

UNDER SECRETARY OF DEFENSE

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

The Honorable Mike D. Rogers Chairman Committee on Armed Services U.S. House of Representatives Washington, DC 20515

DEC 1 9 2023

Dear Mr. Chairman:

The Department's response to House Report 117–397, page 199, accompanying H.R. 7900, the National Defense Authorization Act for Fiscal Year 2023, "Parent Stress Index Analysis," is enclosed. House Report 117–397, page 199, requests that the Secretary of Defense provide a report on "the utility, value, functionality and effectiveness of the Autism Care Demonstration, Applied Behavior Analysis, Parenting Stress Index."

On March 23, 2021, the Defense Health Agency published a comprehensive update to the Autism Care Demonstration (ACD) policy that included a new requirement to administer a parent stress measure to participating parents. The purpose of the parent stress measures under the ACD is to help identify the impact of stress on the family and to subsequently connect families with appropriate resources. This report provides a summary of the literature regarding parent stress including parent stress in the context of autism, a description of the Parenting Stress Index, a review of the ACD requirements, and preliminary findings of the measures administered under the ACD.

The Department is committed to ensuring military dependents diagnosed with autism spectrum disorder and their families receive comprehensive, high quality services and support. Thank you for your continued strong support for the health and well-being of our Service members and their families.

Sincerely,

Ashish S. Vazirani Acting

Enclosure: As stated

cc: The Honorable Adam Smith Ranking Member

Report to the Committee on Armed Services of the House of Representatives



Parent Stress Index Analysis

December 2023

The estimated cost of this report or study for the Department of Defense is approximately \$2,680 in Fiscal Years 2023. This includes \$0 in expenses and \$2,680 in DoD labor.

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INTRODUCTION

This report is in response to House Report 117–397, page 199, accompanying H.R. 7900, the National Defense Authorization Act for Fiscal Year (FY) 2023, which requests a report to the Committee on Armed Services of the House of Representatives on an analysis of the "parent stress index." Specifically, this report is requested to address: "… the utility, value, functionality and effectiveness of the Autism Care Demonstration, Applied Behavior Analysis, Parenting Stress Index."

BACKGROUND

The TRICARE Basic (i.e., medical) benefit covers a wide range of medically necessary and appropriate services for beneficiaries with the diagnosis of Autism Spectrum Disorder (ASD) including, but not limited to, physical therapy, occupational therapy, speech therapy, medication management, and psychotherapy. The Defense Health Agency (DHA), under the TRICARE Program authority to cost share on claims for private sector care, currently covers clinically necessary and appropriate Applied Behavior Analysis ("ABA") services for TRICARE covered beneficiaries diagnosed with ASD outside the statutorily defined TRICARE Basic (medical benefit) Program. ABA services are offered in accordance with the Agency's separate (and limited) demonstration authority found in 10 U.S.C. § 1092, as implemented by 32 CFR § 199.1(o).

While the ACD and the TRICARE Basic benefit addresses the clinical needs of beneficiaries diagnosed with ASD, focusing only on the individual diagnosed with ASD limits the long-term impact and success of any intervention. DHA approaches the diagnosis of ASD from a comprehensive perspective to include not only the individual diagnosed with ASD but also the family who provides the primary support outside of the clinical treatment.

As part of the comprehensive revisions to the ACD on March 23, 2021, the DHA is focusing on providing enhanced beneficiary and family support, incorporating all appropriate services and resources into a comprehensive care plan, improving outcomes, and increasing parental involvement. These comprehensive revisions move the program to a more beneficiary-and family-centric model. Specific improvements in parent and family support include: the Managed Care Support Contractor created "ACD parent tool-kit" (an introduction to the ACD and the other TRICARE services), assignment of an Autism Services Navigator, enhanced parent participation via the parent training requirements, access to parent mediated interventions, and access to additional medical and non-medical services within and outside the military system. With this enhanced focus on parent and family support, the 2021 policy update also included measures to evaluate parent stress. The purpose of the parent stress measures under the ACD is to help identify the impact of stress on the family and to subsequently connect families with appropriate resources, should they be identified.

UTILITY OF MONITORING PARENT STRESS: RESEARCH

For the purpose of this report, DHA defines the term "utility" as the "fitness for some purpose or worth to something."¹

Parent Stress Research: General

Use of the Parenting Stress Index (PSI) within the ACD is grounded in over a century of research in this area. The impact of stress has been studied through a variety of models over time. For example, the Yerkes-Dodson law (originally developed in 1908) states that performance increases with physiological or mental arousal, but only up to a point. When levels of arousal (or stress) become too high, performance decreases. Additionally, the simplicity or complexity of the task also impacts the ability to moderate stress. Similarly, the Transactional Model of Stress and Coping (1984) suggests that a person's capacity to cope and adjust to challenges and problems is a consequence of transactions (interactions) that occur between a person and their environment (the appraisal of the situation and the coping strategies available to manage the perceived stress).

Several models of stress specific to parenting have also been developed. For example, the ABC-X model (developed in 1958) is used for analyzing stress and coping within families that includes the stressor event (A), the available resources of the family (B), the family's perception of stress (C), and the likelihood of a crisis (X). The double ABC-X model (developed in 1983) was refined to include additional factors such as a family's social context, the compounding factors of stress, and the likelihood of adapting to stress. A preliminary theoretical model of parenting stress was developed in 1983 followed by the 1990 Parenting Stress model (Abidin) that proposed parenting stress is caused by various child and parent characteristics.

A simple definition of parenting stress "is the experience of distress or discomfort that results from demands associated with the role of parenting." Stress is a subjective process that stems from an incompatibility between stressors and resources where the parents' appraisal is critical. Stressors or stress events can be "normative stressors" meaning common or everyday life events such as daily hassles, or "non-normative stressors" meaning unpredictable, sudden, dramatic events that may significantly disrupt everyday life such as natural disasters, sudden death, or an injury, or "chronic stressors" meaning an atypical circumstance that occurs over an extended period of time such as a chronic condition. Resources for coping can range from personal resources such as physical health or knowledge of child development, to family and social resources such as support systems. Research has stated that the more resources are available, the less likely there is a negative impact from stress.

¹ Merriam-Webster. Utility. In *Merriam-Webster.com dictionary*. Retrieved July 9, 2023, from https://www.merriam-webster.com/dictionary/utility.

² Hayes and Watson. 2013. The impact of parenting stress: A meta-analysis of studied comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. Journal of Autism and Developmental Disorders, 43: 629-642.

³ Pastor-Cerezuela et al. 2016. Parental stress and ASD: Relationship with autism symptoms severity, IQ, and resilience. Focus on Autism and Other Developmental Disabilities, 31(4), 300-311.

Parental stress impacts both individuals and family relationships. Parental stress also can contribute to parents being less responsive and affectionate toward their children or even disconnected and isolated from roles and responsibilities both within and outside the family. Therefore, the utility of monitoring parent stress is enormous.

Parent Stress Research: ASD

Research has also studied the impact of stress and parents of children diagnosed with ASD. Following diagnosis, parental response can vary dramatically depending on the severity of presenting symptoms.⁴ As noted by Bonis (2016), many aspects of parents' lives change following a diagnosis of ASD, including family and friend relationships, routines, and future plans. Several articles state that parents of children diagnosed with ASD experience higher levels of stress, depression, anger, anxiety, and more general life stress when compared to other parents.^{5,6,7,8} For parents of children diagnosed with ASD who experience chronic stress, the negative effects of this stress can have an impact on the health and well-being of both the parent and the child.⁹

According to Rao and Beidel (2009), ¹⁰ when families perceive stress as overwhelming, families will often forgo treatment or between session work impacting any gains that may have been achieved during intervention times. Families may even remove their children from treatment altogether if they feel that the intervention is overwhelming. ¹¹ Therefore, understanding what contributes to parental stress may lead to not only better opportunities to manage and cope with stress, but also to positive impacts to parental engagement in parenting and treatment.

VALUE OF THE PARENT STRESS MEASURE

For the purpose of this report, DHA defines the term "value" as "having relative worth, utility, or importance." ¹²

⁴ Bonis. 2016. Stress and parents of children with autism: A review of literature. Issues in Mental Health Nursing, 37·153-163

⁵ Hayes and Watson, (2013). The impact of parenting stress: A meta-analysis of studied comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. Journal of Autism and Developmental Disorders, 43: 629-642.

⁶ Sheperd et al. 2018. Symptom severity, caregiver stress and intervention helpfulness assessed using ratings from parents caring for a child with autism. Autism, 22(5); 585-596.

⁷ Tomanik et al. 2004. The relationship between behaviors exhibited by children with autism and maternal stress. Journal of Intellectual & Developmental Disabilities; 29(1), 16-26.

⁸ Markowitz et al. 2016. Developmental and psychometric evaluation of a psychosocial quality of life questionnaire for individuals with autism and related developmental disorders. Autism, 20(7); 832-844.

⁹ Cooury et al. 2020. The autism treatment network: Bringing best practices to all children with autism. Pediatrics; 145(1); 13-19.

¹⁰ Rao and Beidel. 2009. The impact of children with high-functioning autism on parental stress, sibling adjustment, and family functioning. Behavior Modification; 33(4); 437-451.

¹¹ Shepard et al. 2018. Brief report: Parent's assessments of their care-related stress and child's ASD symptoms in relation to their child's intervention history. Journal of Autism and Developmental Disorders; 48; 2879-2885.

¹² Merriam-Webster. Value. In *Merriam-Webster.com dictionary*. Retrieved July 9, 2023, https://www.merriam-webster.com/dictionary/value.

The 2021 policy update added two parent stress measures: the Parenting Stress Index, Fourth Edition, Short Form (PSI-4-SF) (developed by Abidin), and the Stress Index for Parents of Adolescents (SIPA) (developed by Shears and Abidin). Consistent with psychometric test development, the PSI-4-SF and the SIPA followed the standard process for establishing a sound measure. A measure must demonstrate content-validity, criterion-related validity, construct validity, and internal consistency. These criteria determine the psychometric validation of measures. Test materials, including the manual, measure items/question content, scoring protocols, and software are published and protected by PAR Inc and are intended to be used in their published form without modification. An eligible provider who agrees to protect the integrity of the measure may purchase the materials under their license. As the specific materials for these measures are protected and trademarked, the following is a summary of the measures from publicly available information. Both measures are designed to screen and evaluate the parenting system and identify issues that may lead to problems in the child's or parent's behavior. The PSI-4-SF is administered to parents of beneficiaries ages 0-12 years, and the SIPA is administered to parents of beneficiaries ages 11-19 years. See the TRICARE Operations Manual Chapter 18, Section 4 regarding the ACD requirements for these measures. ¹³ In FY 2022, there were 16,156 beneficiaries diagnosed with ASD participating in the ACD. Eightyfour percent of beneficiaries participating in the ACD are under 12 years of age; 14 percent are ages 12-19 years old, and 2 percent are 20 years of age or older. As the majority of the ACD participants are under 12 years of age, and consistent with the committee request, the remainder of this report focuses on only the PSI-4-SF as any analysis of the SIPA would provide insufficient data for review.

The PSI-4-SF is a brief (36 items) version of the PSI-4 and is designed to offer a quick screening of the domains of parenting stress. The PSI is the most widely used instrument to evaluate parental stress in parents of children diagnosed with ASD.¹⁴ This measure has strong psychometric properties and its validity is supported in numerous studies (more than 250 studies) across different disability groups.^{15, 16}

The PSI-4 measures stress, according to the Parenting Stress model, in the parent-child system based on the parent's perception of child characteristics, the personal characteristics of the parent, and the interaction between the child and parent. The model incorporates parental characteristics (e.g., physical and mental health, attachment, social isolation, interpersonal relationships, sense of competence), child characteristics (e.g., adaptability, demandingness, mood), social and environmental factors, and the relationships between these variables.

There are four scales that result from the 36 items in the PSI-4-SF: Total Stress Score, Parental Distress (PD) Subscale, Parent-Child Dysfunctional Interaction (P-CDI) Subscale, and Difficult Child (DC) Subscale. Responses to these 36 items contribute to the collective picture consistent with the scale. The Total Stress score is designed to provide an indication of the

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¹³ https://manuals.health.mil/pages/DisplayManualHtmlFile/2023-06-23/AsOf/TO15/C18S4.html.

¹⁴ Zaisman-Zait et al. 2011. Factor analysis of the parenting stress index-short form with parents of young children with autism spectrum disorder. Autism Research 4: 336-346.

¹⁵ Pastor-Cerezuela et al. 2016. Parental stress and ASD: Relationship with autism symptom severity, IQ, and resilience. Hammill Institute on Disablities, 31(4), 300-311.

¹⁶ Zotero reference list of PSI articles: https://www.parinc.com/Products/Pkey/335.

overall level of parenting stress that an individual, in this case the parent, is experiencing. The PD subscale is designed to determine the level of stress a parent is experiencing as a function of personal factors that are directly related to parenting. The P-CDI subscale is designed to focus on the extent to which the parent perceives the child as not meeting their expectations and finds that interactions with the child are not reinforcing her or her parenting role. Additionally, the DC subscale is designed to focus on the temperament or behavioral characteristics of the child that influence the parent-child relationship. In addition to the four clinical scales, the measure includes a Defensiveness Responding Scale. This is designed to assess the extent to which the respondent approaches the questionnaire with a strong bias to present the most favorable impression of himself or herself or to minimize indications of problems or stress in the parent-child relationship. According to the PSI-4 manual, the normal range for scores is within the 16th to 84th percentiles. Scores in the 85th to 89th percentiles are considered high, and scores in the 90th percentile or higher are considered clinically significant.

Following the administration of a measure, the administering provider should review the findings with the respondent (parent) including addressing any indications of defensive responding, explore the implications, and discuss appropriate recommendations. Monitoring parent stress under the ACD is consistent with the literature that provides value when making recommendations for treatment and other support services.

FUNCTIONALITY AND EFFECTIVENESS OF PARENT STRESS MEASURES IN THE ACD

For the purpose of this report, DHA defines the term "functionality" as "the quality of being useful, practical, and right for the purpose for which something was made;" and the term "effectiveness" as "the ability to be successful and produce the intended results." ¹⁹

ACD Requirements Regarding the PSI-4-SF

The parent stress measures are administered by a qualified health care provider at baseline and every 6 months thereafter following active treatment engagement and continuing participation in the ACD. Following administration, the various treating providers are expected to develop appropriate goals to address respective domains that fall within the scope of practice. For example, elevated scores on the PD might suggest that a parent education class or a support group may be beneficial. Or perhaps the ABA provider could target specific ABA principles to help the parent more effectively apply intervention strategies consistently and frequently between treatment sessions. Following the periodic administration of this measure, providers can use the results therefrom to better monitor the impact of parent stress and adjust treatment goals accordingly.

¹⁸ Merriam-Webster. Functionality. In *Merriam-Webster.com dictionary*. Retrieved July 9, 2023, https://www.merriam-webster.com/dictionary/functionality.

¹⁷ https://www.parinc.com/Products/Pkey/335.

¹⁹ Merriam-Webster. Effectiveness. In *Merriam-Webster.com dictionary*. Retrieved July 9, 2023, https://www.merriam-webster.com/dictionary/effectiveness.

In addition to the treating providers addressing stress, the scores are submitted to the managed care support contractors, who in turn, report percentile scores to DHA for program evaluation. For this report, DHA completed an initial analysis of the impact of parent stress over time. In addition to understanding the impact of stress on parents participating in the ACD, DHA is also assessing the impact of the support (e.g., providing information and connections to the range of clinical and non-clinical services available) offered by the ACD on parent stress levels over time. DHA, through the ACD, is evaluating parental stress to aid in enhancing family support, increasing parental involvement, and ultimately, improving the clinical outcomes for each beneficiary. The PSI-4-SF serves its intended function under the ACD.

ACD PSI-4-SF Analysis

The analysis for the PSI-4-SF was conducted in conjunction with the analysis for Annual Report to the Committees for FY 2023. While additional information about the full analysis is available in that report, this report focused on the findings specific to the ACD's data collection on the PSI-4-SF. The following data should be interpreted with caution as these findings are preliminary given that this is the first time DHA conducted an analysis following the administration of the PSI-4-SF. Resultantly, any determinations of effectiveness are premature.

The Annual Report analysis included a sample population of 497 beneficiaries who met the inclusion criteria (enrolled into the ACD in FY 2022, had at least two Pervasive Developmental Disorder Behavior Inventory (PDDBI) – Parent Form scores that were at least 120 days apart, and all fields of data were complete). Of the 497 beneficiaries in the Annual Report analysis, there were 451 beneficiaries who had both an initial and a final PSI-4-SF score within this review period. The remaining 46 beneficiaries from the Annual Report analysis either did not have a first or last PSI-4-SF or they completed the SIPA (27 beneficiaries over age 12) and therefore are not included in this analysis.

Figure 1 displays the distribution of initial and last PSI-4-SF Total scores. Of the 451 beneficiaries included in this analysis, 394 parents (87 percent) had initial PSI-4-SF Total scores in the normal range and 411 parents (91 percent) had last PSI-4-SF Total scores in the normal range. A total of 57 parents (12.6 percent) had initial PSI-4-SF Total scores above 85 and a total of 40 (8.9 percent) had last PSI-4-SF scores above 85 (which is considered high). A total of 43 parents (9.5 percent) had initial PSI-4-SF Total scores above 90 and a total of 27 (5.9 percent) had last PSI-4-SF scores above 90 (which is considered high and clinically significant).

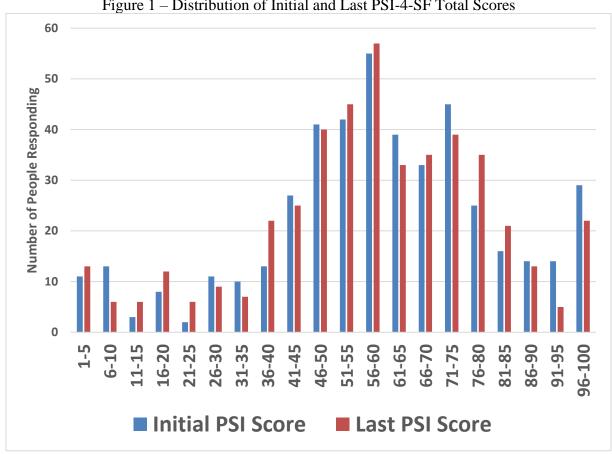


Figure 1 – Distribution of Initial and Last PSI-4-SF Total Scores

The analysis also observed the distribution of changes in scores between the initial and last score. The average score for the first administration was 59.19 and the average score for the second administration was 57.64. A total of 243 parents (53.9 percent) had a reduction in scores (improvement), 22 parents (4.9 percent) had no change in scores, and 186 parents (41.2 percent) had increased (worsening) scores. The overall average change was a 1.55 point (2.6 percent) reduction (improvement) in scores.

ACD PSI-4-SF Scores in Relation to Clinical Outcomes

PSI-4-SF scores were also compared to the clinical outcomes of the PDDBI – Parent Form to assess whether parent stress had an impact on treatment gains. As expected, if parent stress was reduced from the first to the second administration, the PDDBI Parent Form Autism Composite scores improved (7.1 percent reduction on average). It was also found that if the parent stress level stayed the same, the total PDDBI Parent Form Autism Composite scores were reduced (improved) by 4.9 percent on average. If parent stress levels increased, the total PDDBI Parent Form Autism Composite scores also increased (got worse) by 0.7 percent on average. In the regression analysis conducted for the Annual report (see the 2023 Annual Report for details), it was estimated that if parental stress levels increased by 10 percent, beneficiary outcomes as reported on the PDDBI Parent Form were significantly degraded by roughly 1 percent, meaning that if parental stress increased, their responses of their child's clinical outcomes worsened.

CONCLUSION

Stress affects people of all ages and of all walks of life. Sometimes people do not even realize how stress is impacting them. Stress may impact work, physical health, behaviors, mood, relationships, and home life. Military life can add stress. Having a child with special health care needs can also add stress. Stress can be cumulative, therefore understanding the summation of stress as well as how stress impacts parenting a child or adolescent is important.

The ACD offers a comprehensive approach to treating the beneficiary diagnosed with ASD as well as supporting the entire family system. The 2021 ACD policy update added both the monitoring of parent stress as well as the enhanced access to clinical and non-clinical services through educational materials, direct engagement with the managed care support contractors, and connections to resources to meet the evolving demands of child development, treatment progress, and family needs. One way to support parents is to assess the impact of stress through use of standardized parent stress measures. Understanding how stress impacts the parent, the child, and the relationship between the two can be useful for designing a treatment plan, for setting priorities for interventions, and for identifying supports and services that may be beneficial in impacting stress.

The authorized provider administers and scores the measures and then makes recommendations for appropriate services or treatment goals. The provider also submits only the Domain scores (standardized and norm-referenced data) to the TRICARE contractors who then report aggregate data to DHA. DHA uses this data to assess the overall impact of the ACD including the impact of successfully reducing parent stress on overall outcomes.

This report provides an initial analysis of the experience and impact of stress for parents and families participating in the ACD. While the majority of respondents' scores in this analysis fell within the normal range, approximately half of the initial and last scores fell above the midway point. As these findings are preliminary, more analysis of the impact of stress is required to ensure that families are connected to appropriate resources to address the experienced stress and whether the ACD is providing that support.

Independent research has demonstrated the utility and value of the parent stress measure. The ACD requirements demonstrate the functionality for monitoring parent stress, and the preliminary findings of these measures begin to explore the effectiveness of monitoring parent stress and the impact on clinical outcomes. More data and analyses are required before DHA can make any determinations regarding the impact of the ACD on reducing parent stress. DHA will continue to collect data, monitor feedback, and adjust supports and services as appropriate.