism_care_report_2020.pdf
- 25. Bottema-Beutel K, Crowley S. Pervasive Undisclosed Conflicts of Interest in Applied Behavior Analysis Autism Literature. *Front Psychol.* 2021;12. Accessed April 15, 2022. https://www.frontiersin.org/article/10.3389/fpsyg.2021.676303
- 26. Wong C, Odom SL, Hume K, et al. Evidence-Based Practices for Children, Youth, and Young Adults with Autism Spectrum Disorder. :114.
- 27. Solomon R, Van Egeren LA, Mahoney G, Quon Huber MS, Zimmerman P. PLAY Project Home Consultation Intervention Program for Young Children With Autism Spectrum Disorders: A Randomized Controlled Trial. *J Dev Behav Pediatr*. 2014;35(8):475-485. doi:10.1097/DBP.0000000000000096
- Autistic Advocacy.org. Health-Insurance-and-Medicaid-Coverage-for-Autism-Services-A-Guide-for-Individuals-and-Families-7-9-15.pdf. Published online July 2015. Accessed March 12, 2022. https://autisticadvocacy.org/wp-content/uploads/2015/07/Health-Insurance-and-Medicaid-Coverage-for-Autism-Services-A-Guide-for-Individuals-and-Families-7-9-15.pdf
- 29. Wetherby AM, Guthrie W, Woods J, et al. Parent-implemented social intervention for toddlers with autism: an RCT. *Pediatrics*. 2014;134(6):1084-1093. doi:10.1542/peds.2014-0757

RELEVANT AMA POLICY

Early Intervention for Individuals with Developmental Delay H-90.969

(1) Our AMA will continue to work with appropriate medical specialty societies to educate and enable physicians to identify children with developmental delay, autism and other developmental disabilities, and to urge physicians to assist parents in obtaining access to appropriate individualized early intervention services. (2) Our AMA supports a simplified process across appropriate government agencies to designate individuals with intellectual disabilities as a medically underserved population. Citation: CCB/CLRPD Rep. 3, A-14; Reaffirmed: Res. 315, A-17;

Community-Based Treatment Centers H-160.963

Our AMA supports the use of community-based treatment centers for substance use disorders, mental health disorders and developmental disabilities.

Citation: BOT Rep. F, I-91; Reaffirmed: Sunset Report, I-01; Modified: CSAPH Rep. 1, A-11; Modified: CSAPH Rep. 1, A-21;