

UNCLASSIFIED

AD NUMBER: AD1212454

LIMITATION CHANGES

TO:

Approved for public release; distribution is unlimited.

FROM:

Distribution authorized to DoD and DoD contractors only;
Administrative/Operational Use; 01 Aug 2023. Other requests shall be
referred to Office of the Deputy Commandant For Combat Development
and Integration, Quantico, VA 22134.

AUTHORITY

OAD ltr dtd 22 Mar 2024



DEPARTMENT OF THE NAVY
HEADQUARTERS UNITED STATES MARINE CORPS
3300 RUSSELL ROAD
QUANTICO, VIRGINIA 22134-5096

IN REPLY REFER TO:
OAD
22 Mar 24

From: Ms. Sherry Starego, Study Lead
To: Defense Technical Information Center

Subj: SUMMARY OF CHANGES TO THE AUTISM PREVALENCE RATE AND THE CAPACITY TO
SUPPORT FINAL REPORT (DTIC# AD1212454)

1. Change the distribution statement from Distribution D to Distribution A: Approved for public release: distribution is unlimited.
2. Remove the UNCLASSIFIED header/footer throughout the document.

3/22/2024

X Sherry Starego

Sherry Starego

Signed by: STAREGO.SHERRY.A.1512993237

SHERRY STAREGO

OPERATIONS ANALYSIS DIRECTORATE
Combat Development and Integration
3300 Russell Road ♦ Quantico, VA 22134

Autism Prevalence Rate and the Capacity to Support
Final Report

Sherry Starego

August 2023



DISTRIBUTION STATEMENT A. Approved for public release: distribution is unlimited.

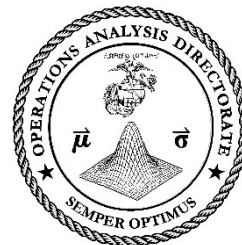
REPORT DOCUMENTATION PAGE

Form Approved
OMB No. 0704-0188

The public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing the burden, to Department of Defense, Washington Headquarters Services, Directorate for Information Operations and Reports (0704-0188), 1215 Jefferson Davis Highway, Suite 1204, Arlington, VA 22202-4302. Respondents should be aware that notwithstanding any other provision of law, no person shall be subject to any penalty for failing to comply with a collection of information if it does not display a currently valid OMB control number.
PLEASE DO NOT RETURN YOUR FORM TO THE ABOVE ADDRESS.

1. REPORT DATE (DD-MM-YYYY) 01/08/2023		2. REPORT TYPE Final Report		3. DATES COVERED (From - To) 09/2021-08/2023	
4. TITLE AND SUBTITLE Autism Prevalence Rate and the Capacity to Support				5a. CONTRACT NUMBER	
				5b. GRANT NUMBER	
				5c. PROGRAM ELEMENT NUMBER	
6. AUTHOR(S) Sherry Starego				5d. PROJECT NUMBER	
				5e. TASK NUMBER	
				5f. WORK UNIT NUMBER 2344	
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) Operations Analysis Directorate Quantico, VA 22134				8. PERFORMING ORGANIZATION REPORT NUMBER	
9. SPONSORING/MONITORING AGENCY NAME(S) AND ADDRESS(ES) Manpower & Reserve Affairs Marine & Family Division Quantico, VA 22134				10. SPONSOR/MONITOR'S ACRONYM(S) M&RA	
				11. SPONSOR/MONITOR'S REPORT NUMBER(S) 2344	
12. DISTRIBUTION/AVAILABILITY STATEMENT Distribution A					
13. SUPPLEMENTARY NOTES					
14. ABSTRACT Headquarters Marine Corps Exceptional Family Member Program (EFMP) supports the assignment of EFMP-enrolled Marines to duty stations where services exist to support the family member(s) with access and availability to medical and educational services. Applied Behavior Analysis (ABA) is frequently used by children with autism and is a TRICARE-approved service under the TRICARE Autism Care Demonstration.					
15. SUBJECT TERMS OAD Collection, Autism, ABA, TRICARE, EFMP					
16. SECURITY CLASSIFICATION OF:			17. LIMITATION OF ABSTRACT	18. NUMBER OF PAGES	19a. NAME OF RESPONSIBLE PERSON
a. REPORT	b. ABSTRACT	c. THIS PAGE			Sherry Starego
Unclass	Unclass	Unclass	Distro D	19	19b. TELEPHONE NUMBER (Include area code)

The Operations Analysis Directorate (OAD) is a unit of the Combat and Development and Integration Command (CD&I) under Headquarters, United States Marine Corps. OAD provides oversight for and executes operations analysis and modeling and simulation for the Marine Corps. OAD also supports organizations across the Marine Corps and provides analysis that informs force development, programmatic, and warfighting decisions.



For more information about this or related studies, please direct your correspondence to OAD, 3300 Russell Road, Quantico, Virginia, 22134 or by emailing OAD at OAD_Studies@usmc.mil. OAD and CD&I can be found online at <http://www.cdi.marines.mil>.

Abstract:

Headquarters Marine Corps Exceptional Family Member Program (EFMP) supports the assignment of EFMP-enrolled Marines to duty stations where services exist to support the family member(s) with access and availability to medical and educational services. Applied Behavior Analysis (ABA) is frequently used by children with autism and is a TRICARE-approved service under the TRICARE Autism Care Demonstration. Over time, it has become increasingly difficult to confirm the availability and accessibility of ABA. EFMP case managers find that even when services are available at a given installation, the queue for seeing a therapist can be three months out or longer. The study confirms that the prevalence rate of autism is, in fact, increasing, and TRICARE does not currently have the capacity to adequately support the growing need for ABA services at Marine Corps installations.

Keywords: autism, ABA, TRICARE, EFMP

Report No.: 2344

Publication Date: August 2023

Approved by:

Douglas K. Hoffman

Douglas K. Hoffman, Director
Operations Analysis Directorate, Combat Development and Integration

DISTRIBUTION STATEMENT A. Approved for public release: distribution is unlimited.
Preparation of this study cost the DOD a total of approximately \$43,000 in fiscal years 2022-2023.



Autism Prevalence Rate and the Capacity to Support

The Exceptional Family Member Program (EFMP) is a mandatory program, administered by Headquarters, United States Marine Corps, that supports families with exceptional needs. Working with the MOS Monitors, EFMP staff helps direct Marines with permanent change of station (PCS) orders to new duty stations where services exist to support the family member(s) who have special medical and educational needs. Currently, there are 8,934 EFMP-enrolled Marines (known as sponsors) with 11,392 enrolled family members. Children account for 7,406 of the enrolled family members and 1,624 (21.9%) of these children have a primary diagnosis of autism. Applied Behavior Analysis (ABA) is a frequently used therapy for children with autism and is a TRICARE-approved service under the TRICARE Comprehensive Autism Care Demonstration. Over time, it has become increasingly difficult to confirm the availability and accessibility of ABA due to increased EFMP enrollment and, possibly, increased prevalence of autism within the Marine Corps population. Case managers find that even when services are available at a given installation, the queue for seeing a therapist can be three months or longer. If ABA services are not readily available, it can cause considerable setbacks in a child's therapy progress and hardship on a Marine's family life. This greatly affects to where an EFMP-enrolled Marine with a child with autism can accept PCS orders. Moreover, having these services available to Marine families at duty locations improves quality of life for these Marines and can even impact retention.

The purpose of the study was to assess the prevalence rate for autism within the EFMP-enrolled population over time and determine whether the existing TRICARE network of ABA providers near Marine Corps installations is sufficient to accommodate the existing need and projected need based on prevalence, enrollment data, and trends. The study only considered installations in the contiguous United States (CONUS).

The study team analyzed EFMP case data from 2013 through 2021 and determined that the number of EFMP-enrolled cases per year requiring ABA has increased every year since 2013 even when Marines end-strength decreased. It has risen by nearly 20% since 2013 with the steepest increases from 2016–2021. Further research showed that the prevalence of autism is, in fact, increasing nationwide. EFMP case managers keep a log of providers at each installation that provide ABA services and whether they are accepting new patients. A comparison of TRICARE's online provider directory and EFMP's provider log data shows a drastic difference in the actual availability of these needed services. These results indicate that TRICARE cannot currently adequately support this rising need for ABA services at Marine Corps Installations.

This page was left intentionally blank.

CONTENTS

BACKGROUND	1
PURPOSE AND SCOPE	1
METHODOLOGY.....	1
RESULTS	3
AUTISM PREVALENCE RATE.....	3
TRICARE CAPACITY TO SUPPORT	4
CONCLUSIONS	7
ABBREVIATIONS	9
REFERENCES	11

TABLES AND FIGURES

Table 1. Prevalence of Autism Spectrum Disorder.....	4
Table 2. ACD Directory/ Provider Log Availability Comparison	5
Figure 1. USMC Cases Requiring ABA FY13 through FY21	3

This page was left intentionally blank.

Background

The Exceptional Family Member Program (EFMP) is a mandatory program, administered by Headquarters, United States Marine Corps, that supports families with exceptional needs. Working with the MOS Monitors, EFMP staff helps direct Marines with permanent change of station (PCS) orders to new duty stations where services exist to support the family member(s) who have special medical and educational needs. Currently, there are 8,934 EFMP-enrolled Marines (known as sponsors) with 11,392 enrolled family members. Children account for 7,406 of the enrolled family members and 1,624 (21.9%) of these children have a primary diagnosis of autism. Applied behavior analysis (ABA) is a frequently used therapy for children with autism and is a TRICARE-approved service under the TRICARE Comprehensive Autism Care Demonstration (ACD). Over time, it has become increasingly difficult to confirm the availability and accessibility of ABA due to increased EFMP enrollment and, possibly, increased prevalence of autism within the Marine Corps population. Case managers find that even when services are available at a given installation, the queue for seeing a therapist can be three months or longer. If ABA services are not readily available, it can cause significant setbacks in a child's progress in therapy and hardship on a Marine's family life. This dramatically affects where an EFMP-enrolled Marine with a child with autism can accept PCS orders.

Purpose and Scope

This study assessed the prevalence rate for autism within the EFMP-enrolled population over time and determined whether the existing TRICARE network of ABA providers can accommodate the existing need and projected need based on prevalence, enrollment data, and trends.

This study sought to answer the following questions:

- Is the prevalence of autism increasing within the Marine Corps?
- Is the Marine Corps prevalence rate comparable to the civilian population prevalence rate?
- Does the TRICARE network have the capacity to support the number of children requiring ABA at the various CONUS Marine Corps installations?

Methodology

The study team first conducted a review of previous research related to the prevalence of autism nationwide. Next, since the EFMP data required for the study is data about Marines, the study team submitted an applicability review form to the USMC Institutional Review Board (IRB) to determine whether the study meets the definition of human subjects research which would necessitate a Human Research Protections Protocol. The IRB found that the study was not human subjects research.

Since there is no data regarding the actual number of children with autism in the Marine Corps, the study team was limited to using EFMP case data as a proxy. From the case data, the team was able to determine the number of children with autism enrolled in EFMP over time. The

study team collected the case data from M&RA for fiscal years 2013– 2021 and used descriptive statistics to analyze. Next the study team examined TRICARE’s capacity to support the number of beneficiaries requiring ABA. To do this, the study team used TRICARE’s online system to locate providers near Marine Corps installations who were accepting new patients at that time. This data was then compared to EFMP case manager provider logs.

Results

Autism Prevalence Rate

In order to estimate the prevalence of autism in the Marine Corps, the study team analyzed EFMP case data. The data consisted of case records from fiscal year 2013 through fiscal year 2021.

The study team calculated the number of cases per year with children requiring ABA services. Figure 1 shows the results of the analysis. The number of EFMP-enrolled cases per year requiring ABA has increased every year since 2013 even when Marines end strength decreased. It has risen by nearly 20% since 2013 with the steepest increases from 2016–2021.



Figure 1. USMC EFMP ABA Cases Fiscal Year 2013 through Fiscal Year 2021

Further research confirmed that the autism rate is increasing not only within the Marine Corps, but nationwide. Several studies addressing this subject have been conducted in recent years. The Center for Disease Control (CDC) began monitoring the prevalence of autism in Atlanta in 1996. In 2000, the CDC established the Autism and Developmental Disabilities Monitoring (ADDM) Network and began tracking autism prevalence in additional areas of the country. There are currently 11 sites being tracked. The ADDM shows the prevalence as the proportion of 8-year-olds diagnosed with autism. Although autism is often diagnosed earlier, the age of 8 was selected to ensure that later diagnoses are captured. Every two years since 2000, results have been published in the *Morbidity and Mortality Weekly Report*, CDC’s journal highlighting public health investigations (*Data and Statistics*, 2022).

During the past two decades, autism prevalence estimates of children aged 8 years have increased markedly per the ADDM Network, from 1 in 150 (0.67%) in 2000 to 1 in 36 (2.77%) in 2020. This means there are more than four times as many 8-year-olds diagnosed with autism in 2020. Table 1 shows the overall results (all 11 sites) by calendar year.

Table 1. Prevalence of Autism Spectrum Disorder by Calendar Year, 2000–2020

Surveillance Year	Prevalence	Percent
2020	1 in 36	2.77%
2018	1 in 44	2.27%
2016	1 in 54	1.85%
2014	1 in 59	1.69%
2012	1 in 69	1.45%
2010	1 in 68	1.47%
2008	1 in 88	1.14%
2006	1 in 110	0.90%
2004	1 in 125	0.80%
2002	1 in 150	0.67%
2000	1 in 150	0.67%

With this confirmation of increased need for autism services, the study team then sought to identify if TRICARE has the capacity to support this need.

TRICARE Capacity to Support

Autism Care Demonstration

In 2014, TRICARE identified a need for improved access to care for patients with an autism diagnosis and introduced the Autism Care Demonstration (ACD), which allows for clinically necessary and appropriate ABA services to be rendered to TRICARE-eligible beneficiaries diagnosed with autism spectrum disorder. Under the ACD, ABA services are authorized to target the core symptoms of autism. TRICARE assigns an Autism Services Navigator to newly diagnosed beneficiaries to support the family as a health care advocate, helping the caregivers navigate ACD and maximize available services. ACD is currently authorized to run through 2028.

TRICARE ABA Providers

A separate directory is available via the TRICARE website for ACD providers. These providers must meet specific requirements and sign an ACD participation agreement. The

agreement necessitates provider training and stipulates certain access-to-care requirements. These include 28 days to obtain an assessment and an additional 28 days to begin ABA services. Parent training is another requirement. Unfortunately, given these new requirements, some of the former TRICARE ABA providers, including ones near Marine Corps installations, have opted not to participate.

Case Manager Provider Log Data Comparison

EFMP case managers keep a log of providers at each installation that provide ABA services and whether they are accepting new patients. The log is kept up to date with the case managers regularly calling providers within 30 miles of each installation to verify that the provider has availability. This study was prompted when case managers noticed a continued lack of availability at several installations. Even when a provider was accepting new patients, case managers were finding that the queue to see a therapist could be three months out or longer. With the newly implemented ASD requirement, the wait times are shorter but often reach the maximum allowed time of nearly two months (28 days to be assessed, then an additional 28 days to start therapy). If ABA services are not readily available, it can cause major setbacks in the child’s progress. In order to ensure EFMP-enrolled Marines in new duty stations receive prompt care for their family members, EFMP case managers only mark the provider as “available” if the wait list is less than one month. Table 2 compares the ACD online directory data to the case manager provider log data.

Table 2. TRICARE ACD Directory-Provider Log Availability Comparison

Installation	ACD Directory	Provider Log
Twentynine Palms, CA	11	3
Albany, GA	3	1
Beaufort-Parris Island, SC	15	5
Cherry Point, NC	17	1
CLNC-New River, NC	25+	5
Camp Pendleton, Camp	25+	3
Hawaii	25+	4
Miramar, CA	25+	11
Norfolk, VA – Fort Story	25+	10
Quantico, VA	25+	10
Washington, DC	25+	6
Yuma, AZ	9	1
<i>Note.</i> ACD directory column represents individual ABA therapists within 30 miles of installation accepting new patients. The provider log column represents practices within 30 miles with no waitlist or an estimated wait of less than one month.		

At all installations, considerably more providers were identified by TRICARE as having availability than the provider log. We expect the ACD directory to show more providers since it includes the individual therapists at each practice, and it does not consider the time to begin therapy, but the table reveals a drastic difference between the number of providers TRICARE considers available, and number that can actually provide ABA service in an acceptable amount of time. The provider log numbers do not even take into account other important factors such as times available or whether the services are provided in home or at the facility. Some providers only have openings during the school day, making these services unavailable to school-aged children. Moreover, some children need a continuity of care in a particular place, i.e., a child getting services at home will not do well getting services at a facility. EFMP generally does not approve PCS orders to a location that does not have readily available and accessible services. In some cases, there is only one provider available at a given location, and since availability regularly changes, services may or may not be available by the time the Marine arrives.

Conclusions

The study team analyzed EFMP case data from fiscal year 2013 through fiscal year 2021 and determined that the number of cases of autism requiring ABA have steadily increased over the years. Further research showed that the prevalence of autism is, in fact, increasing nationwide. The study team next looked at TRICARE's ability to support this growing need for ABA services. A comparison of TRICARE's online provider directory and EFMP's provider log data shows a drastic difference in actual availability of these much-needed services. Despite the introduction of the ACD, providers are limited. Currently, these results indicate that TRICARE cannot adequately support this rising need for ABA services at Marine Corps installations where these providers can be overwhelmed due the increasing numbers and fluctuating Marine population. This limited capacity greatly affects where an EFMP-enrolled Marine with a child with autism can accept PCS orders. This can negatively impact the Marine's quality of life and possibly retention.

This page was left intentionally blank.

Abbreviations

ABA	Applied behavioral analysis
ACD	Autism Care Demonstration
ASD	Autism Spectrum Disorder
ASN	Autism Services Navigator
CONUS	Contiguous United States
EFMP	Exceptional Family Member Program
IRB	Institutional Review Board

This page was left intentionally blank.

References

Autism Care Demonstration. TRICARE. <https://www.tricare.mil/Plans/SpecialPrograms/ACD>. Retrieved 23 Mar 2023.

Data & Statistics on Autism Spectrum Disorder. Autism and Developmental Disabilities Monitoring (ADDM) Network. <https://www.cdc.gov/ncbddd/autism/data.html>. Retrieved 2 Nov 2022.

Maenner MJ, Shaw KA, Bakian AV, et al. *Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years—Autism and Developmental Disabilities Monitoring Network*, 11 sites, United States, 2018. *Morbidity and Mortality Weekly Report Surveillance Summaries* 2021;70(No. SS-11):1–16.

MCO 3900.18, Human Research Protections Program

Shaw KA, Maenner MJ, Bakian AV, et al. *Early Identification of Autism Spectrum Disorder Among Children Aged 4 years—Autism and Developmental Disabilities Monitoring Network*, 11 sites, United States, 2018. *Morbidity and Mortality Weekly Report Surveillance Summaries* 2021;70(No. SS-10):1–14.

TRICARE ACD Directory, <https://www.goperspecta.com/VPD/HumanaMilitary/public/ProviderSearch/Main4>, Retrieved July 2022