Exceptional Families
of the Military

One Community,
One Voice

CASP The Council of Autism
Service Providers

Association of
apba
Professional
Behavior Analysts

June 30, 2021

On behalf of our nonprofit organizations supporting military families who have children diagnosed with autism spectrum disorders (ASD) and providers of applied behavior analysis (ABA) services, we are writing to share the attached letter to the Defense Health Agency (DHA) outlining concerns, questions, and requests regarding changes in policies governing the TRICARE Autism Care Demonstration (ACD) program that appear in the latest version of Chapter 18 of the TRICARE Operations Manual (TOM). The letter reflects input from numerous ACD beneficiaries, ABA providers, and concerned professionals as well as discussions with several members of Congress.

If you have any questions about the attached document or would like additional information, please do not hesitate to contact us.

Respectfully,

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June 30, 2021

Lieutenant General Ronald Place
Director, Defense Health Agency
7700 Arlington Boulevard, Suite 5101
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22042-5101
via email: ronald.j.place.mil@mail.mil

Dear Lieutenant General Place:

We are writing as representatives of three nonprofit organizations that support TRICARE beneficiaries with autism spectrum disorders and the families and providers who care for them -- Exceptional Families of the Military (EFM), the Association of Professional Behavior Analysts (APBA), and the Council for Autism Service Providers (CASP) -- regarding the changes to policies governing the TRICARE Autism Care Demonstration (ACD) that were published in the TRICARE Operations Manual (TOM) on March 23, 2021. Although we appreciate that some of the new policies might result in improvements to the ACD, many of them provoke serious concerns that providers of applied behavior analysis (ABA) services may find it difficult to deliver services that comport with professional standards of care, and that ACD beneficiaries will find it more difficult to access effective services than it is already. We respectfully offer the following comments, questions, and requests in the spirit of collaborating to help ensure the military readiness of families who have children diagnosed with autism spectrum disorder (ASD). They are presented with reference to specified paragraphs and subparagraphs of Chapter 18 of the TOM.

3.4 indicates that the goal of the ACD is to determine what beneficiary age groups utilize and benefit most from ABA interventions. Please explain exactly how the DHA will make those determinations, in particular how "benefit" will be defined and measured and by whom.

3.5 How does the DHA plan to examine the relationship between receipt of ABA services and utilization of the "established" medical interventions that are listed? How are "relationship" and "established" defined? How will such findings be used?

4.2.1.1 & 4.2.1.2 Requiring beneficiaries to be diagnosed via the administration of a validated assessment tool by an accepted or specialized TRICARE diagnosing provider will delay access to care. Many of the diagnosing provider types listed do not own the specified diagnostic instruments. Additionally, many diagnosing providers accept appointments in 15-minute time slots, so the time required to administer the listed diagnostic instruments may not be built into their practice schedule. In those instances, families may be referred to a developmental pediatrician or child clinical psychologist. Needless to say, that results in the loss of invaluable time until treatment can begin. We urge you to remove the requirement for an accepted or specialized diagnosing TRICARE provider to render a diagnosis before the beneficiary can begin receiving services. Please allow the beneficiary a year to obtain a confirmatory diagnosis so as to not delay their access to care.

4.4 Please clarify the qualifications and role of the non-clinical outreach coordinator. How will they help families meet eligibility requirements? What training and competencies will they have that are specific to identifying appropriate providers, support groups, and local services for military families of children with ASD?

6.0 AUTISM SERVICES COORDINATION

Although we appreciate the need for coordination of care, many beneficiaries and providers have very serious concerns about the Autism Service Navigator (ASN) as described here and in paragraph 11.11. The concerns include but are not limited to the following:

- Families are deeply offended that the ASN is identified as the primary advocate for the child. A funding source could never begin to understand the heartache, stress, work, effort, compassion,

and most of all the love that every parent pours into advocating for their child with ASD. There is no substitute for a parent as the primary advocate.

- It is unclear how the roles of the "non-clinical outreach coordinators" and ASNs will differ and how they will be integrated or coordinated. That creates confusion for contractors, providers, and beneficiaries alike, with the latter likely to suffer the effects of delayed, disrupted, and fragmented services.
- It appears that ASNs would function as gatekeepers with significant influence over the information and services families receive. Given the complex nature of ASD, the plethora of interventions that are promoted for the disorder, and the quantities of information and disinformation with which families of people with ASD are bombarded, it would seem essential for individuals in such a powerful role to be very knowledgeable about the characteristics of ASD, evaluating scientific evidence about all manner of medical and behavioral interventions, the various service systems that parents of children with ASD must navigate, coordinating multidisciplinary services for children with ASD, and more. We find no assurances in the TOM that ASNs will be required to demonstrate competence in those and related areas critical to effective care coordination for this population.
- In a similar vein, we find no assurance that ASNs will have the knowledge and skills required to develop comprehensive care plans (CCPs), 6-month updates, discharge plans, and transition plans for children with ASD as required in this section of the TOM. Even if they did, there is concern that the requirement for the ASN to complete the CCP and update it every 6 months will result in harmful delays to the onset or continuation of treatment.
- The provision in 6.2.2 for contractors to suspend ABA services if a family is deemed "noncompliant" with the ASN's efforts to develop a CCP is unreasonable and tantamount to punishing the child.
- Although the DHA has asserted that ASNs will provide "unbiased" treatment recommendations to beneficiaries, the fact that they will be employed by TRICARE contractors means that they cannot be truly objective and unbiased. Additionally, adding oversight of ASNs to contractors' responsibilities is likely to exacerbate the substantial challenges that beneficiaries and providers already experience in trying to coordinate care via contractors.

In light of these and other problems, we very strongly recommend (a) clarifying the functions, qualifications, and oversight of ASNs; (b) deleting the requirement for all new ACD participants to have an ASN; (c) letting all ACD beneficiaries choose whether to work with an ASN after they have been given a clear, complete description of what that individual will and will not do vis a vis the services received by the child and the family and an objective summary of scientific research on the efficacy of this service model for people with ASD and their families; and (d) allowing families to opt out of ASN services at any time without jeopardizing their other services.

8.0 ABA SERVICES

8.4.1.2.1 To be consistent with the American Medical Association's criteria for qualified health care providers (QHPs) for the services encompassed in the current CPT codes for adaptive behavior/ABA services, the most recent job task analyses for the practice of behavior analysis and the practice of psychology, most state licensure laws, and the American Psychological Association's code of ethics, after "psychology" please add, "provided that behavior analysis is in the scope of practice definition in the state psychology licensure law and the individual psychologist's scope of competence."

8.4.1.2.1 The term "full clinical practice" is ambiguous and does not typically appear in state laws to license or otherwise regulate professional practitioners of applied behavior analysis. Please replace it with "to practice applied behavior analysis independently."

8.4.2.1 gives the DHA Director authority to approve entities that certify assistant behavior analysts. We strongly recommend that the Director exercise due diligence in evaluating such entities against well-established standards for accredited programs to certify ABA practitioners (e.g., see https://cdn.ymaws.com/www.apbahome.net/resource/collection/1FDDBDD2-5CAF-4B2A-AB3F-DAE5E72111BF/APBA_Guidelines_EvaluatingCredentials_180906.pdf) .

8.4.2.3 and 8.4.2.4 After "board," please insert "or state licensing board where applicable."

8.6.2.2.1 Please specify who will conduct the "clinical necessity review" on behalf of contractors and how it will be assured that such individuals are qualified to evaluate the medical necessity of ABA services for people diagnosed with ASD.

8.6.3.1.4 Please define "clinically sufficient progress," and specify who will make that determination on behalf of the contractor and how it will be assured that such individuals are qualified to interpret the outcome measures and use those results appropriately to determine if a beneficiary has made "clinically sufficient progress." Professional standards of care call for other measures to be considered in making such determinations, individualized to each beneficiary. If other measures are to be considered, please specify; if not, please provide rationale as to why this TRICARE policy contradicts professional standards.

8.6.4 Publishers of most, if not all, of the instruments being used as outcome measures have strict policies on copying and sharing test protocols, reports, score sheets, and other copyrighted and sensitive materials. Professional behavior analysts are obligated to comply with such policies as well as related ethical standards. If the DHA is going to require ABA providers to submit the information described in this paragraph, please revise the paragraph to include clear statements that the DHA (a) has obtained explicit written permission from the publishers of each of the assessment instruments for ABA providers to share such documents with the DHA, and (b) assumes full responsibility for protecting the confidentiality of ACD beneficiaries' test results and seeing that those results are provided only to professionals who are fully qualified to interpret and use them correctly.

8.6.4.1.1 Please revise this paragraph to specify what the ABA supervisor is to do when the LBA/BCBA/BCBA-D does not meet the criteria in the PDDBI manual (p. 6) for completing the "teacher" form of the instrument: "*A teacher or other educational professional ….must have had at least daily contact (i.e., 5 days per week) for at least 1 month, or more than 4 weeks of several-days-per week contact with the child/student…*."

8.6.4.4, 8.6.4.5 Many ACD families have expressed concern that the results of these parental stress measures could jeopardize their military careers and/or their child's services. Some are reporting that merely completing the assessments is stressful. That is no doubt attributable in part to the fact that parents have not been given any explanation as to why they are being subjected to these assessments and how the DHA will use the reported results. We strongly recommend deleting these two paragraphs. If it is necessary to measure the effects of the ACD on families, we strongly recommend that the DHA consider using a quality-of-life instrument that has been validated with this population, and providing families with a clear explanation of the purpose of the assessment and how the results will be used.

8.7.1.5.3 See previous comments about the ASN, specifically their training and competence in making the kinds of complex judgements required here. Please provide rationale derived from controlled scientific studies for the requirements specified in 8.7.1.5.3. 2 - 8.7.1.5.3.3 and reconcile that evidence with the findings of several studies and meta-analyses that an eclectic mix of "therapies" is ineffective for most young children with ASD.

8.7.1.8 Is it acceptable to have the parent's signature on a document that is attached to the TP, or must their signature be under the provider's signature on the TP itself? Is an electronic signature acceptable?

8.7.2.11 Please clarify whether checked boxes indicating "techniques" used during a session are acceptable or a written narrative statement is required.

8.11.5 A recent study by Dr. Erick Dubuque and colleagues found that thousands of individuals have obtained NPI numbers using the healthcare provider taxonomy codes for Behavior Analyst, Assistant Behavior Analyst, and Behavior Technician who do not meet the American Medical Association (AMA) National Uniform Claims Committee's defined criteria for those codes. We urge the DHA to check to see if that is the case for ACD providers.

8.11.6 The policies pertaining to the current CPT codes for adaptive behavior/ABA services are not consistent with the descriptors and uses of those codes as approved by the AMA CPT Editorial Panel. We understand that the authors of those codes (members of the ABA Coding Coalition) are preparing a letter outlining the key discrepancies and recommending changes to the policies in this section of the TOM. We urge you to give their recommendations your most careful consideration.

9.1.4 Please specify exactly how contractors will determine that a beneficiary made no progress in the previous 6 months. What data and criteria will be used to make those decisions?

9.3.1 states that all contractors will be required to have an online directory for ACD providers. That will necessitate updating systems as employees enter and exit provider organizations. Unfortunately the contractors for both regions already struggle to keep their provider rosters accurate and up to date. Will providers be penalized if information on the contractor's website is incorrect?

9.3.4.3, 9.3.4.4, & 9.3.5 If the contractor does not have a record that a provider attended a training but the ACSP can document that they did, will a penalty still apply?

8.9.8.1 & 8.10.10 Please define "aversive techniques" and "restraint" with reference to applicable scientific research and professional standards and guidelines in behavior analysis rather than the definitions that have been provided by DHA officials. It is very important to note that procedures that the DHA deems "restraint" do not always involve high risk to the patient and do not always have to be implemented in in-patient settings requiring the services of nurses and physicians, as asserted in the June 24 DHA webinar for ACD beneficiaries. On the contrary, substantial research shows that the careful use of certain procedures within the framework of a bona fide ABA treatment plan are much less harmful, much more effective, and far less expensive than the chemical and mechanical restraints that are often applied to such behaviors in hospitals and other in-patient settings. Examples include briefly and gently blocking or holding a patient's hands to prevent self-injurious or aggressive behaviors, blocking attempts to consume inedible items (pica), and preventing a patient from running into an unsafe area. Those and other maladaptive behaviors are often directly related to core symptoms of ASD, such as difficulties with communication and social interaction and restricted interests and activities. Appropriate ABA interventions involving judicious use of certain restraint procedures in combination with procedures to develop core adaptive skills have been shown to prevent maladaptive behaviors from becoming dangerous and to save people with ASD from costly and ineffective admissions to hospitals and other in-patient facilities. We strongly urge the DHA to consult with behavior analysts who have the relevant expertise to develop policies to ensure that ACD beneficiaries receive the safest, most effective, least restrictive interventions for maladaptive behaviors based on the best available scientific evidence and professional standards of care.

8.10.3 ASD often affects multiple areas of functioning, either as a direct result of the core symptoms or secondary to them. ABA interventions have proved effective for ameliorating adaptive skills deficits and maladaptive behaviors so as to prevent injuries, deterioration, and regression and enhance safe, healthy functioning; hence the American Medical Association's approval of 8 Category I CPT codes for those services. The DHA's policy limiting ABA services for ACD beneficiaries to the core symptoms of ASD as those are interpreted by DHA officials contradicts the views and recommendations of many experts on ASD, the American Academy of Pediatrics, Medicaid's Early Periodic Screening, DIagnosis, and Treatment (EPSDT) program, mental health parity laws, and the best available scientific evidence. Please revise that policy to better align with widely accepted views of medically necessary services for people with ASD.

8.10.11 Prohibiting the authorization of ABA services in community settings such as "sporting events, camps, and other settings as determined by the contractor" will deprive beneficiaries of interventions to promote generalization -- essential to optimize benefits and consistent with medical/clinical necessity and professional standards of care. Families will be left to figure out how to address the symptoms of ASD and corollary behaviors so as to support their children and keep them safe in situations like dental appointments, getting haircuts, interacting with their peers, and engaging in community activities. We

understand that the ACD benefit is not meant to supplant care provided by a parent or other caregiver, but neither the effects of ASD nor the clinical necessity of ABA treatment are negated by settings in which they occur. Please remove these restrictions.

8.10.15 & 8.10.15.1 The rationale outlined above applies here as well. Limiting ABA services as specified in these paragraphs is contraindicated by substantial research documenting the necessity of implementing interventions consistently across times, settings, and people in order to produce meaningful, lasting improvements in core symptoms and the areas of functioning they affect. To our knowledge, TRICARE does not prohibit the delivery of speech-language, occupational therapy, physical therapy, nursing, or other services in schools when they are deemed clinically necessary for beneficiaries with ASD or other diagnoses. It should not prohibit the delivery of prescribed ABA services in those settings either. Please delete these policies.

We acknowledge that it is difficult to ensure that all ACD beneficiaries and their families receive appropriate services. Unfortunately many of the policies in the current version of Chapter 18 of the TOM will make it less likely that beneficiaries will receive clinically necessary ABA services in a timely fashion. That will have a negative impact on the overall health and military readiness of their families. The changes we have recommended will remove unnecessary barriers to care. Please consider them seriously. If you have any questions or would like to schedule a phone or internet discussion, please do not hesitate to contact us. Thanks in advance for your timely response to our questions and requests.

Sincerely,

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The Honorable Tommy Tuberville
The Honorable James Inhofe
The Honorable Jeanne Shaheen
The Honorable Tammy Duckworth
The Honorable Dan Sullivan
The Honorable Tim Kaine
The Honorable Mark Kelly
The Honorable Jackie Speier
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