



National Coalition for Access to Autism Services

September 30, 2019

The Honorable James N. Stewart
Assistant Secretary of Defense for Manpower and Reserve Affairs,
Performing Duties of the Under Secretary of Defense
for Personnel and Readiness
1500 Defense Pentagon 2E556,
Washington, DC 20301

Dear Secretary Stewart,

We are writing to you to share our factual and policy concerns about the recently released “*Department of Defense Comprehensive Autism Care Demonstration Annual Report*,” June 2019. The National Coalition for Access to Autism Services (NCAAS) represents providers and advocates of evidence-based autism treatment serving tens of thousands of families affected by autism spectrum disorder (ASD), including 16,000 military families. We write to you once again because the Department of Defense continues to challenge the efficacy of Applied Behavior Analysis (ABA) for the treatment of ASD. All commercial insurers and state health care services agencies have determined ABA to be an effective treatment for ASD. All 50 states mandate commercial coverage of the treatment of autism. Yet despite this evidence, and even the conclusions of other federal agencies,¹ the Department continues to express doubt about the value of ABA for treating ASD. In particular, we raise the following concerns with the June 2019 Annual Report.

Efficacy of ABA Treatment

The Department of Defense has in the past and continues to assert that there is a lack of “reliable evidence” for the use of ABA services. We have provided with this letter and submitted in a May 30th letter to the Department several studies that meet the Department’s “reliable evidence” standard (codified at 32 CFR 199.2) yet the Department fails to acknowledge such studies. Our literature review includes 479 studies² published in peer-reviewed medical literature and surely qualify under the Department’s reliable evidence standard. Sixty-one of these studies are well-controlled between-groups experimental studies, 11 are well-controlled meta-analyses of published data, and 407 are well-controlled within-subjects experimental studies. The Department, in support of its lack of credible evidence assertion, cites analysis by the Cochrane Database of Systemic Reviews which found the quality of research on ABA it reviewed was “low or very low.” The Department fails to note, however, that the Cochrane analysis only *examined five studies*. Nonetheless, it still found ABA to be beneficial for some children with ASD. In contrast, the U.S. Agency for Healthcare Research

¹ See “FAQs About Mental Health and Substance Use Disorder Party Implementation and the 21st Century Cures Act Part 39,” U.S. Department of Labor, p. 4-5 (Sept 5, 2019) available at <https://www.dol.gov/sites/dolgov/files/EBSA/about-ebsa/our-activities/resource-center/faqs/aca-part-39-final.pdf>.

² See attachment. Note this list also includes 47 reports by national professional medical associations, policy organization positions, and expert opinion organizations that support the medical effectiveness of ABA including the Surgeon General of the United States, the U.S. Agency for Healthcare Research and Quality, the American Academy of Pediatrics, the American Psychological Association, the Blue Cross and Blue Shield Technology Evaluation Center, and the American Academy of Child and Adolescent Psychiatry.

and Quality conducted a much more extensive review of 65 studies and found children receiving ABA-based interventions demonstrate improvements in cognitive, language, adaptive, and ASD impairments compared to children low-intensity and non-ABA-based interventions.³

The Department of Defense asserted in its June 2018 ACD Annual Report that the clinical efficacy in the documented literature on ABA treatment of ASD “does not meet the American Medical Association (AMA) evidence-based medicine level standards for category I codes.”⁴ However, in the fall of 2018 the AMA adopted several Category I codes for ABA (adaptive behavior) services which TRICARE adopted on January 1, 2019. In this year’s Annual Report, this AMA assertion goes away, but the Department continues to insist that ABA services do not meet the “reliable evidence” standard. That hierarchical standard, however, in no way suggests that within-subjects experimental studies are not acceptable, particularly if they have had meaningful endpoints and are published in peer-reviewed medical literature, as are the studies we have supplied to the Department. Additionally, there is no requirement that randomized trials are a part of the Department’s reliable evidence regulation as has been asserted by Department officials; and even if the Department were to insist on randomized studies, these raise serious ethical considerations involving children, especially those children who would need to go untreated in a randomized controlled study.

In addition to discounting the available research, the Department holds that there are no standards of care for ASD treatment. This assertion seems to once again ignore the heterogeneity of ASD; the fact that the same treatment protocol will not work for every patient; and the Behavior Analyst Certification Board (BACB)’s best practices followed by all treatment professionals.⁵ While the treatment of ASD may not have one universal protocol, standards do exist for treatment practices and should not be discounted.

NCAAS encourages the Department to reconsider its stance on the efficacy of ABA for ASD treatment and remove the threat of withdrawing treatment by the Department’s continual insistence that ABA fails to meet its reliable evidence regulation. These policy statements have serious implications for military families’ continued reliable access to medically necessary services.

Continued Reliance on PDDBI Data

Once again, the Department uses the analysis of the Pervasive Development Disabilities Behavior Inventory (PDDBI) to argue ABA services have shown little results. The FY 2019 First Quarter Report, which the Department issued 31 days before the Annual Report, readily recognizes the flaws in the PDDBI data and cautions against using it to draw conclusions⁶; yet the Department asserts the PDDBI analysis’ credibility 31 days later. The Department should be consistent in its treatment of PDDBI data. NCAAS has commented previously on the improper use and inaccuracy of this data to show patient improvement and remains concerned it continues to be used. The Department’s citation of the PDDBI report notes it was only able to use reports submitted by one of two contractors, leaving half the country unrepresented in its analysis. In addition, the PDDBI reports it did review represent only approximately 10.6 percent of beneficiaries participating in the ACD and only 8 percent of total beneficiaries diagnosed with ASD. The Department should reassess how the PDDBI data is interpreted and be consistent in its treatment of PDDBI data.

³ Weitlauf, et al. (2014). Therapies for Children With Autism Spectrum Disorder: Behavioral Interventions Update. Comparative Effectiveness Review No. 137. (Prepared by the Vanderbilt Evidence-based Practice Center under Contract No. 290-2012-00009-I.) AHRQ Publication No. 14-EHC036-EF. Rockville, MD: Agency for Healthcare Research and Quality, pp. ES-11

⁴ See “Criteria for CPT Category I and Category III codes,” American Medical Association *available at* <https://www.ama-assn.org/practice-management/cpt/criteria-cpt-category-i-and-category-iii-codes>.

⁵ See “Applied Behavior Analysis Treatment of Autism Spectrum Disorder: Practice Guidelines for Healthcare Funders and Managers,” Behavior Analyst Certification Board, 2nd ed. *available at* https://www.bacb.com/wp-content/uploads/2017/09/ABA_Guidelines_for_ASD.pdf.

⁶ *Autism Care Demonstration Quarterly Report to Congress, First Quarter, Fiscal Year 2019*, Defense Health Agency, p. 12 (July 2019).

Proposed Manual Revisions

In the Annual Report, the Department suggests several changes it may make to the ACD Manual. We recommend that the Department not rely on the acknowledged flawed data which it cites in the Annual Report as the basis for the proposed Manual changes. In addition, these potential limitations completely contradict the best practices developed by BACB and used by all ABA treatment professionals and disregard the standard of care among the nation's health plans and insurers.

Treatment Hours

The Department suggests amending the ACD Manual to include utilization management controls. However, the Department provides no further details on how it would implement these "solutions" or what patient impact they may have. The report discusses a Congressionally Directed Medical Research Program (CDRMP) study comparing an "adaptive model" (20 hours or less per week) to standard early intensive intervention of 20 hours or more per week. NCAAS notes that by the Department's own reporting,⁷ TRICARE beneficiaries in only one state – Indiana – currently receive the 20 hours standard early intensive intervention threshold, with most states falling far, far below the 30 to 40 hours recommended in the ABA literature for early intensive intervention. This suggests that children in the ACD are receiving levels of care far less than recommended in the ASD literature and far below their civilian counterparts.

Parent Participation

The Department holds that patient outcomes are better when parents are actively involved in treatment citing its own PDDDBI analysis and other research. However, the Department provides no citation for this research in the report. NCAAS is concerned this assertion could lead to discrimination against families of individuals with ASD. The statement "if families cannot support intensive services for ASD, then family issues should be addressed first" suggests treatment for a child should be postponed if there cannot be adequate parent involvement or support. This would be a serious detriment to children with ASD as early intervention is critical for affected children, and it is well understood that any postponement of services will only hurt the child. Such a policy also discriminates against military families where parents may not always be available to participate in treatment due to deployment and duty schedules over which they have little control. In addition, requiring parent involvement would violate mental health parity and subject active duty and retired servicemembers and their families to benefits unequal to those readily provided in the private sector. Early intervention is critical, and any imposed delays will only produce irreparable harm to affected children.

Thank you for taking the time to consider our concerns. NCAAS hopes to serve as a resource for the Department and provide any assistance we can to help strengthen the ACD.

We look forward to your response,

Sincerely,



Michael E. Moran
Chairman

Cc:

House Committee on Armed Services
Senate Committee on Armed Services

⁷ *Id* at P. 8 – Average Hours per Week per Beneficiary