

#### OFFICE OF THE UNDER SECRETARY OF DEFENSE

4000 DEFENSE PENTAGON WASHINGTON, D.C. 20301-4000

OCT 25 2019

The Honorable James M. Inhofe Chairman Committee on Armed Services United States Senate Washington, DC 20510

Dear Mr. Chairman:

The enclosed report is in response to the Senate Report 114–255, page 205, accompanying S. 2943, the National Defense Authorization Act for Fiscal Year (FY) 2017, which requests the Department to provide a quarterly report on the effectiveness of the Autism Care Demonstration (ACD). This second-quarter report for FY 2019 covers data from January 2019 to March 2019.

This is the fifth submission of ACD data under the new T2017 TRICARE contracts, and the first opportunity to report health-related outcome measures for three intervals of 6-month data. Based on outcome measures data for this reporting quarter, 76 percent of TRICARE beneficiaries in the ACD had little to no change in symptom presentation over the course of 12 months of applied behavior analysis (ABA) services, with an additional 9 percent demonstrating worsening symptoms. While the findings are of concern, they should be interpreted with caution as this data is just one metric in a comprehensive review, and further exploration and analysis is required. The Department will provide an update in subsequent reports and a comprehensive analysis after the conclusion of the demonstration, which is currently set for December 2023.

In summary, the Department is committed to ensuring military dependents diagnosed with Autism Spectrum Disorder have timely access to medically necessary and appropriate ABA services. Thank you for your interest in the health and well-being of our Service members, veterans, and their families. A similar letter is being sent to the Chairman of the House Armed Services Committee.

Sincerely,

lames N. Stewart

Assistant Secretary of Defense for Manpower and Reserve Affairs, Performing the Duties of the Under Secretary of Defense for

Personnel and Readiness

Enclosure: As stated

cc: The Honorable Jack Reed Ranking Member



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OCT 25 2019

The Honorable Adam Smith Chairman Committee on Armed Services U.S. House of Representatives Washington, DC 20515

Dear Mr. Chairman:

The enclosed report is in response to the Senate Report 114–255, page 205, accompanying S. 2943, the National Defense Authorization Act for Fiscal Year (FY) 2017, which requests the Department to provide a quarterly report on the effectiveness of the Autism Care Demonstration (ACD). This second-quarter report for FY 2019 covers data from January 2019 to March 2019.

This is the fifth submission of ACD data under the new T2017 TRICARE contracts, and the first opportunity to report health-related outcome measures for three intervals of 6-month data. Based on outcome measures data for this reporting quarter, 76 percent of TRICARE beneficiaries in the ACD had little to no change in symptom presentation over the course of 12 months of applied behavior analysis (ABA) services, with an additional 9 percent demonstrating worsening symptoms. While the findings are of concern, they should be interpreted with caution as this data is just one metric in a comprehensive review, and further exploration and analysis is required. The Department will provide an update in subsequent reports and a comprehensive analysis after the conclusion of the demonstration, which is currently set for December 2023.

In summary, the Department is committed to ensuring military dependents diagnosed with Autism Spectrum Disorder have timely access to medically necessary and appropriate ABA services. Thank you for your interest in the health and well-being of our Service members, veterans, and their families. A similar letter is being sent to the Chairman of the Senate Armed Services Committee.

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James N. Stewart

Assistant Secretary of Defense for Manpower and Reserve Affairs, Performing the Duties of the Under Secretary of Defense for

Personnel and Readiness

Enclosure: As stated

cc:

The Honorable William M. "Mac" Thornberry Ranking Member

### **Report to Congress**



# The Department of Defense Comprehensive Autism Care Demonstration Quarterly Report to Congress Second Quarter, Fiscal Year 2019

In Response to: Senate Report 114–255, Page 205, Accompanying S. 2943, the National Defense Authorization Act for Fiscal Year 2017

The estimated cost of this report or study for the Department of Defense (DoD) is approximately \$5,700 for the 2019 Fiscal Year. This includes \$0 in expenses and \$5,740 in DoD labor.

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## EFFECTIVENESS OF THE DEPARTMENT OF DEFENSE COMPREHENSIVE AUTISM CARE DEMONSTRATION

#### **EXECUTIVE SUMMARY**

This quarterly report is in response to Senate Report 114–255, page 205, accompanying S. 2943, the National Defense Authorization Act for Fiscal Year (FY) 2017, which requests the Department of Defense (DoD) provide a quarterly report on the effectiveness of the Comprehensive Autism Care Demonstration (ACD). Specifically, the committee requests the Secretary of Defense to report, at a minimum, the following information by state: "(1) the number of new referrals for services under the program; (2) the number of total beneficiaries enrolled in the program; (3) the average wait-time from time of referral to the first appointment for services under the program; (4) the number of providers accepting new patients under the program; (5) the number of providers who no longer accept new patients for services under the program; (6) the average number of treatment sessions required by beneficiaries; and (7) the health-related outcomes for beneficiaries under the program." The data presented below was reported by the Managed Care Support Contractors (MCSCs) with oversight from the government, and represents the timeframe from January 1, 2019 through March 31, 2019. This is the fifth submission of ACD data under the new T2017 TRICARE contracts. The Defense Health Agency (DHA) continues to work with both contractors to obtain uniform data across regions. Although the DHA has made improvements on the timeframes of data collection, the data may be underreported due to the delays in receipt of claims.

Approximately 16,111 beneficiaries currently receive Applied Behavior Analysis (ABA) services through the ACD as of March 31, 2019. Total ACD program expenditures were \$313.7 million in FY 2018. The average wait time from the date of referral to the first appointment for ABA services is also improving as evidenced in Table 3 below. The average number of ABA sessions rendered are outlined below in Table 6, by state. These sessions were reported as the paid average number of hours per week per beneficiary, as the number of sessions does not represent the intensity or frequency of services. Further, conclusions about ABA services utilization variances by locality or other demographic information cannot be confirmed due to the unique needs of each beneficiary. Finally, this is the first opportunity to report health-related outcome measures for three intervals of 6-month data. While the findings are of concern, since the majority of beneficiaries are reporting little to no change in their symptom presentation, these findings should be interpreted with caution as this is just one metric in a comprehensive review and further exploration and analysis is required. The DoD will provide an update in subsequent reports and a comprehensive analysis after the conclusion of the demonstration, which is currently set for December 2023.

#### **BACKGROUND**

ABA services are one of many TRICARE covered services available to mitigate the symptoms of Autism Spectrum Disorder (ASD). Other services include, but are not limited to: speech and language therapy; occupational therapy; physical therapy; medication management; psychological testing; and psychotherapy. In June 2014, TRICARE received approval from the Office of Management and Budget to publish the ACD Notice in the Federal Register. In July 2014, three previous programs were consolidated to create the ACD.

The program is based on limited demonstration authority with the goal of striking a balance that maximizes access while ensuring the highest level of quality services for

beneficiaries. The consolidated demonstration ensures consistent ABA service coverage for all TRICARE eligible beneficiaries, including active duty family members (ADFMs) and non-ADFMs diagnosed with ASD. ABA services are not limited by the beneficiary's age, dollar amount spent, number of years of services, or number of sessions provided. All care is driven by medical necessity. Generally, all ABA services continue to be provided through purchased care. Additionally, several innovative programs are ongoing at military medical treatment facilities to support beneficiaries diagnosed with ASD and their families. For example, Fort Belvoir Community Hospital has initiated an Autism Resource Clinic to connect families with local resources and provide support. The ACD began July 25, 2014 and was originally set to expire on December 31, 2018; however, an extension for the demonstration until December 31, 2023 was approved via a Federal Register Notice published on December 11, 2017. The notice stated that additional analysis and experience is required in order to determine the appropriate characterization of ABA services as a medical treatment, or other modality, under the TRICARE program coverage requirements. By extending the demonstration, the government will gain additional information about what services TRICARE beneficiaries are receiving under the ACD, how to most effectively target services where they will have the most benefit, collect more comprehensive outcomes data, and gain greater insight and understanding of the diagnosis of ASD in the TRICARE population.

#### **RESULTS**

#### 1. The Number of New Referrals with Authorization for ABA Services Under the Program

The number of new referrals with an authorization for ABA services under the ACD during the period of January 1, 2019 through March 31, 2019, was 1,689. This was a decrease from the previous quarter (1,858). A breakdown by state is included in Table 1.

Table 1

State	New Referrals
	with
	Authorization
AK	18
AL	21
AR	6
AZ	20
CA	256
CO	93
CT	7
DC	2
DE	2
FL	118
GA	79
HI	92
IA	0
ID	6
IL	20
IN	7

KS	25
KY	24
LA	19
MA	6
MD	37
ME	3
MI	8
MN	1
MO	29 7
MS	7
MT	4
NC	96
ND	0
NE	2
NH	1
NJ	6
NM	5
NV	27
NY	9
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OH	10
OK	20
OR	3
PA	8
RI	0
SC	31
SD	4
TN	31
TX	174
UT	22
VA	205
VT	0
WA	125
WI	4
WV	1
WY	13
Total	1,689

#### 2. The Number of Total Beneficiaries Enrolled in the Program

As of March 31, 2019, the total number of beneficiaries participating in the ACD was 16,111, a slight increase from the last reporting period (16,044). A breakdown by state is included in Table 2 below.

Table 2

State	Total Beneficiaries Participating
AK	157
AL	255
AR	36
AZ	272
CA	1930
CO	865
CT	46
DC	23
DE	37
FL	1440
GA	773
HI	555
IA	19
ID	14
IL	197
IN	108

KS	262
KY	258
LA	137
MA	52
MD	10
ME	419
MI	76
MN	22
MO	177
MS	122
MT	25
NC	1160
ND	4
NE	88
NH	6
NJ	112
NM	72
NV	234
NY	92

OH	121
OK	164
OR	21
PA	89
RI	18
SC	295
SD	15
TN	331
TX	1835
UT	206
VT	0
VA	1822
WA	1067
WI	31
WV	6
WY	35
Total	16,111

# 3. <u>The Average Wait Time from Time of Referral to the First Appointment for Services Under the Program</u>

For 39 states, the average wait time from date of referral to the first appointment for ABA services under the program is within the 28-day access standard for specialty care, which is an improvement from the previous quarter (25 states). For this reporting period, 12 states are beyond the access standard. The MCSCs, with oversight from the government, continue to review causative key factors; however, it appears process improvements are starting to show positive effects. The MCSCs continue to work diligently building provider networks and will continue to monitor states and locations where provider availability is an issue. Although the field of behavior analysis is growing, locations remain with an insufficient number of ABA providers able to meet the demand for such services. This shortage is consistent with shortages seen with other types of specialty care providers such as developmental pediatricians and child psychologists, and is not limited to TRICARE. A breakdown by state is included in Table 3 below.

Table 3

State	Average Wait Time (# days)
AK	13
AL	13
AR	11
AZ	25
CA	24
CO	30
CT	0
DE	0
DC	0
FL	25
GA	22
HI	36
IA	0
ID	40
IL	45

IN	38
KS	34
KY	31
LA	34
MA	15
MD	25
ME	28
MI	21
MN	0
MO	19
MS	43
MT	0
NC	27
ND	0
NE	0
NH	0
NJ	19
NM	29

NV	16
NY	25
ОН	25
OK	38
OR	0
PA	11
RI	0
SC	17
SD	0
TN	20
TX	27
UT	24
VA	22
VT	0
WA	21
WV	1
WI	34
WY	20

#### 4. The Number of Practices Accepting New Patients for Services Under the Program

For this reporting quarter, the number of ABA practices accepting new patients under the ACD is 3,847, an increase from the last reporting period (3,253). A breakdown by state is included in Table 4 below.

Table 4

State	Practices Accepting New Beneficiaries
AK	13
AL	56
AR	15
AZ	14
CA	217
CO	58
CT	20
DC	3
DE	4
FL	854
GA	124
HI	20
IA	3
ID	6
IL	219

IN	181
KS	17
KY	93
LA	92
MA	23
MD	14
ME	76
MI	202
MN	2
MO	77
MS	13
MT	4
NC	74
ND	5
NE	5
NH	21
NJ	33
NM	15
NV	4

Total	3,847
WY	2
WI	102
WV	2
WA	38
VT	2
VA	226
UT	16
TX	441
TN	117
SD	1
SC	77
RI	4
PA	81
OR	6
OK	16
OH	65
NY	87

#### 5. The Number of Practices No Longer Accepting New Patients Under the Program

The number of ABA practices that stopped accepting new TRICARE beneficiaries for ABA services under the program is 210, a slight increase from the last quarter (199). In reviewing the data, it appears part of this increase is related to providers being unable to accept new beneficiaries due to having a full caseload. A breakdown by state is included in Table 5 below.

Table 5

State	Practices No Longer Accepting New Beneficiaries
AK	0
AL	1
AZ	0
AR	1
CA	0
CO	0
CT	0
DE	1
DC	0
FL	13
GA	29
HI	0
ID	0
IL	15
IN	1

IA	0
KS	0
KY	0
LA	0
MA	21
MD	0
ME	1
MI	3
MN	0
MO	0
MS	1
MT	0
NC	8
ND	0
NE	0
NH	0
NJ	3
NM	0
NV	0

NY	4
OH	0
OK	4
OR	0
PA	3
RI	1
SC	0
SD	0
TN	1
TX	90
UT	0
VT	1
VA	7
WA	0
WV	0
WI	1
WY	0
Total	210

#### 6. The Average Number of Treatment Sessions Required by Beneficiaries

The average number of ABA sessions required by beneficiaries is difficult to determine in isolation. ABA research has not established a dose–response relationship between severity, treatment needs, and intensity of services. Additionally, ABA services may be one component of a comprehensive treatment plan for a beneficiary diagnosed with ASD. A comprehensive treatment plan may include speech language pathology, occupational therapy, and physical therapy, psychotherapy, etc., for the best outcomes for any one beneficiary. Therefore, the numbers outlined by state in Table 6 (below), report only the paid average number of hours of 1:1 ABA services per week per beneficiary receiving services. As noted in previous reports, conclusions could not be made about ABA services utilization variances by locality or other demographic information due to the unique needs of each beneficiary.

Table 6

State	Average Hours/Week
	per Beneficiary
AK	7
AL	11
AR	15
AZ	6
CA	7
CO	8
CT	6
DC	7
DE	7
FL	11
GA	10
HI	7
IA	4
ID	9
IL	10

IN	30
KS	6
KY	12
LA	10
MA	9
MD	10
ME	7
MI	15
MN	8
MO	5
MS	5
MT	6
NC	11
ND	5
NE	5
NH	4
NJ	6
NM	8

NV	5
NY	15
ОН	10
OK	12
OR	10
PA	15
RI	6
SC	11
SD	12
TN	11
TX	14
UT	7
VT	0
VA	9 7
WA	7
WV	6
WI	5
WY	5

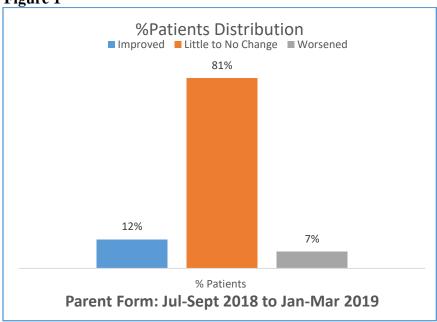
#### 7. <u>Health-Related Outcomes for Beneficiaries Under the Program</u>

The DoD continues to support evaluations on the nature and effectiveness of ABA services. The publication of TRICARE Operations Manual Change 199, dated November 29, 2016, for the ACD included the evaluation of health-related outcomes through the requirement of norm-referenced, valid, and reliable outcome measures; the data collection began on January 1, 2017. Currently, there are three outcome measures required under the ACD: the Vineland Adaptive Behavior Scales, Third Edition (Vineland-3) is a measure of adaptive behavior functioning; the Social Responsiveness Scale, Second Edition (SRS-2) is a measure of social impairment associated with ASD; and the Pervasive Developmental Disabilities Behavior Inventory (PDDBI) is a measure that is designed to assist in the assessment of various domains related to ASD. Additionally, the PDDBI is a measure that is designed to assess the effectiveness of treatments for children with pervasive developmental disabilities, including ASD, in terms of response to interventions. The outcome measure scores are completed and submitted to the MCSCs by eligible providers authorized under the ACD who completed an evaluation of each beneficiary's symptoms related to ASD at the time of assessment. The Vineland-3 and SRS-2 are required every 2 years and the PDDBI is required every 6 months.

This report provides a review of three sets of PDDBI scores, including data submitted for the time periods of January to March of 2018, July to September of 2018, and now January to March of 2019. The same 1,577 beneficiaries submitted in the July to September 2018 quarterly report were reviewed and of the 1,577 beneficiaries, 709 beneficiaries had usable scores for comparison of the PDDBI. Many beneficiary scores noted "0," indicating an incomplete or an unable to answer sections of the PDDBI based on a variety of factors (i.e., direction to not complete a section if the child is non-verbal).

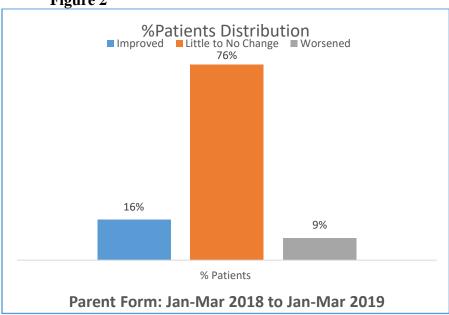
For the reporting periods of July to September of 2018 and January to March of 2019, based on the Autism Composite Score on the parent form of the PDDBI (which is a measure of lack of appropriate social communication skills along with repetitive/ritualistic behaviors), approximately 81 percent (572 total comparable Parent Forms) of beneficiaries made little to no change in their symptom presentation after six months of ABA services). Of significance, seven percent of the population had a decline of one standard deviation (SD) or more, indicating worsening symptom presentation after six months of ABA services. Only 12 percent of the sample had improvements (one SD or better) in symptom presentation after 6 months of ABA services. See Figure 1 for the distribution of change scores for the parent score for the 6-month comparison period.

Figure 1



For the reporting periods of January to March of 2018 and January to March of 2019, based on the Autism Composite Score on the parent form of the PDDBI, approximately 76 percent of beneficiaries made little to no change in their symptom presentation after 1 year of ABA services. In this comparison, nine percent of the population had a decline of one SD or more, indicating worsening symptom presentation after one year of ABA services. Only 16 percent of the sample had improvements (one SD or better) in symptom presentation after one year of ABA services. See Figure 2 for the distribution of change scores for the parent score for the annual comparison period.

Figure 2



Of particular interest, Figure 2 indicates a 4 percent increase in improved ASD symptoms scores and a 2 percent increase in worsening ASD symptoms scores after 12 months of ABA services. Of concern is that 76 percent of beneficiaries continue to not report symptom improvement after 12 months of ABA services.

Also reviewed was the concordance/discordance between parent and teacher (or Board Certified Behavior Analysts (BCBA) completed forms of this quarter's score submission. Of the 709 beneficiaries pulled for this analysis, 647 beneficiaries had both parent and teacher forms submitted for this reporting quarter. Approximately 58 percent of the completed parent and teacher forms were within 10 points or one SD of one another suggesting that there was agreement in slightly more than half of the T-scores for the Autism Composite Score regarding the perception of symptom presentation. According to the research regarding the PDDBI, there is a high degree of interrater reliability between parent and teacher forms. This discrepancy in TRICARE beneficiaries continues to require further exploration. See Figure 3 for the distribution of scores for the parent form and Figure 4 for the teacher form.

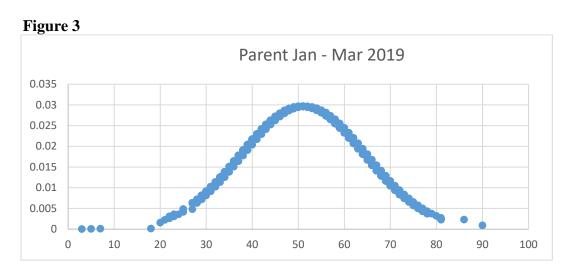
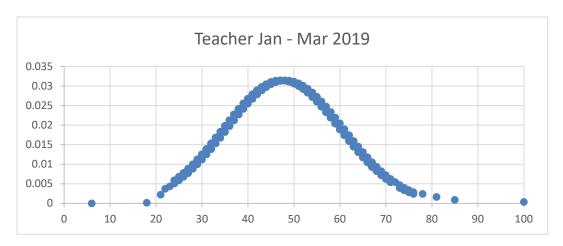


Figure 4



Of note, these findings should be interpreted with caution as the PDDBI is just one metric of many collected and reported. Additionally, caution should be used as there are no other factors considered in this summary such as age, symptom severity, number of hours of services, total duration of ABA services, other services, academic placement, etc. TRICARE will continue to collect this data and analyze trends, as well as use these as one part of comprehensive treatment planning.

#### **CONCLUSION**

As evidenced in the above information, participation in the ACD by beneficiaries continues to remain steady. As of March 31, 2019, there were 16,111 beneficiaries participating in the ACD. The average wait time from referral to first appointment is improving. The MCSCs track every patient who has an authorization for ABA services to ensure they have an ABA provider who can render services within the access to care standards; this data is used at the state and local level, which will help identify areas with potential network deficiencies. For any beneficiary with an active authorization for ABA services who does not have an ABA provider, the MCSCs continue to work to place those patients with a qualified provider as quickly as possible.

Determining health-related outcomes is an important requirement added to the ACD. A contract modification, effective January 1, 2017, provided direction for MCSCs to begin collecting the outcome measures data for all ACD participants. The MCSCs use these scores, as well as other scores and data, to guide and engage ABA providers in identifying treatment plan development and adjustments that may be required to see improvements. The DHA remains committed to ensuring all TRICARE-eligible beneficiaries diagnosed with ASD reach their maximum potential, and that all treatment and services provided support this goal. Based on this reporting quarter outcome measures data, the majority of TRICARE beneficiaries (76 percent – parent form) had little to no change in symptom presentation over the course of 12 months of ABA services, with an additional nine percent demonstrating worsening symptoms. Additionally, the 42 percent discrepancy in responses between parents and teacher/BCBA (Figure 3 and 4) is also of note, suggesting DHA should continue to explore the possible reasons for the wide range in perceptions of symptom presentation. Further analysis is required to observe trends and utility. While it is concerning that 76 percent of the population saw little to no change, the DHA via the MCSCs will work with the providers to ensure effective treatment is being delivered.