OFFICE OF THE UNDER SECRETARY OF DEFENSE
4000 DEFENSE PENTAGON
WASHINGTON, D.C. 20301-4000

PERSONNEL AND
READINESS

FEB 21 2020

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 directs the Secretary of Defense to provide a quarterly report on the effectiveness of the Autism Care Demonstration (ACD) program. The third-quarter report for FY 2019, covering data from April 2019 to June 2019, is enclosed.

Participation in the ACD program by beneficiaries and providers is robust, and the average wait time from the date of referral to the first appointment for Applied Behavior Analysis services is improving. The lack of measureable clinical outcomes remains an area of concern, but findings should be interpreted with caution as outcome measures are just one metric in a comprehensive review of the program. The Department will provide updates to outcomes in subsequent reports and a comprehensive analysis after the conclusion of the ACD program, which is currently set for December 2023.

The Department is committed to ensuring military dependents diagnosed with Autism Spectrum Disorder have timely access to medically necessary and appropriate Applied Behavioral Analysis services. Thank you for your interest in the health and well-being of our Service members, veterans, and their families. I am sending identical letters to the Chairman and Ranking Member of the House Armed Services Committee, and the Ranking Member of the Senate Armed Services Committee.

Sincerely,

Matthew P. Donovan
Performing the Duties of the Under Secretary of
Defense for Personnel and Readiness

Enclosure:
As stated

OFFICE OF THE UNDER SECRETARY OF DEFENSE
4000 DEFENSE PENTAGON
WASHINGTON, D.C. 20301-4000

PERSONNEL AND
READINESS

The Honorable William M. "Mac" Thornberry
Ranking Member
Committee on Armed Services
U.S. House of Representatives
Washington, DC 20515

FEB 21 2020

Dear Representative Thornberry :

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 directs the Secretary of Defense to provide a quarterly report on the effectiveness of the Autism Care Demonstration (ACD) program. The third-quarter report for FY 2019, covering data from April 2019 to June 2019, is enclosed.

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PERSONNEL AND
READINESS

FEB 21 2020

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

Dear Mr. Chairman:

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As stated

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WASHINGTON, D.C. 20301-4000

PERSONNEL AND
READINESS

FEB 21 2020

The Honorable Jack Reed
Ranking Member
Committee on Armed Services
United States Senate
Washington, DC 20510

Dear Senator Reed:

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 directs the Secretary of Defense to provide a quarterly report on the effectiveness of the Autism Care Demonstration (ACD) program. The third-quarter report for FY 2019, covering data from April 2019 to June 2019, is enclosed.

Participation in the ACD program by beneficiaries and providers is robust, and the average wait time from the date of referral to the first appointment for Applied Behavior Analysis services is improving. The lack of measureable clinical outcomes remains an area of concern, but findings should be interpreted with caution as outcome measures are just one metric in a comprehensive review of the program. The Department will provide updates to outcomes in subsequent reports and a comprehensive analysis after the conclusion of the ACD program, which is currently set for December 2023.

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Sincerely,

Matthew P. Donovan
Performing the Duties of the Under Secretary of
Defense for Personnel and Readiness

Enclosure:
As stated

Report to Congress

The Department of Defense Comprehensive Autism Care Demonstration

Quarterly Report to Armed Services Committees

Third 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 $6,130 for the 2019 Fiscal Year. This includes $0 in expenses and $6,130 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 directs the Secretary of Defense to provide a quarterly report on the effectiveness of the Comprehensive Autism Care Demonstration (ACD). The data presented below was reported by the Managed Care Support Contractors (MCSCs) with oversight from the Government and represents the timeframe from April 1, 2019 through June 30, 2019. Although the Defense Health Agency (DHA) has made improvements on the timeframes of data collection, the data may be underreported due to the delays in receipt of claims.

As of June 30, 2019, approximately 16,138 beneficiaries are enrolled in the ACD. Total ACD program expenditures were $313.7M in FY 2018 and $169.1M for the first half of FY 2019. The average wait time from the date of referral to the first appointment for applied behavior analysis (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, outcome measures for 3 intervals of 6 month data are also presented. 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 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.

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 (SLP); occupational therapy (OT); physical therapy (PT); 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 the purchased care. Additionally, several innovative programs are ongoing at military treatment facilities (MTFs) to support

beneficiaries diagnosed with ASD and their families. For example, Fort Belvoir Community Hospital (FBCH) created an Autism Resource Clinic (ARC) to connect families with local resources and provide support. Subsequently, three additional MTFs have established ARC programs following the FBCH model (Walter Reed National Military Medical Center, Naval Hospital Portsmouth, and Madigan Army Medical Center). 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 April 1, 2019 through June 30, 2019, was 1,741. This was a slight increase from the previous quarter (1,689). A breakdown by state is included in Table 1.

Table 1

State	New Referrals with Authorization
AK	25
AL	34
AR	11
AZ	43
CA	231
CO	114
CT	9
DC	6
DE	2
FL	100
GA	85
HI	102
IA	1
ID	0
IL	17
IN	9
KS	29
KY	13
LA	19
MA	4
MD	23
ME	0
MI	8
MN	1
MO	38
MS	19
MT	4
NC	89
ND	0
NE	2
NH	1
NJ	6
NM	5
NV	27
NY	11
OH	17
OK	20
OR	3
PA	9
RI	2
SC	27
SD	4
TN	27
TX	229
UT	22
VA	174
VT	1
WA	125
WI	1
WV	4
WY	13
Total	**1,741**

2. The Number of Total Beneficiaries Enrolled in the Program

As of June 30, 2019, the total number of beneficiaries participating in the ACD was 16,138, a slight increase from the last reporting period (16,111). A breakdown by state is included in Table 2 below.

Table 2

State	Total Beneficiaries Participating
AK	169
AL	276
AR	47
AZ	278
CA	1898
CO	852
CT	54
DC	27
DE	36
FL	1415
GA	774
HI	551
IA	17
ID	13
IL	205
IN	102
KS	269
KY	246
LA	133
MA	48
MD	10
ME	401
MI	84
MN	16
MO	196
MS	133
MT	30
NC	1152
ND	8
NE	83
NH	9
NJ	116
NM	74
NV	241
NY	96
OH	132
OK	164
OR	16
PA	84
RI	16
SC	302
SD	16
TN	335
TX	1856
UT	197
VT	1
VA	1833
WA	1050
WI	27
WV	10
WY	40
Total	**16,138**

3. The Average Wait Time from Time of Referral to the First Appointment for Services Under the Program

For 42 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 (39 states). For this reporting period, nine states are only slightly beyond the access standard. The MCSCs, with oversight from the Government, continue to review causative key factors; however, it appears process improvements are continuing to show positive effects. The MCSCs work diligently building provider networks and will continue to monitor states and locations where provider availability is an issue. Currently, the biggest factor for wait times is parent choice for after school appointments or a particular provider. 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	25
AL	19
AR	15
AZ	24
CA	33
CO	44
CT	15
DE	0
DC	14
FL	18
GA	22
HI	30
IA	0
ID	0
IL	27
IN	19
KS	15
KY	19
LA	25
MA	0
MD	36
ME	0
MI	25
MN	0
MO	26
MS	16
MT	0
NC	22
ND	0
NE	0
NH	2
NJ	17
NM	40
NV	34
NY	7
OH	37
OK	14
OR	0
PA	14
RI	14
SC	14
SD	0
TN	14
TX	35
UT	32
VA	25
VT	0
WA	28
WV	1
WI	21
WY	12

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 4,360, an increase from the last reporting period (3,847). While this number increased, there are still states (represented in Table 3) that have averages beyond the access to care standards. Discussions with the MCSCs reveal that a large majority of the beneficiaries accessing care beyond the access to care standards are due to parental choice for a particular appointment time or provider. A breakdown by state is included in Table 4 below.

Table 4

State	Practices Accepting New Beneficiaries
AK	13
AL	59
AR	21
AZ	16
CA	223
CO	60
CT	23
DC	3
DE	6
FL	938
GA	134
HI	20
IA	3
ID	6
IL	245
IN	214
KS	17
KY	101
LA	97
MA	33
MD	15
ME	98
MI	272
MN	2
MO	87
MS	14
MT	5
NC	86
ND	5
NE	5
NH	22
NJ	46
NM	15
NV	4
NY	102
OH	76
OK	15
OR	6
PA	88
RI	6
SC	77
SD	1
TN	130
TX	519
UT	17
VA	266
VT	4
WA	43
WV	3
WI	110
WY	2
Total	**4,360**

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

The number of ABA practices who stopped accepting new TRICARE beneficiaries for ABA services under the program is 198, a slight decrease from the last quarter (210). A breakdown by state is included in Table 5 below.

Table 5

State	Practices No Longer Accepting New Beneficiaries
AK	0
AL	0
AZ	0
AR	0
CA	0
CO	0
CT	0
DE	0
DC	0
FL	7
GA	28
HI	0
ID	0
IL	7
IN	1
IA	0
KS	0
KY	0
LA	0
MA	22
MD	0
ME	1
MI	2
MN	0
MO	0
MS	2
MT	0
NC	7
ND	0
NE	0
NH	0
NJ	2
NM	0
NV	0
NY	2
OH	0
OK	6
OR	0
PA	1
RI	0
SC	0
SD	0
TN	1
TX	106
UT	0
VT	0
VA	3
WA	0
WV	0
WI	0
WY	0
Total	**198**

6. The Average Number of Treatment Sessions Required by Beneficiaries

The average number of ABA sessions required by beneficiaries is difficult to answer 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 SLP, OT, PT, 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, we are unable to make conclusions 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	8
AL	13
AR	11
AZ	6
CA	7
CO	9
CT	10
DC	5
DE	10
FL	13
GA	10
HI	7
IA	4
ID	6
IL	10
IN	31
KS	7
KY	14
LA	11
MA	7
MD	12
ME	5
MI	16
MN	8
MO	6
MS	9
MT	5
NC	12
ND	9
NE	6
NH	3
NJ	8
NM	8
NV	6
NY	14
OH	14
OK	13
OR	10
PA	10
RI	6
SC	12
SD	11
TN	11
TX	14
UT	7
VT	0
VA	9
WA	7
WV	14
WI	13
WY	6

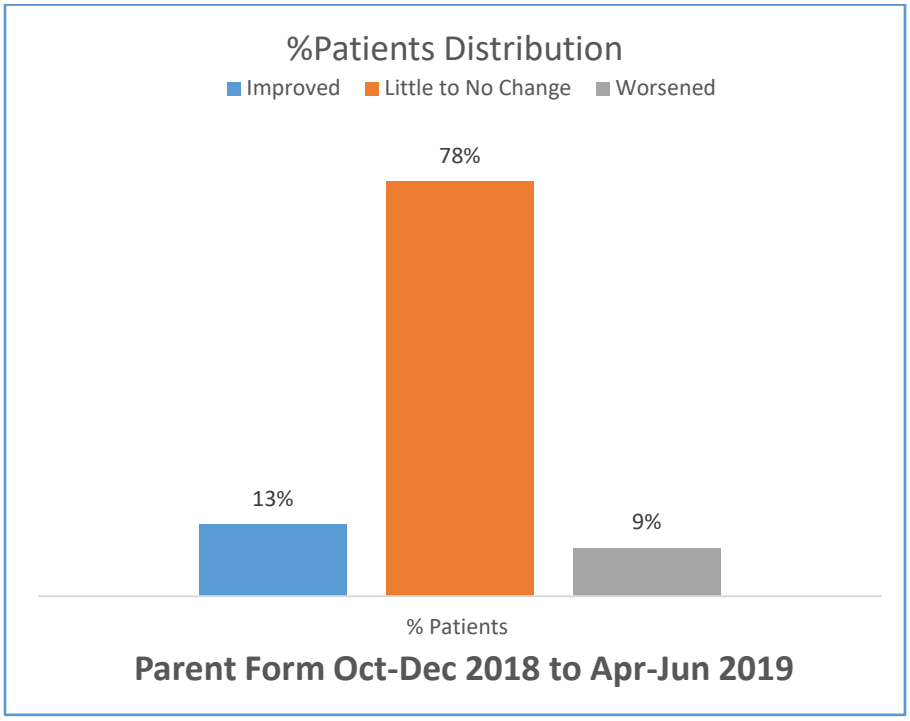
7. Health-Related Outcomes for Beneficiaries Under the Program

The Department 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 April to June of 2018, October to December of 2018, and now April to June of 2019. The scores were reviewed for matches between the 6 month data and 1 year data comparisons. Many beneficiary scores noted "0," indicating an incomplete or "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).

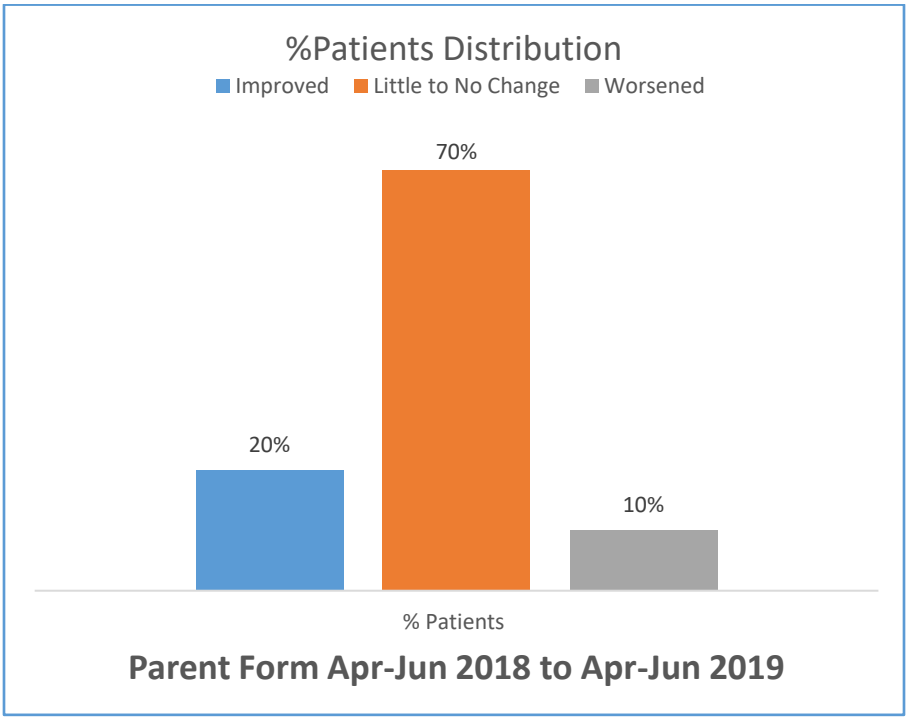
The following data represents scores compared to each individual beneficiary and compiled as change data, not compared to other beneficiaries. The data does not report when the individual beneficiary started or ended, but the data describes a summary of change scores (improving or worsening scores by more than one standard deviation (SD) in the respective directions or little to no change (less that one SD) For the reporting periods of October to December of 2018 and April to June 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 77.6 percent (807 total comparable Parent Forms) of beneficiaries made little to no change in their symptom presentation after 6 months of ABA services). Of significance, nine percent of the population had a decline of one standard deviation (SD) or more indicating worsening symptom presentation after 6 months of ABA services. Only 13.4 percent of the sample had improvements (1 SD or better) in symptom presentation after this 6 months of ABA services. See Figure 1 for the distribution of change scores for the Parent Form score for the 6 month comparison period.

Figure 1



For the reporting periods of April to June of 2018 and April to June of 2019, based on the Autism Composite Score on the Parent Form of the PDDBI, approximately 70 percent of beneficiaries made little to no change in their symptom presentation after 1 year of ABA services. In this comparison, 10 percent of the population had a decline of one SD or more indicating worsening symptom presentation after 1 year of ABA services. Only 20 percent of the sample had improvements (1 SD or better) in symptom presentation after 1 year of ABA services. While the improved scores have increased as compared to the 6 month comparison, it is important to note that the sample size for matching scores for this comparison was only 240, and, therefore it would be difficult to make any conclusions regarding overall change. The DHA is further analyzing why the reduction in matching sample scores occurred over the year and plans to implement process improvements for collecting outcomes measures in the next manual revision. See Figure 2 for the distribution of change scores for the Parent score for the annual comparison period.

Figure 2



Also reviewed was the concordance/discordance between Parent and Teacher (or BCBA) completed forms of this quarter's score submission. For the April to June 2019 time frame, 1,403 beneficiaries had both a parent and teacher score reported. Of the 1,403 beneficiaries pulled for this analysis, 549 beneficiaries' scores, or 39 percent, were greater than 10 points of one SD of one another. Approximately 61 percent of the completed Parent and Teacher forms were within 10 points or one SD of one another suggesting that there was agreement in 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 form. This discrepancy in TRICARE beneficiaries continues to require further exploration.

Of note, these findings should be interpreted with caution as the PDDBI is just one metric of several 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 using these as one part of comprehensive treatment planning. As a reminder, the PDDBI was selected as a measure of progress in people diagnosed with ASD after review of the literature and consultation with many experts in the field, including ABA providers, advocates, and stakeholders. It is also important to note that this one data point just like any other data point, by itself, would not drive policy decisions. However, this is still data, and is relevant when considering the larger picture of a comprehensive program.

Additionally, research has not identified what frequency, duration, and intensity of services nor for what characteristics of ASD services are most appropriate for optimal outcomes. The DHA continues to track the literature for research on ABA services, and DHA is committed to helping advance the science of autism treatments and services. The Department of Defense is also sponsoring a Congressionally Directed Medical Research Program (CDMRP) study which will contribute to the field. DHA worked with the CDMRP to award a contract to a research group to study ABA service delivery models. The CDMRP study was competitively awarded to a research group from the University of Rochester in September 2018. This study will compare an "adaptive" model (20 hours or less per week) to the standard early intensive intervention (20 hours or more per week) including outcome measures for each group. Findings from this study may benefit the larger community of individuals diagnosed with ASD and their families in several ways, including but not limited to, offering more choices to families, potentially identifying response to treatment through predictive factors, and lowering cost while increasing access.

Furthermore, the DHA is continuously evaluating beneficiary progress in the ACD as well as steps to improve the program to ensure the best possible outcomes for all TRICARE beneficiaries receiving services under the ACD. To date, ABA services under TRICARE continue to grow exponentially in cost with no data that demonstrates that TRICARE beneficiaries diagnosed with ASD are improving in their core deficits of ASD. In part due to this concerning finding, DHA is proposing significant changes to the ACD. These proposed comprehensive changes will provide an opportunity to improve support to beneficiaries and their families by providing more information about ASD and potential services, linking beneficiaries to the right care at the right time, and increasing services to eligible family members (especially parents). The improvements will create a beneficiary and parent-centered model of care and support that encompasses all of the beneficiary and family's needs into one comprehensive approach. This manual change will incorporate all needed services (including but not limited to ABA services) into one treatment plan, and empowering parents to have a greater role in determining the most appropriate services for their child. The change will also include the option for treatment team meetings with participation by all providers treating the child and participation by the family (and when appropriate, the beneficiary). This comprehensive change aims to move the ACD from the current ABA-centric model to one focused on the beneficiary and family with the goal of helping the beneficiary diagnosed with ASD reach their maximum potential.

CONCLUSION

As evidenced in the above information, participation in the ACD by beneficiaries continues to remain relatively steady. As of June 30, 2019, there were 16,138 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.

As of now, ABA services do not meet the TRICARE hierarchy of reliable evidence standard as defined in regulation (the Code of Federal Regulation, Title 32, Part 199.2) required to allow cost-sharing of ABA as scientifically proven medical care. Two well-respected medical literature review services, external to DHA, continue to find weak evidence for ABA services (Intensive Behavior Intervention) for the diagnosis of ASD noting, "An overall low-quality body of evidence mainly from poor-quality studies suggests that Intensive Behavior Intervention (IBI) improves intelligence or cognitive skills, visual-spatial skills, language skills, and adaptive behavior compared with baseline levels or other treatments. Six years after this agency's extensive June 2013 ABA coverage review, the published reliable evidence does not reflect any consensus as to whether the reported improvements are clinically significant; very few studies reported on the clinical significance of findings. A paucity of evidence regarding the durability of treatment following treatment cessation, as well as uncertainty regarding optimal therapy parameters, preclude firm conclusions regarding the efficacy of IBI for ASD" (Hayes 2019). Cochrane (2018) noted, "The strength of the evidence in this review is limited because it mostly comes from small studies that are not of the optimum design. Due to the inclusion of nonrandomized studies, there is a high risk of bias and we rated the overall quality of evidence as 'low' or 'very low' using the GRADE system, meaning further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change the estimate."

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 developing appropriate treatment plans 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 (77.6 percent – Parent Form) had little to no change in symptom presentation over the course of 6 months of ABA services, with an additional nine percent demonstrating worsening symptoms. Additionally, the 39 percent discrepancy in responses between parents and teacher/BCBA 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 almost 78 percent of the population saw little to no change and an additional 9 percent reported worsening symptoms, the DHA via the MCSCs will work with the providers to ensure effective treatment is being delivered.

In review of the current ACD, the DHA understands that the ACD needs to improve and therefore is completing a comprehensive rewrite of the program and the sections of the TRICARE Manual that govern it. The improvements will shift the program to focus on the beneficiary, providing the right services by the right provider at the right time. DHA will complete the updated policy guidance no later than Summer 2020.