

4-20-2018

## "Thou Shalt Not Ration Justice": The Importance of Autism Insurance Reform for Military Autism Families, and the Economic and National Security Implications of Improving Access to ABA Therapy Under TRICARE

Ariana Cernius

Follow this and additional works at: <https://scholarship.law.nd.edu/jleg>

 Part of the [Health Law and Policy Commons](#), [Insurance Law Commons](#), [Legislation Commons](#), and the [National Security Law Commons](#)

---

### Recommended Citation

Ariana Cernius, *"Thou Shalt Not Ration Justice": The Importance of Autism Insurance Reform for Military Autism Families, and the Economic and National Security Implications of Improving Access to ABA Therapy Under TRICARE*, 44 J. Legis. 201 (2017).  
Available at: <https://scholarship.law.nd.edu/jleg/vol44/iss2/3>

This Article is brought to you for free and open access by the Journal of Legislation at NDLScholarship. It has been accepted for inclusion in Journal of Legislation by an authorized editor of NDLScholarship. For more information, please contact [lawdr@nd.edu](mailto:lawdr@nd.edu).

---

---

“THOU SHALT NOT RATION JUSTICE”: THE  
IMPORTANCE OF AUTISM INSURANCE REFORM FOR  
MILITARY AUTISM FAMILIES, AND THE ECONOMIC  
AND NATIONAL SECURITY IMPLICATIONS OF  
IMPROVING ACCESS TO ABA THERAPY UNDER  
TRICARE

Ariana Cernius<sup>†</sup>

ABSTRACT

*According to the CDC, Autism Spectrum Disorder now affects 1 in every 68 children, making it the fastest-growing developmental disability in the U.S. today. Although no one knows the cause and cure of autism, productive ways of treating the disorder leading to significant improvements in decreasing symptoms and enabling independent living of those with autism have developed over the years. Applied Behavior Analysis (“ABA”) therapy is the most prominent, effective, evidence-based early intervention treatment. Prior to the autism insurance reform movement of the early 2000s, health insurance did not cover treatment for autism, and due to dwindling state budgets, many states were unable to adequately address the autism population’s early intervention treatment needs through state-funded programs, which meant that families could not get treatment for their children with autism unless they were able to bear the expense out-of-pocket. In the past two decades, the movement to mandate insurance coverage for autism has led to the enactment of autism insurance reform laws applicable to the major health insurance carriers—including commercial, Medicaid, and TRICARE military insurance—mandating coverage of treatment for autism and specifically, of ABA therapy. While such reform has been widely heralded by those in the autism community as a positive adjustment in legal policy to account for the needs of the increasing autism population, many autism families have faced barriers in accessing ABA therapy programs for their children under the mandates within each of the three major insurance carriers. In order to ensure that those with autism have true access to ABA that the mandates purport to afford them, it is imperative that policymakers now turn their attention to addressing the breakdowns in autism health insurance policy that currently prevent*

---

<sup>†</sup> Skadden Fellow, Bet Tzedek Legal Services, Los Angeles, CA. J.D., 2017, UCLA School of Law, A.B. 2013, Harvard College. I am extremely grateful to my adviser, UPenn Law Professor Allison Hoffman, for providing invaluable guidance and encouragement throughout the writing process, and to Karen Driscoll, autism mom, advocate, and military spouse, for generously lending her time to share her insights, experiences, and expertise. Thanks also to the Notre Dame Journal of Legislation for their hard work and thoughtful edits. This work is dedicated to Andrew, my younger brother with autism, whose ceaseless strength, positive attitude, and continuing achievements are my inspiration.

---

*autism families from obtaining and maintaining ABA. Such access issues are particularly well-illustrated by—and remedial action is especially urgent for—military autism families, who have faced unique struggles in accessing ABA. The realities of military service—extended family separation, frequent changes of duty stations, and varying access to specialized healthcare—often undermine military autism families’ ability to secure adequate individualized services. These challenges have been compounded by TRICARE’s most recent adjustments in coverage of ABA, which have run counter to trend. In late 2015, TRICARE announced a 15% slash to reimbursement rates for ABA providers, justifying this dramatic change with a statement of the need to bring TRICARE rates, which had previously been higher than Medicaid and commercial rates, in line with other commercial plans. Although the intent behind this rate reduction was to avoid government overpayment, it demonstrated a fundamental misunderstanding about the nature and treatment of autism and the functioning of the health insurance industry, and a lack of recognition of the fact that the commercial insurance, Medicaid, and TRICARE business models are not identical or based solely on revenues. First, simultaneous with its cut to provider reimbursement rates, TRICARE implemented higher credentialing standards for ABA providers, essentially demanding more skilled and educated employees for significantly lower pay. Additionally, because TRICARE does not reimburse providers for certain services that commercial insurance and Medicaid do provide reimbursement for, TRICARE’s move to slash rates was particularly harmful to ABA providers. This combination of policy changes essentially rendered children with autism from military families the least-desirable clients for ABA providers, because the lowered rates and profit margin per autistic child with TRICARE insurance are so significantly below the national average that it is unsustainable for the ABA provider business model to maintain their military autism family clients, and many providers are deterred from taking on new autism families with TRICARE insurance. It is estimated that 23,000 military dependents have a diagnosis of autism, and many stand to join them in the coming years; aside from the harm caused to the children with autism of the families that serve our nation by the increase in hardship in accessing ABA, there are negative implications for broader society as well. Studies show that lack of care and interrupted services have negative impacts to the progress of children with autism, leading to an increase in the economic burden of this population to society due to anticipated higher health costs, and the greater chance that these children with autism will be dependent on society as adults. Furthermore, inadequate or inconsistent access to ABA through TRICARE jeopardizes the health and well-being of military families, which affects national security, given the direct impact family health care plays on military readiness. This article examines the history of TRICARE’s coverage of autism treatment, analyzes the most recent policy missteps, and provides recommendations for policymakers in future efforts to care for and improve the lives of the autism population.*

TABLE OF CONTENTS

INTRODUCTION ..... 204

I. WHAT IS AUTISM, AND WHY SHOULD WE CARE? DEFINING AUTISM SPECTRUM  
DISORDER, EFFECTIVENESS AND AVAILABILITY OF TREATMENT, AND THE  
ECONOMIC IMPLICATIONS OF A RISING AUTISM POPULATION..... 208

    A. Autism, Defined..... 208

    B. Applied Behavior Analysis—What Is “ABA” Therapy and Why Is It  
    Effective? ..... 210

    C. Why We Should Care About an Increasing Autism Population: The Cost  
    of Autism to Society, and the Impact on Military Readiness of Military  
    Autism Families’ Lack of Access to ABA ..... 214

        1. The Economics of Autism ..... 214

        2. Past Coverage Schemes for Treating Autism and the Issue of Access  
        ..... 218

        3. The Struggle of Military Autism Families..... 222

II. THE TROUBLE WITH TRICARE ..... 224

    A. A History of TRICARE’s Treatment of Autism ..... 225

        1. TRICARE Basic, Program for Persons with Disabilities, and the  
        Extended Care Health Option..... 225

        2. Enhanced Access to Autism Services Demonstration ..... 227

        3. ABA Pilot..... 228

        4. Autism Care Demonstration ..... 228

    B. Effect of New TRICARE Reduced Reimbursement Rates Policy on  
    Military Autism Families ..... 231

III. THE PATH FORWARD—NEW TRICARE POLICY, AND LESSONS FOR THE FUTURE  
..... 232

    A. TRICARE’s Conceptual Mistakes About the Insurance Industry and  
    Providing ABA..... 232

        1. The Increased Credentialing Standards Problem..... 233

        2. Services Covered by Commercial Insurance and Medicaid but not by  
        TRICARE..... 235

    B. Analysis and Suggestions for the Future ..... 235

CONCLUSION ..... 238

"We must be doing everything we can to ensure that those who have sacrificed so much for our nation have the peace of mind that their children will be able to access the care they need."<sup>1</sup>

— Rep. John Larson

## INTRODUCTION

Autism is the most rapidly growing developmental disability in the United States today.<sup>2</sup> Clinically known as “Autism Spectrum Disorder,” autism describes a range of complex neuro-biological disorders characterized by deficits in functioning, including impaired language development, impaired social development, and the presence of excessive repetitive behaviors or interests, and according to the Centers for Disease Control and Prevention (“CDC”), it now affects one in every sixty-eight children in the U.S.<sup>3</sup> It is a disorder that manifests in each person differently and in different degrees, meaning a large number of symptom presentations are possible, which makes treatment challenging and expensive.<sup>4</sup> Because the soaring prevalence of autism is a relatively recent development, society has only recently become aware that this underserved and underrepresented community is on the rise and in need of a broad range of services—and improved access to those services—to allow its members to participate in society. Autism Speaks estimates that autism costs the United States \$236 billion per year.<sup>5</sup> Since the severity of autism is a main driver of costs across a person’s lifespan, the key to reducing costs is better access to quality early intervention “Applied Behavior Analysis (‘ABA’)” therapy services, which have been shown to “improve functioning and have lasting, long-term benefits with the potential to improve lives while reducing lifetime costs.”<sup>6</sup> However, despite the existence of this effective, evidence-based early intervention treatment, the growing prevalence of autism has been declared a public health crisis by many states, because those with autism who do not receive any or enough consistent treatment have a greater dependence on society from childhood through adulthood.<sup>7</sup> Due to receding

---

1. Press Release, United States Representative John Larson, Larson, Rooney Announce Passage of Amendment for Military Children with Development Disabilities (May 21, 2014), *available at* <https://larson.house.gov/media-center/press-releases/larson-rooney-announce-passage-amendment-military-children-development>.

2. Press Release, Center for Disease Control and Prevention, CDC Estimates 1 in 68 Children Has Been Identified with Autism Spectrum Disorder (Mar. 27, 2014), *available at* <http://www.cdc.gov/media/releases/2014/p0327-autism-spectrum-disorder.html>.

3. *Id.*

4. Melissa Stuart, Note, *Autism Insurance Reform: A Comparison of State Initiatives*, 8 IND. HEALTH L. REV. 497, 499 (2011).

5. *Lifetime Costs of Autism Average \$1.4 Million to \$2.4 Million*, AUTISM SPEAKS (June 9, 2014), <https://www.autismspeaks.org/science/science-news/lifetime-costs-autism-average-millions>.

6. *Id.*

7. Scott M. Myers & Chris Plauché Johnson, *Management of Children with Autism Spectrum Disorders*, 120 PEDIATRICS 1162, 1664 (2007). (“The effectiveness of the ABA-based intervention in ASDs has been well documented through 5 decades of research using single-subject methodology and in controlled studies of comprehensive early intensive behavioral intervention programs in university and community settings. Children who receive early intensive behavioral treatment have been shown to make substantial, sustained gains in IQ, language, academic performance, and adaptive behavior as well as some measures of social behavior, and their outcomes have been significantly better than those of children in control groups.”); *see also* Ariana

---

state budgets, many states are not able to adequately address the autism population's early intervention treatment needs through state-funded programs, and prior to the autism insurance reform movement, families could not get treatment for their children unless they were able to pay out of pocket.<sup>8</sup>

To close this gap and provide a secure means of accessing treatment for people with autism, autism advocates have pushed over the past two decades to improve the health insurance industry's treatment of autism, resulting in a major shift in policy towards mandating coverage of autism services and, within that coverage, ABA therapy. While reforming health insurance law to mandate coverage for autism treatment is no doubt a positive step in legal policy and a productive adjustment to the needs of the increasing autism population, autism families with all three major insurance carriers—commercial insurance, Medicaid, and TRICARE—have faced serious challenges in accessing adequate, consistently-provided ABA therapy under this new system. It is essential that policymakers now turn the focus to addressing the barriers to access and breakdowns in autism health insurance policy that currently prevent autism families from obtaining and maintaining ABA programs, because in order to achieve the goal of reducing the long term costs of these individuals to society and giving them the best chance to obtain independence, it is equally important to ensure that quality ABA treatment is consistently accessible to autism families, regardless of which insurance carrier the family has. One place where this problem is particularly well-illustrated and where action is most urgently needed, because it affects our military readiness as a nation in addition to its implications on the country's economic health, is among the population of military families with autism.

Military families who have a child with autism face unique burdens in obtaining and maintaining coverage for ABA therapy. The realities of military service—extended family separation, frequent changes of duty stations, and varying access to specialized health care—often undermine the family's ability to secure adequate individualized services.<sup>9</sup> These challenges are compounded by the inadequacy of TRICARE, the U.S. Department of Defense (“DOD”) military health system's policy of providing access to this treatment for autism to the families of the people who risk their lives serving the country. In 2009, it was nearly impossible for military autism families to get coverage for ABA therapy under TRICARE because ABA was not considered “medically necessary,” even though it was well-established under commercial autism insurance reform mandates in multiple states that ABA therapy is medically necessary treatment for children with autism.<sup>10</sup> Additionally, the

---

Cernius, “No Imbecile at All”: *How California Won the Autism Insurance Reform Battle, and Why Its Model Should be Replicated in Other States*, HARV. L. & POL'Y REV. 565, 565 (2016).

8. Stuart, *supra* note 4, at 499.

9. *Autism Speaks Salutes Military Families!*, AUTISM SPEAKS, <https://www.autismspeaks.org/military-families> (last visited Mar. 18, 2018).

10. *Autism Speaks Applauds Representatives Sestak, Jones, and Rodriguez for Introducing H.R. 1600*, AUTISM SPEAKS (Apr. 30, 2009) <https://www.autismspeaks.org/advocacy/advocacy-news/autism-speaks-applauds-representatives-sestak-jones-and-rodriguez-introducing>; see also Kimberly Johnson, *Military Families Advance Lawsuit to Force DOD to Provide Autism Care*, CARE (May 26, 2011) <https://www.care.com/c/stories/4376/military-families-advance-lawsuit-to-force-do/>.

restrictive nature of TRICARE's coverage of ABA therapy created further obstacles for military autism families seeking treatment due to the fact that TRICARE only offered coverage for ABA to active duty military autism families, and only at a fixed monetary rate of \$36,000 a year rather than using a tiered system based on the severity of the child's autism and the level of therapy needed.<sup>11</sup> In 2014, these problems were resolved through the Autism Care Demonstration Project, a thoughtful measure introduced by the DOD to consolidate all ABA programs into one uniform benefit for eligible TRICARE beneficiaries with autism and make access to treatment permanent.<sup>12</sup> While TRICARE has taken steps forward to improve coverage of ABA for autism families in the past few years, the latest proposed changes are believed by most to be a step backwards in facilitating access to ABA. In late 2015, TRICARE announced a 15% cut<sup>13</sup> to reimbursement rates for ABA therapy providers, which resulted in reduced access to ABA services, because the lowered rates and profit margin per autistic child with TRICARE insurance were so significantly below the national average that ABA providers were deterred from taking on autism families with TRICARE insurance as clients.<sup>14</sup> Even worse, if military families did manage to secure therapy despite TRICARE's slash to reimbursement rates, if they then had to move due to military assignment, the chances of securing a different ABA provider were very low given the high demand for therapy. While the cut to reimbursement rates was recently resolved by the National Defense Authorization Act ("NDAA") for Fiscal Year 2017, which President Obama signed into law in December 2016 and which restored previous reimbursement rates, the revised TRICARE policies present new issues preventing timely access to care and reflect further misunderstanding about the nature of autism and the model of treatment that is needed.<sup>15</sup>

It is estimated that 23,000 active duty family members have a diagnosis of autism, and a recent report to the U.S. Congress indicated that the annual number of active duty family members receiving care for autism under TRICARE nearly tripled

---

11. *Autism Speaks Lauds Senator Kirsten Gillibrand's Introduction of 2009 Bill Expanding Military Insurance Coverage of Autism Therapies*, AUTISM SPEAKS (June 2, 2009), <https://www.autismspeaks.org/advocacy/advocacy-news/autism-speaks-lauds-senator-kirsten-gillibrand%C2%92s-introduction-2009-bill-expan>; see also DEP'T OF DEFENSE, TRICARE EXTENDED CARE HEALTH OPTION FACT SHEET (2018), available at [https://www.tricare.mil/~media/Files/TRICARE/Publications/FactSheets/ECHO\\_FS.pdf](https://www.tricare.mil/~media/Files/TRICARE/Publications/FactSheets/ECHO_FS.pdf).

12. *TRICARE Launches New Consolidated ABA Demo Program*, AUTISM SPEAKS (Sept. 22, 2014), <https://www.autismspeaks.org/advocacy/advocacy-news/tricare-launches-new-consolidated-aba-demo-program>.

13. Tom Philpott, *Families, Therapists Brace for Cuts to Autism Care Fees*, MILITARY ADVANTAGE (Mar. 24, 2016), <https://www.military.com/militaryadvantage/2016/03/families-therapists-brace-for-cuts-to-autism-care-fees> [hereinafter Philpott, *Autism Care Fees*]; see also Tom Philpott, *Tricare Fee Cuts for Autism Therapy Stir Access Worries*, STARS & STRIPES (Dec. 23, 2015), <https://www.stripes.com/tricare-fee-cuts-for-autism-therapy-stir-access-worries-1.385626> [hereinafter Philpott, *Access Worries*].

14. *Autism Speaks Statement on TRICARE Proposed Reimbursement Rate Cut*, AUTISM SPEAKS, (Feb. 19, 2016), <https://www.autismspeaks.org/advocacy/advocacy-news/autism-speaks-statement-tricare-proposed-reimbursement-rate-cut>.

15. Press Release, United States Representative John Larson, Larson Supports FY17 National Defense Authorization Act, (Dec. 2, 2016), available at <https://larson.house.gov/media-center/press-releases/larson-supports-fy17-national-defense-authorization-act>.

---

---

between 2009 and 2012.<sup>16</sup> TRICARE is not the only health insurance carrier with clients encountering barriers to accessing ABA, but TRICARE's most recent policy decisions have run counter to trend and resulted in increased hardship for military autism families—all of which has unique implications for broader society. Lack of care and interrupted services have negative impacts on the health and progress of children with autism, leading to an increase in the economic burden of this population to society due to anticipated higher health costs, and the greater chance that these children with autism will be dependent on society in their adult years.<sup>17</sup> Additionally, inadequate or inconsistent access to ABA through TRICARE means that the health and well-being of military families is jeopardized, which imperils the nation's safety given the direct impact family health care plays on military readiness.<sup>18</sup> The Honorable Learned Hand, Chief Judge of the United States Court of Appeals for the Second Circuit, once said, "It is the daily; it is the small; it is the cumulative injuries of little people that we are here to protect...If we are able to keep our democracy, there must be one commandment: Thou shalt not ration justice."<sup>19</sup> Military autism families have held up their end of the bargain, risking their lives to ensure that freedom and democracy endure in the U.S.; there is little we as citizens can do to honor and fully repay their sacrifice, but providing an accessible, quality system of care for their children with special needs would go a long way towards alleviating the burdens and challenges they currently face. This Article will give a history of the development of military insurance coverage of treatment for children with autism and argue for improved and robust access to ABA therapy for all military autism families.

Part I will characterize the autism population, treatments for autism and their effectiveness, and the importance of making services for autism available, and discuss the current cost of an increasing autism population to the United States. Part II provides a brief history of how TRICARE has dealt with the treatment of autism and lays out what coverage looks like in the broader United States as of 2017. Part III will posit an analysis of the effect on military autism families of the most recent changes in policy and draw lessons about the potential for improved coverage of ABA for this population in the future.

---

16. *Outcry Grows Over Looming ABA Cuts for Military Kids*, AUTISM SPEAKS, (July 16, 2013), <https://www.autismspeaks.org/advocacy/advocacy-news/outcry-grows-over-looming-aba-cuts-military-kids>.

17. Karen Driscoll, *Military Families: Autism's Impact*, AUTISM RES. INST., [https://www.autism.com/military\\_impact](https://www.autism.com/military_impact) (last accessed Mar. 19, 2018).

18. Leada Gore, *Tricare Changes Could Limit Treatment for 23,000 Military Children with Autism*, AL.COM, (July 16, 2013, 7:55 AM), [http://blog.al.com/breaking/2013/07/tricare\\_changes\\_could\\_limit\\_tr.html](http://blog.al.com/breaking/2013/07/tricare_changes_could_limit_tr.html).

19. Judge Learned Hand, Keynote Address at the 75<sup>th</sup> Anniversary Celebration of the Legal Aid Society of New York (Feb. 16, 1951).

I. WHAT IS AUTISM, AND WHY SHOULD WE CARE? DEFINING AUTISM SPECTRUM DISORDER, EFFECTIVENESS AND AVAILABILITY OF TREATMENT, AND THE ECONOMIC IMPLICATIONS OF A RISING AUTISM POPULATION

A. *Autism, Defined*

Pediatrician Dr. Jay Gordon recounts:

Any doctor who did a pediatric residency twenty or more years ago has a story similar to this one: During a pediatrics ward rotation, when I was a resident at Children’s Hospital of Los Angeles, our attending called the medical residents into one child’s room. He told us that this was an unusual case, that we might never see another child with this severe disorder for the rest of our careers. We filed into the small hospital room, and there in bed was a four-year-old boy with autism. He was staring out the window, not even noticing the five doctors cramming into his space. He was destined to live his life in an institution. In 1978 there was no hope for this autistic child. Autism was considered a static, unchanging, controversial, mysterious, and unchangeable condition then.<sup>20</sup>

The growing incidence of autism in the U.S. has been referred to as “the Silent Epidemic” because autism is now the most common developmental disability affecting children in the U.S. today.<sup>21</sup> According to the most recent CDC report, since the 1970s, the prevalence of autism in the United States has risen to one in every sixty-eight persons, a staggering increase from a prevalence of one in 10,000 just a few decades ago.<sup>22</sup> Clinically referred to as “Autism Spectrum Disorder (‘ASD’),” autism is a complex medical disorder that affects people of all races, ethnicities, and socioeconomic levels.<sup>23</sup> Excitement at the novel opportunity of engaging with a child with autism no longer occurs because everyone today knows someone with autism—it is four times more likely to occur in boys than in girls and is “more common than childhood cancer, juvenile diabetes, and pediatric AIDS *combined*.”<sup>24</sup>

Autism is a lifelong disability, typically manifesting by the age of three, for which the cause and the cure are unknown.<sup>25</sup> The etiology of the disorder is a controversial subject within the medical community and among advocates of all kinds. “Despite much research, there has yet to be conclusive evidence of a cause

---

20. JAY GORDON, M.D., PREVENTING AUTISM: WHAT YOU CAN DO TO PROTECT YOUR CHILDREN BEFORE AND AFTER BIRTH 17 (2013).

21. *About Autism*, TALK ABOUT CURING AUTISM, <http://www.tacanow.org/about-autism/> (last accessed Mar. 18, 2018).

22. Cernius, *supra* note 7, at 569.

23. *About Autism*, *supra* note 21.

24. Dawn Brink-Cymerman, M.D., Autism: The Spectrum, The Silent Epidemic, <https://netforum.avectra.com/public/temp/ClientImages/NYSAFP/4a4840f9-9999-4f72-975d-d18aa17b13b7.pdf>; *Autism & Autism Spectrum Disorder*, THE ARC, <https://www.thearc.org/learn-about/autism> (last visited Apr. 8, 2018); DANIEL R. UNUMB & LORRI SHEALY UNUMB, AUTISM AND THE LAW: CASES, STATUTES, AND MATERIALS 3 (2011) (emphasis added).

25. UNUMB, *supra* note 24 at 3; Cernius, *supra* note 7, at 569.

for ASD.”<sup>26</sup> But what is known is that autism is a medical-neurodevelopmental disorder and a spectrum disorder, which means “symptoms are unique in intensity and combination for every individual,”<sup>27</sup> with common features including “delayed speech or lack of speech; repetitive, obsessive actions; inflexible adherence to routine; unusual sensitivity to light, sound, or touch; and lack of social or emotional reciprocity.”<sup>28</sup> People with autism along the spectrum vary greatly in type and severity of deficits—the spectrum “contains verbal and non-verbal people, self-injurious people, persons with savant gifts, and others who obsess over narrow topics, such as train schedules or calendars.”<sup>29</sup>

While the increase in the prevalence of autism is due in part to “greater awareness of the disorder among clinicians,” it is undeniable that there has been an actual and dramatic “increase in the occurrence of [the] disorder,” and the latest research indicates that the risk of autism is influenced equally by genetic predisposition and environmental factors.<sup>30</sup> The disorder is characterized by developmental abnormality in three areas: “deficits in reciprocal social interaction skills, deficits in communication skills, and presence of stereotypical behavior interests and activities,” and “[a]lthough symptoms are unique in intensity and combination for every individual, common features include delayed speech or lack of speech; repetitive, obsessive actions; inflexible adherence to routine; unusual sensitivity to light, sound, or touch; and lack of social or emotional reciprocity.”<sup>31</sup> More simply, people with autism at all levels of severity have difficulty comprehending the world around them, have sensory processing problems that cause them to see, hear, and feel aspects of their environment differently, and often more intensely, than their neuro-typical peers.

Until recently, autism has been considered by many to be a “hopeless, incurable, and absolute condition.”<sup>32</sup> Although the cause and cure for autism remain unresolved mysteries, productive ways of treating people with autism to decrease symptoms and enable independent living have developed over the years, with the most effective,

---

26. UNUMB, *supra* note 24, at 6.

27. *Id.* at 3.

28. *Autism Spectrum Disorder: Communication Problems in Children*, NAT’L INST. ON DEAFNESS AND OTHER COMM. DISORDERS (NIDCD), <https://www.nidcd.nih.gov/health/autism-spectrum-disorder-communication-problems-children> (last visited Apr. 8, 2018); UNUMB, *supra* note 24, at 3, 6. (“The trauma of an ASD diagnosis is further heightened by the fundamental mystery that surrounds the cause of this disorder. Despite much research, there has yet to be conclusive evidence for a cause for ASD.”)

29. UNUMB, *supra* note 24, at 6.

30. Doreen Granpeesheh et. al., *Applied Behavior Analytic Interventions for Children with Autism: A Description and Review of Treatment Research*, 21 ANNALS OF CLINICAL PSYCHIATRY 162, 163 (2009) (As Alycia Halladay, Autism Speaks Senior Director for Environmental and Clinical Sciences comments, “It’s not an either/or scenario. A complex interaction of genetics and environmental factors, working together, underlie the development of ASD.” This position is supported by most doctors as of 2016.); *Large Study Suggests Genes & Environment Contribute Equally to Autism Risk*, AUTISM SPEAKS (May 03, 2014), <https://www.autismspeaks.org/science/science-news/large-study-suggests-genes-environment-contribute-equally-autism-risk>; UNUMB, *supra* note 24, at 7. (“ASD is now considered to possibly be the result of a genetic predisposition interacting with environmental factors.”)

31. UNUMB, *supra* note 24, at 3.

32. CATHERINE MAURICE & GINA GREEN, *BEHAVIORAL INTERVENTION FOR YOUNG CHILDREN WITH AUTISM* xiii (1996).

evidence-based form of treatment being Applied Behavior Analysis (“ABA”) therapy.

*B. Applied Behavior Analysis—What Is “ABA” Therapy and Why Is It Effective?*

Although many approaches to treating autism exist, including speech therapy, physical therapy, occupational therapy, dietary adjustments, music therapy, deep pressure therapy, vitamins, and other “natural” substances, etc., there is no one approach that is perfect for every child, and very few treatments have been the subject of scientific research.<sup>33</sup> ABA therapy is a refined and practical form of behaviorism, which focuses on the adjustment of the person with autism’s behavior through systematic use of rewards and penalties to condition responses and “reduce interfering behaviors, build the child’s attention span, use effective consequences for behavior, [and] sequence the teaching materials to shape more complex behaviors.”<sup>34</sup> In other words, ABA aims to “address socially important problems and . . . bring about meaningful behavior change” through a “one-on-one model of intense engagement [with the] goal of bringing these kids into the world” and “both increasing useful behaviors and reducing or eliminating harmful or undesired behaviors.”<sup>35</sup> ABA is unique because it is one of the only treatments backed by substantial empirical research and because of its demonstrated wide and long-term effectiveness among those with autism.<sup>36</sup> “Studies show that, if ABA is administered intensively and by properly-trained therapists, approximately half of the treated individuals will ‘overcome’ their autistic characteristics to such an extent that they can enter school indistinguishable from their peers,” and “the other half make significant gains, too, such that they need less support for the rest of their lives.”<sup>37</sup>

---

33. UNUMB, *supra* note 24. “Since the unknown cause cannot be the target of treatment, therapies that seek to alleviate the debilitating nature of the symptoms must be tailored for the unique diagnosis of every individual.” *Id.* at 7.

34. RON SUSKIND, LIFE, ANIMATED: A STORY OF SIDEKICKS, HEROES, AND AUTISM 13–14 (2014); *About Autism*, *supra* note 21; UNUMB, *supra* note 24, at 4 (explaining that behavior analysis is a scientific approach to understanding behavior and how it is affected by the environment).

35. SUSKIND, *supra* note 34, at 15. *About Autism*, *supra* note 21; UNUMB, *supra* note 24, at 10.

36. Granpeesheh, *supra* note 30, at 162 (“Scientific research shows that [ABA] has consistently achieved the most significant results for children with autism,” and “can have a lasting positive impact.”); “In the past 20 years, 7 long-term, large-scale controlled studies have demonstrated that children who receive more than 25 hours per week of ABA for more than 1 year make tremendous gains, with some participants achieving functioning within the average range for their age.” *Id.* at 165; *see also* Thomas Frazier & Leslie Sinclair, *Behavior Therapy Beyond Childhood*, INTERACTIVE AUTISM NETWORK (Jan. 24, 2008), [https://iancommunity.org/cs/therapies\\_treatments/beyond\\_childhood](https://iancommunity.org/cs/therapies_treatments/beyond_childhood) (“Continued benefit from behavior therapy in adulthood also is consistent with changing conceptualizations of brain development with age. It was previously assumed that the brain was no longer changing after adolescence. However, brain circuits continue to be modified throughout the lifespan. In particular, the frontal lobe of the brain, which is responsible for the most complex cognitive functions (planning, organizing, directing attention, etc.) and is impaired in autism, is still growing and changing dramatically well into the late 20s and early 30s. These data suggest that behavioral approaches may be useful for not just temporarily changing autism symptoms but also for providing lasting changes to brain circuitry that persist throughout life.”).

37. MAURICE & GREEN, *supra* note 32, at 9; UNUMB, *supra* note 24, at 10.

Thus, ABA has emerged as the most widely-prescribed and most thoroughly examined approach to treating autism in scientific literature.<sup>38</sup>

The ABA method was pioneered in part by Dr. Ole Ivar Lovaas, a psychologist at UCLA. Prior to the development of Dr. Lovaas's method, the dominant dogma was that "autistic children were biologically normal youngsters who had withdrawn from human contact because of supposed psychological mishandling by their 'refrigerator mothers,'" and that the only two treatment options available for people with autism were psychotherapy and drugs, the first of which has since been found to be ineffective, and the second harmful.<sup>39</sup> Dr. Lovaas reversed this dogma with the development of ABA, which employs techniques "based on scientific principles of behavior to build socially useful repertoires and reduce problematic ones" and is based on the view that "autism is a syndrome of behavioral deficits and excesses that have a neurological basis, but are nonetheless amenable to change in response to specific, carefully programmed, constructive interactions with the environment."<sup>40</sup> Lovaas recognized that "the spectrum nature of [autism] also allows individuals to move along the symptom continuum."<sup>41</sup> Essentially, ABA relies on the breakdown of tasks, such as communicative language, into a series of hierarchical steps, with

---

38. MAURICE & GREEN, *supra* note 32, at 29. ("Historically, most people with autism have required extensive treatment and supports throughout their lives. Today, the mainstream position is that autism is a 'severely incapacitating lifelong developmental disability.' It is considered treatable; indeed, a wide variety of treatments, therapies, and techniques are claimed to help (or even cure) people with autism, and new ones are invented regularly. Until recently, however, none of those treatments has offered any solid, realistic basis for changing the view that autism is a permanent disability. Several studies have now shown that one treatment approach—early, intensive instruction using the methods of Applied Behavior Analysis—can result in dramatic improvements for children with autism: successful integration in regular schools for many, and *completely normal functioning* for some.") (emphasis added).

39. *About Autism*, *supra* note 21; UNUMB, *supra* note 24, at 57. (It was Dr. Leo Kanner of John Hopkins Hospital who obtained official recognition for autism in the twentieth century through his 1943 paper describing a group of children with impaired language skills and social interactions and restricted, repetitive behaviors. "About the same time that Kanner made his observations, an Austrian pediatrician named Hans Asperger published an account of children with an 'autistic psychopathy.' The work of Kanner and Asperger helped to establish autism as a distinct condition." It was, unfortunately, also Kanner who believed that autism was caused by "cold, unloving mothers," a theory that was perpetuated by renowned professor of child development Bruno Bettelheim. "Their promotion of the idea that unloving mothers, termed 'refrigerator mothers,' caused their children's autism created a generation of parents who carried the tremendous burden of guilt for their children's disability.").

40. MAURICE & GREEN, *supra* note 32, at 29, 51 (Prior to ABA replacing psychotherapy as the treatment of choice for children with autism, in most states, autism "fell within the purview of mental health professionals: 'Tell me, Mother, just how did you make your child autistic?' California, for one, had specifically excluded autistic children from the public schools on the grounds that their problem was considered psychiatric. Unfortunately, the 'refrigerator mother' theory was popular even until the late 1980s, when Catherine Maurice's daughter was diagnosed. She writes, 'We discovered almost immediately that autism research, at least on the medical/biological front, was in its infancy. This was partly due to early fallacious assumptions about its cause. For about twenty-five years after Kanner's initial identification of autism as a diagnostic category, psychiatrists and psychologists, almost universally, had gone barking frantically and insistently off in the wrong direction. The consensus among the experts had been that autism was caused by—now who would have guessed it?—Mommy! Along with schizophrenia, mass murder, hyperactivity, and manic depression, it was only logical that mommies should take the rap for autism."); *Id.* at 51. ("They were thought to be emotionally disturbed and in dire need of psychotherapy and reassurance if they were to recover. The only two treatment options were psychotherapy and drugs.").

41. UNUMB, *supra* note 24, at 7.

each step preparing the way for the next.<sup>42</sup> With rigorous early intervention treatment, the symptoms of autism can be made less disabling—“a non-verbal child might gain the ability to communicate; a non-social child might gain interaction skills,” and “[w]hile individuals who make such progress are not ‘cured,’ . . . they might overcome the disabling aspects of the condition enough to participate as functioning members of society.”<sup>43</sup>

“As an ardent early proponent of behavior modification, I was frequently asked, ‘Since you believe autism is a biological disorder, how can you advocate a behavioral approach as an effective treatment?’ My response was simple: ‘behavior modification did not restore sight and hearing to Helen Keller—her biological handicaps remained with her—but it did permit her to learn the skills she needed to adapt to her environment.’”<sup>44</sup> Behavioral therapists observe and “seek to adjust three components when examining an individual’s behavior: an *antecedent*, such as a command or request; a *behavior*, in response to the antecedent; and a *consequence*. The consequence depends on the behavior and can include positive reinforcement, such as social praise or a desired snack.”<sup>45</sup> By using “discrete trials,” therapists and family members work together to create a highly structured and consistent learning environment in which the child with autism is rewarded for the mastery of each small unit.<sup>46</sup> Gradually, children learn “not only the discrete bits of subject matter they are being taught, but, far more important, to focus their attention, to concentrate more effectively, and thus to learn more easily.”<sup>47</sup> Extensive research has shown that children with autism do not learn readily from typical environments, but can learn if provided with appropriate instruction. As such, the goal of ABA is to “totally shape the environment” and “help children learn how to learn”—to teach the child how to learn from the normal environment and act on that environment in ways that will consistently produce positive outcomes for the child, the child’s family, and others in society.<sup>48</sup> In other words, ABA is a medical treatment because it causes the developmental process to occur in those in whom it is not naturally occurring; it

42. *About Autism*, *supra* note 21.

43. UNUMB, *supra* note 24, at 7.

44. MAURICE & GREEN, *supra* note 32, at xvi (quoting Dr. Bernard Rimland, a psychologist who pioneered modern autism research and advocacy and founded the Autism Society of America, and who was a contributor to LET ME HEAR YOUR VOICE); in 1958, Rimland diagnosed autism in his two-year-old-son Mark with the help of a college textbook. In 1964, he published INFANTILE AUTISM, a landmark book that argued autism had biochemical roots and upended the then conventional wisdom that it was a child’s response to “refrigerator mothers” who didn’t show adequate affection. An adviser to the makers of *Rain Man* - his son was a model for Dustin Hoffman’s Oscar-winning 1988 turn as an autistic savant. MILESTONES, TIME MAGAZINE, Dec. 11, 2006.

45. UNUMB, *supra* note 24 at 10.

46. MAURICE & GREEN, *supra* note 32, at 30; Press Release, *supra* note 1; SUSKIND, *supra* note 34, at 13. (“To build eye contact, for instance, the ABA therapist will put the reward (M&M’s being a favorite) on the bridge of the child’s nose to make them look up toward the therapist’s face. If, after succinct instruction — ‘Look at me’—eye contact is made, the M&M is popped into the little mouth. Crisp instructions, like ‘Quiet hands’ (autistic kids often flap their hands) or ‘Mouth quiet’ (so self-talking), are backed up with some grabbing and manipulating, moving the child’s hands into their proper place.”).

47. *About Autism*, *supra* note 21.

48. MAURICE & GREEN, *supra* note 32, at 8; Meldestefano, *Dr. John Mantovani, Child Neurologist—Testimony in Support of SB 618*, YOUTUBE (Jan. 22, 2010), <https://www.youtube.com/watch?v=0a7WxgiRdsA>; *see also* SUSKIND, *supra* note 34, at 15–16.

“changes the functioning of the brain in ways that are visible on fMRI and PET scans.”<sup>49</sup>

An intervention model with demonstrated success is called the “tiered model,” and involves intensive treatment requiring thirty to forty hours of therapy a week for several years, conducted by professionals who have been certified by the Behavior Analyst Certification Board (“BACB”),<sup>50</sup> a nonprofit 501(c)(3) corporation established in 1998 to meet professional credentialing needs identified by Behavior Analysts, governments, and consumers of behavior analysis services.<sup>51</sup> In such a model, Board Certified Behavior Analysts with masters degrees (“BCBA-Ms”), and doctoral-level Behavior Analysts (“BCBA-Ds”)<sup>52</sup> perform the initial patient assessment and treatment planning for the child with autism, develop and oversee the delivery of ABA, and can also perform one-on-one ABA therapy with the child.<sup>53</sup> One-on-one ABA therapy can also be provided by Bachelors Degree level Board Certified Assistant Behavior Analysts (“BCaBAs”) and Behavior Technicians (“BTs”) who are supervised by a BCBA.<sup>54</sup> Dr. Lovaas was the first to provide evidence of ABA’s efficacy for children with autism in a landmark study which reported that “nearly half (47%) of the children in the ABA program achieved higher functioning in comparison to only 2% of the control group not receiving treatment,” and these results have been replicated by “several hundred single case experiments and an increasing number of between-groups studies” in the 30 years since.”<sup>55</sup> The

---

49. MAURICE & GREEN, *supra* note 32, at 30.

50. BEHAVIOR ANALYST CERTIFICATION BD., GUIDELINES: HEALTH PLAN COVERAGE OF APPLIED BEHAVIOR ANALYSIS TREATMENT FOR AUTISM SPECTRUM DISORDER 25 (2012), [https://autism-center.ucsd.edu/autism-information/Documents/ABA\\_Guidelines\\_for\\_ASD\\_11.2012.pdf](https://autism-center.ucsd.edu/autism-information/Documents/ABA_Guidelines_for_ASD_11.2012.pdf). “Most ABA treatment programs involve a tiered service delivery model where the Behavior Analyst designs and supervises a treatment program delivered by Behavioral Technician. . . . Tiered service delivery models which rely upon the use of Behavioral Technicians have been the primary mechanism for achieving many of the significant improvements in cognitive, language, social, behavioral, and adaptive domains that have been documented in the peer-reviewed literature.” *Id.* See also DEP’T OF DEFENSE, TRICARE OPERATIONS MANUAL 6010.56-M at Ch. 18, § 12, 4 (2008), available at <http://manuals.tricare.osd.mil/pages/DisplayManual.aspx?SeriesId=OPERATIONS>. (The mission of the BACB is to develop, promote, and implement an international certification program for Behavior Analyst practitioners.)

51. For more details regarding the evidentiary support for ABA therapy, its components, the level of intensity necessary to produce results, and the duration and quality of the therapy, see MAURICE & GREEN, *supra* note 32, at 40–42.

52. Since BCBA-Ms and BCBA-Ds are both able to perform one-on-one ABA therapy with autistic children and supervise therapy programs administered by BCaBAs and BTs, for purposes of this paper, the term “BCBA” will refer to both BCBA-Ms and BCBA-Ds.

53. MARGARET MAGLIONE ET AL., TRICARE APPLIED BEHAVIOR ANALYSIS (ABA) BENEFIT: COMPARISON WITH MEDICAID AND COMMERCIAL BENEFITS 2 (explaining that “[t]he certification of master’s-level (BCBA) and doctoral-level (BCBA-D) providers is relatively new, beginning with the creation of the Behavior Analyst Certification Board (BACB) in 1998”).

54. *Id.*

55. Joseph B. Ryan et al., *Research-Based Educational Practices for Students with Autism Spectrum Disorders*, 47 TEACHING EXCEPTIONAL CHILDREN 94 (2014); see also Granpeesheh, *supra* note 30, at 166–67; UNUMB, *supra* note 24, at 10 (“Lovaas conducted his study of the effectiveness of behavioral modification treatments on very young children affected by autism. For his study, Lovaas split his 38 subjects into two groups: 19 subjects were put into an intensive-treatment experimental group that received more than 40 hours of one-to-one treatment per week, and 19 subjects were placed in a minimal treatment control group that received 10 hours or less of one-to-one treatment per week. Both groups were identical at intake in terms of

United States Surgeon General stated in 1999 that “[t]hirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior,” and in 2007, an American Academy of Pediatrics clinical report on the medical management of children with autism noted ABA’s decades-long record of efficacy: “the effectiveness of ABA-based intervention in ASDs has been well documented through 5 decades of research.”<sup>56</sup> Research, therefore, suggests that intensive ABA interventions implemented early in a child’s development can result in long-term positive outcomes, with treated individuals achieving goals including part or full-time employment in jobs in the community and semi-independent living that would not have been attempted prior to treatment.<sup>57</sup>

*C. Why We Should Care About an Increasing Autism Population: The Cost of Autism to Society, and the Impact on Military Readiness of Military Autism Families’ Lack of Access to ABA*

1. The Economics of Autism

Children with autism are more likely than other special needs children to lack general access to health care services or to delay or forego care entirely, and early intervention treatment is still out of reach for many families.<sup>58</sup> “Although autism is typically thought of as a disorder of childhood, its costs can be felt well into adulthood. The substantial costs resulting from adult care and lost productivity of both individuals with autism and their parents have important implications for those aging members of the baby boom generation approaching retirement, including large financial burdens affecting not only those families but also potentially society in general.”<sup>59</sup> Historically, the financial cost of providing treatment for people with autism has been borne by families.<sup>60</sup>

Those unfamiliar with the obstacles autism parents face in accessing treatment for their children might wonder what makes this group of particular concern in the discussion of whether or not our society ensures access; the issue relates to the time-sensitivity of autism. “Early, efficient, and intensive treatment is critical in the autism context”—from the time the child is diagnosed the goal becomes obtaining

---

intellectual functioning abilities, and both received their assigned treatment for 2 or more years.” Upon follow-up at age 7, the 19-subject experimental group who received intensive ABA therapy by properly-trained therapists showed nine children (47%) achieved normal intellectual functioning and, as a result, were placed in mainstream general educational environments with no additional supports.); MAURICE & GREEN, *supra* note 32, at 31.

56. UNUMB, *supra* note 24, at 12; *About Autism*, *supra* note 21.

57. *About Autism*, *supra* note 21; “The substantial body of research supporting ABA for children with autism has led several independent entities to acknowledge ABA and endorse its use for children with autism, including the US Surgeon General, the New York State Department of Health, the National Academy of Sciences, and the American Academy of Pediatrics.” Myers & Plauché Johnson, *supra* note 7, at 1164.

58. Laura Hoffman, Comment, *Ensuring Access to Health Care for the Autistic Child: More is Needed than Federal Health Care Reform*, 41 SW. L. REV. 435, 441 (2012); *See also* UNUMB, *supra* note 24, at 5.

59. Hoffman, *supra* note 58, at 438.

60. *Id.* at 441.

immediate access to ABA at a rate proportional to the severity of the specific child's needs.<sup>61</sup> As Dr. Stephen Shore states:

[T]he autism bomb hits the mark, and life is never the same again for the person on the autism spectrum for the family members, educators, doctors, and others who provide support. The first questions that bubble up are: What should I do? What is the best intervention for my child with autism?<sup>62</sup>

It is the substantial potential for improvement that sets autism apart from most developmental or intellectual disabilities, and which “gives rise to both tremendous hope and tremendous pressure on parents struggling to secure adequate and timely treatment for their child. It is why the stakes are so high and early, efficient, and intensive treatment is critical in the autism context.”<sup>63</sup>

Because autism is a dynamic disorder, autism families are more likely to spend themselves into debt in pursuit of progress than are families affected by other special needs.<sup>64</sup> In theory, health insurance should pay for the therapeutic interventions medically necessary to improve the condition of children diagnosed with autism, because autism does not differ from other non-curable chronic medical conditions that are routinely covered by health insurance, such as diabetes, asthma, and hypertension. In reality, however, children with autism are more likely to lack general access to health care services as compared to children with other chronic conditions.<sup>65</sup> As the Agency for Healthcare Research and Quality wrote in 2009, “delivery and organization of care for ASD is very fragmented, with pieces scattered about in the primary care, school, and specialty clinical settings. It is left to the families and caregivers of patients with ASD to find and assemble these pieces.”<sup>66</sup>

ABA therapy involves a great deal of time and can be quite expensive. Projected costs range from \$30,000 to \$100,000 per year, depending on the individual child's needs, and most medical insurance policies did not cover it, or cover it properly, prior to the enactment of insurance mandates.<sup>67</sup> “Parents who have the educational and financial resources can provide these therapies for their children. They pay for it themselves. They move to wealthier school districts. They hire lawyers. They spend hours on the phone with insurance companies. They network with other parents to learn about new doctors and compare services in other school districts. Parents who

---

61. *Id.* at 441; See UNUMB, *supra* note 24, at 7. Lorri Unumb, *Legislating Autism Coverage: The Conservative Insurance Mandate*, 2 BELMONT L. REV. 59, 68 (2015).

62. *Who Are You: Living with Autism*, U.S. AUTISM & ASPERGER ASS'N, [http://www.usautism.org/who\\_are\\_you\\_autism.html](http://www.usautism.org/who_are_you_autism.html) (last visited Apr. 9, 2018).

63. UNUMB, *supra* note 24, at 7 (explaining that Autism appears on Axis I in the DSM, which is for Clinical Disorders and Other Conditions That May Be a Focus of Clinical Attention, rather than Axis II, which is for the more static Personality Disorders and Mental Retardation).

64. *Id.*

65. Hoffman, *supra* note 58, at 441.

66. UNUMB, *supra* note 24, at 7.

67. Hoffman, *supra* note 58, at 458–59.

don't have those resources are unable to get the right help for their children.”<sup>68</sup> In 2004, the New York Times wrote, “no disability claims more parental time and energy than autism.”<sup>69</sup> The problem is that without access to early intensive ABA therapy, or with ABA that is inconsistently available or provided only at the minimum level, children with autism are more likely to place a significant economic strain on society at large through both direct and indirect costs.<sup>70</sup>

The most recent analysis of the societal cost of autism is estimated at \$268 billion to care for all individuals with autism during childhood and throughout their lifetimes.<sup>71</sup> University of California, Davis Professor of Public Health Paul Leigh has stated “the current costs of ASD are more than double the combined costs of stroke and hypertension and on a par with the costs of diabetes.”<sup>72</sup> Direct costs are incurred through medical expenses similar to those expended by parents in caring for non-disabled children, but because children with autism utilize health care services more frequently than typically developing children, their health care costs are higher.<sup>73</sup> “On average, medical expenditures for individuals with autism are 4 to 6 times greater than for individuals without autism.”<sup>74</sup> Indirect costs include “lost productivity by parents who may reduce the hours they work outside the home or forego outside employment entirely to care for their child” and the loss of production to society that results from adults with autism being unable to contribute to society due to the limitations created by their disability.<sup>75</sup> “According to the 2005/2006 National Survey of Children with Special Health Care Needs, the presence of autism in a family causes financial problems and work reductions for parents significantly more often than the presence of other special health care needs in children.”<sup>76</sup> In sum, these families “have greater out-of-pocket costs, diminished work hours, more lost income, and more negative health plan experiences.”<sup>77</sup> If a child with autism

---

68. Megan McArdle, *The Economic Impact of Autism on Families*, ATLANTIC (May 31, 2012), <http://www.theatlantic.com/business/archive/2012/05/the-economic-impact-of-autism-on-families/257892/>.

69. UNUMB, *supra* note 24, at 9.

70. Stuart, *supra* note 4; *see also* Cernius, *supra* note 7, at 573. (citing MARY C. SELECKY, INFORMATION SUMMARY OF RECOMMENDATIONS: TREATMENT OF AUTISM SPECTRUM DISORDERS MANDATED BENEFIT SUNRISE REVIEW 12 (2009), <http://www.doh.wa.gov/portals/1/Documents/Pubs/631002Autism.pdf>). (“Lack of early intensive intervention can often lead to children with autism being placed in foster care, residential homes, and institutions. Lack of a current benefit is likely to increase the number of individuals who are dependent on others (including state sponsored programs) for housing, supervision, and vocational support as adults. Costs of institutionalization ranges from \$76,000 per year to over \$192,000.”).

71. Ashley Welch, *Autism Costs Could Skyrocket, Experts Warn*, CBS NEWS (July 30, 2015), <http://www.cbsnews.com/news/autism-costs-skyrocket-1-trillion-by-2025/>. (“Researchers from the University of California, Davis, Health System calculated costs for the current calendar year and projected where they’ll be 10 years from now if effective interventions and preventive treatments are not identified and made widely available. They estimated that for medical, non-medical, and productivity losses associated with the disorder, autism will cost \$268 billion for 2015 and \$461 billion for 2025. But the researchers said these projections are conservative and if prevalence of autism continues to increase at current rates, the costs could reach \$1 trillion in the next decade.”).

72. *Id.*

73. Cernius, *supra* note 7, at 574.

74. UNUMB, *supra* note 24, at 3.

75. Stuart, *supra* note 4, at 499.

76. UNUMB, *supra* note 24, at 7.

77. *Id.* at 5.

does not have proper access to quality treatment, the societal cost for that one child over his or her lifetime could be as steep as \$3.2 million.<sup>78</sup>

The good news is that early diagnosis and intervention can reduce the costs of life-long care for each person with autism by two-thirds.<sup>79</sup> To better understand the cost implications of autism treatments, Autism Speaks<sup>80</sup> engaged leading independent actuarial firm Oliver Wyman Group to develop a cost model and cost estimates for various state autism insurance reform bills.<sup>81</sup> Based on the results of several studies, Oliver Wyman determined that the costs of the ABA treatments covered under mandates could be recovered through reductions in educational and medical expenditures alone, confirming that preventive services can mitigate other long-term health costs and save insurance companies money over time by reducing the need for expensive inpatient hospitalizations.<sup>82</sup> Oliver Wyman's results confirm the findings of other studies and have been validated by the experiences of states that have had mandates for many years. For instance, University of Pennsylvania health policy researcher Dr. David Mandell calculated the cost-savings produced by a high-quality and intensive early behavioral intervention program and found that, while early intensive ABA intervention costs more to deliver in the early years, "it more than pays for itself in terms of reduced needs for therapy and educational support by the time a child reaches high school."<sup>83</sup> Following the enactment of mandates in twenty-nine states, Autism Speaks began collecting data from states where such laws apply to members of the state employee health plan and have been in effect for at least one year, showing that the average first year cost of coverage per member per month was \$0.15, and the average second year cost was \$0.31 per member per month.<sup>84</sup> More recently, annual reports done by the Department of Insurance in

78. Stuart, *supra* note 4, at 499.

79. Carin Yavorcik, *ASA Publishes Model Legislation for Autism Insurance Coverage*, AUCD (Feb. 12, 2009), [https://www.aucd.org/ecp/template/news.cfm?news\\_id=3582&parent=0&parent\\_title=ITAC:%20CAA1%20old%20\(AUCD\)%20page&url=/ecp/template/news\\_mgt.cfm?type%3D406%26topic%3D118](https://www.aucd.org/ecp/template/news.cfm?news_id=3582&parent=0&parent_title=ITAC:%20CAA1%20old%20(AUCD)%20page&url=/ecp/template/news_mgt.cfm?type%3D406%26topic%3D118).

80. Autism Speaks is a leading autism advocacy organization that sponsors autism research and conducts awareness and outreach activities aimed at families, governments, and the public. Autism Speaks played a major role in changing the landscape of coverage of ABA therapy services for autism families through commercial insurance by spearheading campaigns to enact individualized insurance mandates for autism treatments in 43 states and Washington D.C. (as of 2015). For more on this subject, see Cernius, *supra* note 7.

81. MARC LAMBRIGHT, ACTUARIAL COST ESTIMATE: ALASKA HOUSE BILL 79 AND SENATE BILL 74 at 2 (2011), [https://www.autismspeaks.org/sites/default/files/docs/gr/ak.wyman\\_3.4.2011.pdf](https://www.autismspeaks.org/sites/default/files/docs/gr/ak.wyman_3.4.2011.pdf). (While the analysis focuses primarily on estimating the insured costs of mandated medical benefits, Oliver Wyman also summarizes information "related to the lifetime costs of Autism, which include the costs associated with medical services education, custodial care, and the lost productivity and wages of individuals affected by Autism, as well as their family caregivers.").

82. *Legislation Requiring Health Plans to Cover Autism Treatment Would Have Minimal Effect on Health Insurance Premiums*, AUTISM SPEAKS (Oct. 8, 2010), <http://advocacy.autismspeaks.org/site/apps/nlnet/content2.aspx?c=frKNI3PCImE&b=3930723&ct=8781579>. For an example of the results of Oliver Wyman's calculations, see MARC LAMBRIGHT, ACTUARIAL COST ESTIMATE: NEBRASKA LEGISLATIVE BILL 1129 (2012), [https://www.autismspeaks.org/sites/default/files/docs/gr/ne.wyamn\\_2.6.2012.pdf](https://www.autismspeaks.org/sites/default/files/docs/gr/ne.wyamn_2.6.2012.pdf).

83. *High-Quality Early Intervention for Autism More Than Pays for Itself*, AUTISM SPEAKS (May 1, 2013), <https://www.autismspeaks.org/science/science-news/high-quality-early-intervention-autism-more-pays-itself>.

84. AUTISM SPEAKS, THE FISCAL IMPACT OF AUTISM INSURANCE REFORM (2011), [https://www.autismspeaks.org/sites/default/files/images/advocacy/Resources.FiscalImpact\\_3.2012.pdf](https://www.autismspeaks.org/sites/default/files/images/advocacy/Resources.FiscalImpact_3.2012.pdf).

individual states reveal that implementing insurance reform mandates has had a low impact on overall health claim costs, even though thousands of individuals accessed autism-related treatment.<sup>85</sup> These reports are important because, unlike the actuarial studies and the data collection done by Autism Speaks, they report the real life impact of the mandates on the entire market.<sup>86</sup> Furthermore, these results are not confined to private insurance mandates alone—the Pennsylvania Commonwealth Insurance Department estimated that Medicaid could save \$16.5 to \$22.2 million in the first year following the adoption of ASD insurance reform.<sup>87</sup>

## 2. Past Coverage Schemes for Treating Autism and the Issue of Access

One reason for the financial difficulties that autism families face is the failure of the health insurance industry to effectively and efficiently cover treatments for, and sometimes even diagnosis of, autism.<sup>88</sup> “Sadly, few individuals with autism reach their potential, because most do not have consistent access to treatment that is appropriate in quality and quantity. Appropriate care is both difficult to find and difficult to afford.”<sup>89</sup> Initially, the health insurance industry was largely deficient in coverage of autism. Prior to the autism insurance reform movement, insurers frequently offered policies that were subject to “exclusion waivers,” which barred reimbursement for any treatment for particular, named conditions.<sup>90</sup> Many insurance companies designated autism as a diagnostic exclusion, “meaning that any services rendered explicitly for the treatment of autism [were] not covered by the plan, even if those services would be covered if used to treat a different condition.”<sup>91</sup> And, when they did not exclude coverage altogether, insurance providers typically imposed strict limitations on the specific treatments and other interventions for which they would pay.<sup>92</sup> In fact, as recently as the turn of the millennium, it was widely accepted that health insurance did not cover even the standard treatment protocols for autism.<sup>93</sup> “Claims filed on behalf of individuals with autism were denied for a variety of reasons—treatments were experimental or educational, non-existent provider

---

85. *MO Regulator: Autism Insurance Reform Works*, AUTISM SPEAKS (Mar. 21, 2014), <https://www.autismspeaks.org/advocacy/advocacy-news/mo-regulator-autism-insurance-reform-works>.

86. See Gregory S. Chasson, Gerald E. Harris, & Wendy J. Neely, *Cost Comparison of Early Intensive Behavioral Intervention and Special Education for Children with Autism*, 16 J. CHILD & FAM. STUD. 401, 40809 (2007). (Several states have also created forecasts predicting the cost of behavioral therapy mandates and found that early intervention programs could lower health care costs overall. For instance, researchers estimated that the state of Texas would save \$208,500 per child across eighteen years of education with early intensive behavioral intervention.)

87. Stuart, *supra* note 4, at 529.

88. UNUMB, *supra* note 24, at 9. (As Lorri Unumb, Vice President of Government Affairs at Autism Speaks and a leading attorney in the fight for autism insurance reform writes, “Families dealing with autism face many hardships, not the least of which is financial hardship. One reason for the financial hardship is the failure of the health insurance industry to cover treatments for, and sometimes even diagnosis of, autism.”)

89. *Id.* at 7.

90. Samuel R. Bagenstos, *The Future of Disability Law*, 114 YALE L. J. 1, 28 (2004).

91. AUTISM SPEAKS, AUTISM SPEAKS SUBMISSION TO THE PENNSYLVANIA HEALTH CARE COST CONTAINMENT COUNCIL: ARGUMENTS IN SUPPORT OF PENNSYLVANIA HOUSE BILL 1150 at 8 (2007), [https://www.autismspeaks.org/docs/gr/HC4\\_testimony.pdf](https://www.autismspeaks.org/docs/gr/HC4_testimony.pdf).

92. Bagenstos, *supra* note 90, at 30.

93. UNUMB, *supra* note 24, at 9.

---

credentials were demanded—notwithstanding a physician’s prescription treatment.”<sup>94</sup>

Indeed, prior to the movement towards mandating insurance coverage for people with autism, few common standards existed for the diagnosis and management of many aspects of care, meaning that families lacking access to comprehensive and coordinated health care had to “fend for themselves to find the best health care, treatments, and services in a complex clinical world.”<sup>95</sup> In the past, traditionally, states have provided coverage for ABA therapy programs through private practitioners, agencies, and some public and private schools.<sup>96</sup> Some states have also made coverage available through state-funded agencies. California’s “Regional Centers,” for instance, are nonprofit private corporations that contract with the Department of Developmental Services (“DDS”) to provide and coordinate services and supports for individuals with developmental disabilities under the authority of the Lanterman Developmental Disabilities Services Act, the state legislation that says people with developmental disabilities and their families have a right to get the services and support they need to live like people without disabilities.<sup>97</sup> While these programs are effective, they are expensive to operate—in 2009, Indiana’s Bureau of Developmental Disabilities Services spent approximately \$536 million on services for people with autism and other developmental disabilities, and in 2012, the California DDS spent \$4.7 billion on services for over 259,000 people with developmental disabilities.<sup>98</sup> Thus, one downfall of this system, in addition to the fact that ABA is medical and medical treatments are not *mandated* under the Lanterman Act, is its dependence on the financial fitness of the state—when the state economy suffers, the budget for ABA therapy programs suffers, and with the state and federal governments increasingly in debt, these volatile circumstances in which treatment is sometimes available in some years and uncertain in others leads to regression in children with autism who experience inconsistency in their treatment *which is premised upon persistence and reinforcement*.<sup>99</sup> The insurance industry has claimed that this should be mitigated by the performance of school districts under the IDEA special education law, which requires the provision of services and treatments to children with autism. This thinking, however, overlooks the current struggle for resources and trained staff special education classrooms are confronted with on a daily basis, as well as the intensity of the therapy and importance of a narrow focus on the child in question that ABA demands in order to be successful. In other words, educational programs are designed to accommodate medical disabilities, but not to treat underlying medical conditions. The treatment of underlying medical conditions

---

94. *Id.*

95. Hoffman, *supra* note 58, at 474.

96. *Id.*

97. DEP’T OF DEV. SERVS., 2012 MAY REVISION’S HIGHLIGHTS 2 (2012), [http://www.dds.ca.gov/Budget/Docs/2012\\_MayRevisionHighlights.pdf](http://www.dds.ca.gov/Budget/Docs/2012_MayRevisionHighlights.pdf); Stuart, *supra* note 4, at 508.

98. Stuart, *supra* note 4, at 505 (citing PETER A. BISBECOS, DIV. DISABILITY & REHAB. SERV., JANUARY MONTHLY FINANCIAL REVIEW 2 (2009), [http://www.in.gov/fssa/files/2.09\\_DDRS\\_MFR.pdf](http://www.in.gov/fssa/files/2.09_DDRS_MFR.pdf)); DEP’T OF DEV. SERVS., *supra* note 97, at 2.

99. Cernius, *supra* note 7, at 578 (citing ASS’N OF REG’L CTR. AGENCIES, ON THE BRINK OF COLLAPSE: THE CONSEQUENCES OF UNDERFUNDING CALIFORNIA’S DEVELOPMENTAL SERVICES SYSTEM 17 (2015), <http://arcanet.org/wp-content/uploads/2015/02/on-the-brink-of-collapse.pdf>).

is the responsibility of qualified medical providers and not educators. Ultimately, schools simply do not have the structure to create productive programs.<sup>100</sup>

While families in which the parents' employer provides insurance that covers autism or covers behavioral therapy within that policy are able to avoid the process of paying out-of-pocket to access ABA for a child with autism and facing the tangled pursuit of services through fragmented state programs or special education, such a scenario is very rare. Many families are currently not served or underserved, and a great many stand to join them in the coming years.

In defense of its reluctance to provide this crucial coverage for autism families, the insurance industry asserted two main arguments. The first was that, although autism is medical, ABA is “habilitative” or “educational,” and should therefore be covered by government-funded rehabilitative agencies and, alternatively, special education classrooms.<sup>101</sup> The second argument was that the autism population is huge, forecasted to keep growing in coming years, and that mandating coverage of ABA would “cause premiums to increase unreasonably, which in turn [would lead] to fewer people being able to afford insurance at all,” citing studies that estimate a 13% increase in the cost to other policyholders not affected by autism.<sup>102</sup> While these arguments appear reasonable, the autism insurance reform movement to improve commercial insurance coverage established that they are, unfortunately, based upon unrealistic expectations and a policy of inefficient burden-shifting. As previously discussed, both autism and ABA are medical, so denying autism families coverage for the reason that ABA is educational or habilitative is no longer a valid argument: “While at some point in the last several decades that was true, such a conclusion is no longer supported by the science.”<sup>103</sup> Moreover, multiple studies of many states executed by organizations like Autism Speaks, actuarial firms like Oliver Wyman, and the insurance departments of state governments all arrive at the same conclusion: despite the thousands of people receiving coverage for ABA every year, the overall rise in cost for policyholders has been uniformly low-impact, and the costs which *are* incurred will be made up for in the money saved in the future due to the increased capacity for independence of those with autism who receive quality early intervention treatment if coverage is subject to no arbitrary monetary or age limitations, but rather

---

100. Cernius, *supra* note 7, at 578–79.

101. UNUMB, *supra* note 24, at 11. (“As evidenced by the publication date of the landmark Lovaas study – 1987 – ABA therapy has been used for several decades to treat autism. Yet the insurance industry has consistently denied coverage, frequently on the basis that ABA therapy is experimental or investigational.”)

102. *An Autism Treatment Worth Funding*, L.A. TIMES (Sept. 30, 2011), <http://articles.latimes.com/2011/sep/30/opinion/la-ed-autism-20110930> (this problem exists in the context of Medicaid as well—“Some states have also raised concerns over the cost of providing Medicaid coverage of ABA.”); *Medicaid: States Cannot “Delay or Deny” Autism Treatment*, AUTISM SPEAKS (Sept. 29, 2014), <https://www.autismspeaks.org/advocacy/advocacy-news/medicaid-states-cannot-delay-or-deny-autism-treatment>); *see also* Unumb, *supra* note 61, at 11.

103. UNUMB, *supra* note 24, at 11–12; AUTISM SPEAKS, *supra* note 102 (“As indicated in professional literature and as held by numerous court cases, there is no question that ABA is medically necessary for many children with autism and therefore it must be made available based on individual determinations of medical necessity,” says Dan Unumb, leading attorney in the issue of Medicaid reform for autism families.”).

---

---

according to the continued efficacy of the treatment.<sup>104</sup> To put it in perspective, “[t]o a family paying for health insurance who is stricken with autism, being told that one’s policy covers autism but does not cover ABA is like being told the policy covers cancer but does not cover chemotherapy. For many autism families, the policy fails to cover the most-needed and most out-of-reach treatment . . . and society pays the price.”<sup>105</sup> Autism insurance reform and mandating meaningful coverage for the diagnosis and treatment of autism is essentially a response by the affected community to the realization that the incidence of autism continues to soar, and that society’s previous strategies to provide treatment for the autism population have been exhausted and are no longer viable for the reasons previously articulated.

A mandate is a law that tells someone what to do. In the insurance and health care context, mandates are laws that dictate to health insuring organizations who or what must be covered.<sup>106</sup> Mandates “remedy the failure of the market to provide effective coverage for a significant public health challenge,” “provide for enhanced treatment, support, services, and research for individuals with autism spectrum disorders and their families,” and reflect the “growing movement away from putting autism in the category of mental illness and toward a recognition of the disability in its own category of health insurance coverage.”<sup>107</sup> Mandated insurance coverage for individuals with autism, therefore, is an important tool in properly caring for the families affected by this disability, and the baseline mark of success in the review of the efforts of the health insurance industry to care for people with autism.<sup>108</sup> However, even though the existence of some form of autism insurance mandate in each of the major health insurance systems—commercial insurance, Medicaid, and TRICARE—demonstrates a uniformity of attitudes that mandating coverage is the best solution, as many autism families and advocates for this population would attest, having laws that mandate coverage does not always or completely ensure that such coverage will be provided or accessible. If the goal of reducing the costs of this population to society is to be achieved, the laws that are on the books, whether they be for commercial insurance, Medicaid, or TRICARE, must reflect an understanding of the nature of autism and the fact that rigorous, quality, consistent early intervention therapy is necessary to make progress. Furthermore, these laws must result in actual, consistent access to ABA. In other words, the next step in autism insurance reform is making sure that all autism families, no matter their background or type of insurance, do not experience barriers in accessing the appropriate level of ABA care under these new laws in every state.

---

104. AUTISM SPEAKS, *supra* note 102 (“‘This is not a new issue,’ said Unumb. ‘In almost all of the three dozen states that have mandated coverage for private insurance, nearly every state initially over-estimated the cost of providing ABA, sometimes by more than 1,000 percent.’”)

105. UNUMB, *supra* note 24, at 312.

106. Stuart, *supra* note 4, at 514.

107. Hoffman, *supra* note 58, at 473, 475, 477.

108. UNUMB, *supra* note 24, at 84.

### 3. The Struggle of Military Autism Families

The need for a resolution of this issue has unique and heightened significance in the context of military families living with autism facing natural barriers in obtaining and maintaining coverage for ABA therapy due to the nature of the military lifestyle. Military life is particularly difficult for children with autism and their families. As discussed in Section I.A, *supra*, “[a] specific feature of autism is extreme difficulty with life, routine, or environmental changes of any kind,” and children with autism “need a set routine, stability, and continuity of services and relationships.”<sup>109</sup> Military life, however, “by its nature provides few of these needs.”<sup>110</sup> Military autism families, like other families with autism, are “substantially affected by the financial and emotional costs of raising a child with autism,”<sup>111</sup> but unlike non-military families, face compounded hardships such as “near-constant wartime deployments that strip households of a parent for extended periods.”<sup>112</sup> “The frequent duty station changes and social turmoil of military service” means that military children with autism “often face challenges with which their civilian counterparts do not have to contend.”<sup>113</sup> These challenges have been compounded over the years by the inadequacy of various policy approaches taken by TRICARE, the U.S. Department of Defense (“DOD”) military health system to provide access to this treatment for autism to military families. The struggles these families face, while unique to military life, have critical implications for wider society as well.

First, there are “the realities of frequent moves that disrupt or end altogether treatment programs such as applied behavior analysis therapy, or ABA, which medical experts say make a huge difference in the lives of autistic children.”<sup>114</sup> In 2016, researchers from Penn State University found that many military families face unique challenges in accessing ABA care for their children, especially when seeking new service after a change in duty station.<sup>115</sup> “Military families are already facing waitlists every time they move, possible regression every time they move and nationwide provider shortages.”<sup>116</sup> Lack of care and interrupted services have negative impacts to the health and progress of children with autism, leading to an increase in the economic burden of this population to society due to anticipated higher health costs, and the greater chance that these children with autism will be dependent

---

109. *Military Families and Autism Advocacy*, AUTISM SPEAKS, [http://advocacy.autismspeaks.org/site/c.frKNI3PCImE/b.5141983/k.A9E4/Military\\_homepage.htm](http://advocacy.autismspeaks.org/site/c.frKNI3PCImE/b.5141983/k.A9E4/Military_homepage.htm) (last visited Apr. 9, 2018).

110. *Id.*

111. *Id.*

112. Kimberly Johnson, *Military Parents Battle the System to Help Their Autistic Children*, U.S. NEWS & WORLD REP. (Dec. 21, 2008), <https://www.usnews.com/news/national/articles/2008/12/21/military-parents-battle-the-system-to-help-their-autistic-children>.

113. AUTISM SPEAKS, *supra* note 16.

114. Johnson, *supra* note 112.

115. Jennifer M. Davis, Erinn Finke & Benjamin Hickerson, *Service Delivery Experiences and Intervention Needs of Military Families with Children with ASD*, 46 J. AUTISM & DEV. DISORDERS 1748 (2016).

116. *Military Autism Families Fear Loss of Services Amidst New TRICARE Policies*, FROM MOTHERHOOD (Jan. 10, 2017), <http://fromthebowelsfrommotherhood.blogspot.com/2017/01/military-autism-families-fear-loss-of.html>.

on society in their adult years.<sup>117</sup> If access to ABA under TRICARE is not improved, in the years to come, the disparity between non-military children with autism who have been afforded more consistent access to ABA therapy and military children who have regressed over time due to inconsistency in treatment or lack of access to treatment entirely will become increasingly apparent.<sup>118</sup> Additionally, inadequate or inconsistent access to ABA through TRICARE means that the health and well-being of military families is jeopardized, which imperils the nation's safety, given the direct impact family health care plays on military readiness.<sup>119</sup> It "is known by the Pentagon's top brass" that "autism is having a ripple effect straight through to the battlefield."<sup>120</sup> Military families who cannot access ABA treatment for their autistic children or who lose and are unable to regain access each time they must move on military assignment are forced to either go without ABA therapy or pay for it out-of-pocket, and "the financial pressures are prompting some to leave the military, a development that officials warn is harming military capabilities."<sup>121</sup> As Vice Admiral Adam Robinson wrote in a 2008 internal memo, "[t]he assurance of family care is critical for mission readiness."<sup>122</sup> Major General Thomas Deppe, Air Force Vice Commander, went further, saying that the quality of life for families in the Air Force is "compromised by the lack of services and supports provided by TRICARE programs."<sup>123</sup> And, according to General Richard Cody, the Army Vice Chief of Staff who wrote an internal memo advocating for "a federal solution to overcome the gaps in care," TRICARE's treatment policies affect "the morale, readiness, and retention of the all-volunteer force."<sup>124</sup>

It is estimated that 23,000 active duty family members have a diagnosis of autism, and a recent report to Congress indicated that the annual number of active duty family members receiving care for autism under TRICARE nearly tripled between 2009 and 2012. If TRICARE does not adjust to meet the needs of military families with autism, in addition to economic consequences, this will have severe implications for our military readiness as a country. While the U.S. health insurance industry has made progress in both its perception and treatment of people with autism, the failure to provide effective, coordinated, and accessible coverage of treatment for autism is a major lapse in government oversight by neglecting one of

---

117. Driscoll, *supra* note 17.

118. KAREN DRISCOLL, STATEMENT FOR THE DEPARTMENT OF DEFENSE MILITARY FAMILY READINESS COUNCIL (2016), <http://download.militaryonesource.mil/12038/MOS/MFRC/DoD-MFRC-Statement-final.pdf>. ("Over time, given the disparity between the national average reimbursement rate and TRICARE's proposed rates, we expect these cuts will only continue the reduction in access to ABA services, which has already been identified as a problem.")

119. Gore, *supra* note 18.

120. Johnson, *supra* note 112.

121. *Id.* (The story of Marine Corps Master Sgt. Buck Doyle and his wife Kyla illustrates this problem. The couple has faced constant hurdles getting therapy for their daughter, Kate. When Buck was given short notice that he would be getting orders to Camp Lejeune in North Carolina, an area where there are virtually no services for autistic children, Buck refused the assignment for that reason but received pushback from within the service that could have led to his leaving the Marines after 20 years. "This is a guy who would give his life for his country," Kyla says of her husband. "The one thing he won't do is give his kids' lives.")

122. *Id.*

123. *Id.* (Internal citations omitted).

124. *Id.* (Internal citations omitted).

its fastest growing and most helpless populations. Advocating for a quality system of insurance coverage of ABA for autism is an argument for the policy of proactive cost reduction of a population that has been demonstrated to be costly, and of giving those in society who require more help the best chance to live at the highest level of independence possible. Ensuring that such a system is in place has the added benefit of securing basic health care services for the noblest of populations in the country—those who risk their lives to fight for the freedom and safety of the U.S. As Stuart Spielman, senior policy adviser for Autism Speaks, states, “Think about the extraordinary sacrifices that military families make . . . [i]f we’re asking someone to risk his or her life . . . do we not have an obligation to help their families?”<sup>125</sup>

## II. THE TROUBLE WITH TRICARE

TRICARE, the health care program of the DOD, has recognized the importance of ABA in treating autism and reducing the long-term costs of this growing population, and has also taken steps, like the commercial insurance and Medicaid systems, to improve coverage of autism treatment for military families. However, TRICARE’s most recent adjustment in its coverage of ABA was a cause for alarm for military autism families and advocates. Until July 2014, TRICARE covered ABA through a combination of programs.<sup>126</sup> As of July 25, 2014, the TRICARE Comprehensive Autism Care Demonstration (“ACD”) combined all ABA services into one demonstration project and expanded coverage for ABA to all beneficiaries with autism, which was considered a positive step forward in autism insurance policy.<sup>127</sup> However, in September 2014, TRICARE announced that reimbursement rates for services provided by Behavior Analysts would be reduced by forty-six percent, stating that the reason for this change was to “put TRICARE rates in line with other commercial plans,” as “studies found TRICARE currently reimburses above Medicaid and most commercial plans.”<sup>128</sup> In response to enormous outcry from military autism families directed at this change, “the Pentagon back-peddled and postponed rate reductions,” later coming out in 2015 with a reduction that slashed rates by fifteen percent.<sup>129</sup> Even though TRICARE Policy & Benefits Office officials assured they would “make sure all beneficiaries receiving ABA services continue having access to high quality ABA services,” and stated that they “do not expect these changes to have a negative impact on our beneficiaries’ continued access to ABA services,” TRICARE’s slashed rates have had a dramatic negative effect on military autism families.<sup>130</sup>

---

125. *Id.*

126. MAGLIONE ET AL., *supra* note 53, at 2.

127. *Id.*

128. *Id.* at 14; *TRICARE Announces Lower ABA Reimbursement Rates*, NAT’L MIL. FAM. ASS’N, (Dec. 18, 2015), <http://www.militaryfamily.org/featured-news/tricare-announces-lower-aba.html>; *see also TRICARE Releasing New Reimbursement Rates for Autism Care*, HEALTH.MIL (Mar. 29, 2016), <http://www.health.mil/News/Articles/2016/03/29/TRICARE-releasing-new-reimbursement-rates-for-autism-care>.

129. FROM MOTHERHOOD, *supra* note 116.

130. NAT’L MIL. FAM. ASS’N, *supra* note 128; MAGLIONE ET AL., *supra* note 53, at 14.

At the time the proposal to slash rates was announced, TRICARE's ABA benefit had not been directly compared with the ABA benefits offered by other health plans; it has since been realized that TRICARE reducing reimbursement rates put military autism families at a disadvantage in accessing, and continuing to access, ABA therapy for several reasons. First, around the same time TRICARE slashed behavior analyst reimbursement rates, the BACB announced the creation of a new credentialing standard for Behavior Technicians in the "Registered Behavior Technician ('RBT')"<sup>131</sup>; TRICARE was the first in the industry to implement this new credential.<sup>132</sup> Simultaneously, TRICARE announced its own increase in credentialing standards for all types of behavior analysts: BCBAs, BCaBAs, and RBTs.<sup>133</sup> Second, there are services that other insurance carriers pay for that TRICARE does not permit ABA providers to bill.<sup>134</sup> This combination of slashing reimbursement rates while demanding more highly-credentialed ABA professionals and failing to cover certain services is one that few business models can sustain. The problem is not just that TRICARE reduced reimbursement rates, but rather that under the new reduced rates, TRICARE children with autism carry a slimmer profit margin for providers than do autistic children with commercial or Medicaid insurance. Consequently, many ABA providers are reluctant to take on or maintain autistic children from military families as clients.<sup>135</sup> As a result, many military autism families lack consistent access to ABA therapy, which puts children with autism at risk of regressing. Even worse, this lack of access is aggravated by the realities of military service—extended family separation, frequent changes of duty stations, and varying access to specialized health care—which often undermine the family's ability to secure adequate individualized services. An examination of the existing scheme of TRICARE coverage can help illuminate the path forward.

### *A. A History of TRICARE's Treatment of Autism*

#### 1. TRICARE Basic, Program for Persons with Disabilities, and the Extended Care Health Option

The package of benefits available to all military families, both active duty and retired, is called the "TRICARE Basic health benefits program."<sup>136</sup> With the exception of up to \$1000 per year for active duty members and their dependents and \$3000 per year for military retirees and their dependents for deductibles and co-pays incurred each year, federal law requires the DOD to pay for all medically necessary

---

131. *Accreditation of RBT Credentials*, BACB, <https://www.bacb.com/accreditation-rbt-credential> (last visited Apr. 9, 2018).

132. *T2017 TRICARE Program: Frequently Asked Questions*, MHN, <https://www.mhn.com/static/pdfs/TRICAREFaqABA.pdf> (last visited Apr. 9, 2018).

133. Press Release, United States Senator Thom Tillis, Senators Call on DoD to Halt Cuts to Autism Therapy for Military Children, (Mar. 8, 2016) <https://www.tillis.senate.gov/public/index.cfm/2016/3/senators-call-on-dod-to-halt-cuts-to-autism-therapy-for-military-children>.

134. Phone Call Interview: Karen Driscoll (Oct. 17, 2016).

135. *See generally* DRISCOLL, *supra* note 118.

136. UNUMB, *supra* note 24, at 189.

health care and mental health care of TRICARE Basic program beneficiaries without limit.<sup>137</sup> By law, the TRICARE Basic program covers all medically or psychologically necessary and appropriate health care and mental health care, unless the care is specifically excluded by the military health benefits statute.<sup>138</sup> One such exclusion is “special education.”<sup>139</sup> Prior to the creation of the Autism Care Demonstration (“ACD”) currently in place, and in addition to the Basic benefits to which all active duty and retiree families are entitled, there were “extended” benefits available to some, but not all, military families. It was under one such program—the Program for Persons with Disabilities (“PFPWD”)—that TRICARE first offered coverage for ABA in 2001.

PFPWD provided financial assistance to qualifying dependents of active duty members who were “moderately or severely mentally retarded or seriously physically disabled.”<sup>140</sup> Although the PFPWD provided financial assistance to reduce the disabling effects of a qualifying condition, it was not intended to be a stand-alone benefit, and instead authorized ABA as a cost-shared educational benefit.<sup>141</sup> More prominent in the history of TRICARE’s treatment of autism coverage is the Extended Care Health Option (“ECHO”), which replaced PFPWD in 2002 after Section 701 of the National Defense Authorization Act (“NDAA”)<sup>142</sup> for Fiscal Year 2002 required the DOD to establish a military health program providing extended benefits to eligible dependents to “assist in the reduction of the disabling effects of a qualifying condition of an eligible dependent.”<sup>143</sup> ECHO benefits were available only to dependents of active duty members with certain disabilities, one of which was autism, and were not available to the autistic dependents of retirees.<sup>144</sup> Under ECHO, ABA was a subset of “Intensive Behavioral Intervention (‘IBI’)” services—behavioral interventions considered special education services—and was provided by ECHO because they were not covered under TRICARE Basic due to TRICARE Basic’s aforementioned exclusion of coverage for “special education” services.<sup>145</sup> In order to be eligible for the ECHO program, a beneficiary had to have “moderate or severe mental retardation,” “a serious physical disability,” or “an extraordinary physical or psychological condition.”<sup>146</sup> If the beneficiary qualified, they would be entitled to \$36,000 in benefits annually for services not covered by the Basic health care program, including ABA.<sup>147</sup> Both PFPWD and ECHO authorized coverage of ABA only if it were provided by a BCBA or BCaBA.<sup>148</sup>

---

137. *Id.* at 190.

138. *Id.*

139. *Id.*

140. MAGLIONE ET AL., *supra* note 53, at 6.

141. *Id.*

142. The NDAA is a United States federal law specifying the budget and expenditures of the United States Department of Defense.

143. MAGLIONE ET AL., *supra* note 53, at 6.

144. UNUMB, *supra* note 24, at 189.

145. *Id.*; MAGLIONE ET AL., *supra* note 53, at 67.

146. MAGLIONE ET AL., *supra* note 53, at 7.

147. UNUMB, *supra* note 24, at 189; *see also* AUTISM SPEAKS, *supra* note 11.

148. *TriCare & ECHO Authorized Services*, THE CAROLINA CTR. FOR ABA & AUTISM TREATMENT, <https://carolinacenterforaba.com/autism-insurance-health-plan/tricare-echo-autism-coverage/>. (BCBAs, as

## 2. Enhanced Access to Autism Services Demonstration

“In an effort to expand services for children with [autism] further within the existing ECHO program, Section 717 of the NDAA for [fiscal year] 2007 required DOD to develop a plan [specifically] to provide services to military dependents with [autism].”<sup>149</sup> To accomplish this mandate, the DOD implemented the Enhanced Access to Autism Services Demonstration (“ECHO Autism Demo”) in March 2008 and expanded all behavioral services including ABA to eligible active duty beneficiaries in the ECHO program.<sup>150</sup> “The purpose of the ECHO Autism Demo was to permit the DOD to determine whether its provider model increased access and provided services to the most appropriate population, and whether quality of service standards and state requirements for IBI (including ABA) providers were being met.”<sup>151</sup> ECHO Autism Demo’s innovative feature was introducing the tiered service delivery model, which gave active duty families access to therapy services delivered by “Behavior Technicians (‘BTs’)”—paraprofessionals who may not conduct the ABA assessment or establish a child’s treatment plan, but who implement the therapy one-on-one with the child under the supervision of BCBAs or BCaBAs.<sup>152</sup>

The ECHO Autism Demo remained in effect until 2013, and while it was an improvement in TRICARE’s treatment of military autism families, three crucial issues were left unaddressed. First, unlike the commercial insurance industry which, as of 2013, had autism insurance reform statutes that mandated coverage of ABA as a medically necessary treatment for autism in thirty-seven states, ECHO Autism Demo still classified ABA under IBI behavioral services that were considered “educational” rather than medical.<sup>153</sup> Second, the \$36,000 annual benefit on autism services not covered by Basic, including ABA, only covered six to eleven hours of therapy per week, well below the recommended level of twenty-five to forty hours for ABA to be effective.<sup>154</sup> Third, although ECHO Autism Demo supplemented the ABA services of active duty families, it ignored the challenges of retiree autism families whose ABA care terminated upon retirement, including services for children of wounded warriors retired due to injuries sustained in combat, causing service members to re-enlist for additional tours of duty simply to maintain coverage for their children with autism.<sup>155</sup>

---

mentioned previously in section I.B and footnote 53, are master’s-level or doctorate-level behavior analysts, while BCaBAs are bachelor’s degree-level behavior analysts.)

149. MAGLIONE ET AL., *supra* note 53, at 7.

150. UNUMB, *supra* note 24, at 189.

151. MAGLIONE ET AL., *supra* note 53, at 7.

152. *See generally* TRICARE OPERATIONS MANUAL, *supra* note 50.

153. Carolina Ctr. For ABA & Autism Treatment, *Autism Insurance Reform in North Carolina—Part 1*, YOUTUBE, <https://www.youtube.com/watch?v=IAjVFrBzRsY>, 20:0021:50 (Oct. 29, 2014); *see also* Johnson, *supra* note 10.

154. UNUMB, *supra* note 24, at 192; *Obama Signs Bill with TRICARE Provision*, AUTISM POL’Y AND POL. (Jan. 5, 2013), <http://www.autismpolicyblog.com/2013/01/obama-signs-bill-with-tricare-provision.html>.

155. *Autism Speaks Salutes Advocate Jeremy Hilton on Winning 2012 Military Spouse of the Year*, AUTISM SPEAKS (May 11, 2012), <https://www.autismspeaks.org/advocacy/advocacy-news/autism-speaks-salutes-advocate-jeremy-hilton-winning-2012-military-spouse-yea>; AUTISM POL’Y AND POL., *supra* note 154.

### 3. ABA Pilot

To remedy these issues, advocates pressed for and succeeded in obtaining an amendment to the NDAA for fiscal year 2013 which clarified that TRICARE should include medically necessary behavioral health treatments like ABA for autism, remove dollar limitations on ABA care, and provide coverage for all TRICARE eligible dependents with autism regardless of their parent's duty status.<sup>156</sup> Section 705 of this bill required the DOD to create a pilot program known as the "ABA Pilot" to "further provide for the treatment of [autism], including through ABA."<sup>157</sup> Under the ABA Pilot, retiree TRICARE beneficiaries were eligible for coverage of ABA therapy provided through ECHO Autism Demo's model of tiered services delivery.

Thus, up until 2014, "TRICARE covered ABA services for different beneficiary populations through either the ECHO Autism Demo [(for active-duty autism families)] or the ABA Pilot [(for retiree autism families)]."<sup>158</sup> "These piecemeal, temporary programs were how TRICARE covered ABA until the [Autism Care Demonstration] went into effect in 2014."<sup>159</sup>

### 4. Autism Care Demonstration

The Autism Care Demonstration ("ACD") began on July 25, 2014 and combines all TRICARE ABA services for all beneficiary categories and TRICARE health plans into one demonstration.<sup>160</sup> The stated purpose of the ACD is to "establish appropriate provider qualifications for the proper diagnosis of ASD and the provisions of ABA . . . and develop a more efficient and appropriate means of increasing access and delivery of ABA services under TRICARE while creating a viable economic model."<sup>161</sup> In combining all existing temporary ABA policies into a single program, the DOD sought to incorporate lessons learned from previous TRICARE autism programs and "ensure continued ABA coverage for all TRICARE beneficiaries . . . diagnosed with ASD."<sup>162</sup> Under the ACD, TRICARE reimburses ABA services subject to no duration of therapy or monetary limits and maintains the tiered delivery model of previous programs in which BCBA's conduct assessments, develop treatment plans, and supervise the BCBA's and BTs who implement the treatment plan with the beneficiaries.<sup>163</sup>

In September 2014, TRICARE announced that reimbursement rates for services provided by BCBA's would be reduced by forty-six percent from \$125 per hour to \$68 per hour—cuts announced without supporting written analysis, which led to

---

156. *Autism Speaks Salutes House Vote to End Insurance Discrimination Against Military Families Raising Kids with Autism*, AUTISM SPEAKS (May 17, 2012), <https://www.autismspeaks.org/advocacy/advocacy-news/autism-speaks-salutes-house-vote-end-insurance-discrimination-against-militar>.

157. MAGLIONE ET AL., *supra* note 53, at 8.

158. *Id.*

159. *Id.*

160. *Id.* at 11.

161. *Id.* at 12.

162. *Id.*

163. *Id.* at 13.

outrage among military autism families who worried that “many providers would have shut down, downsized or stopped taking TRICARE clients, leaving families with no option for services for their autistic children.”<sup>164</sup> Military autism families and advocacy organizations, namely Autism Speaks, expressed immediate concern and argued that such a policy would “risk a rollback of the substantial progress TRICARE has made in meeting the needs of military family members with ASD.”<sup>165</sup> Reacting to this vehement response, The DOD, through the Defense Health Agency (“DHA”)<sup>166</sup> and at the request of the Office of the Under Secretary of Defense for Personnel and Readiness (“OUSDR”)<sup>167</sup> made the decision to delay any ABA reimbursement changes and commissioned an independent review of the proposed rate cuts by hiring RAND Corporation (“RAND”),<sup>168</sup> a research organization, to conduct a study comparing reimbursement rates for ABA services across the industry.<sup>169</sup>

The sixty-five page RAND study, completed in 2015, identified information on state Medicaid ABA provider reimbursement rates from twenty-two states, and calculated state-level ABA commercial insurance rates from twenty-nine states.<sup>170</sup> It found that weighted average calculations using all of the available Medicaid and commercial insurance rates resulted in a mean hourly rate for BCBA’s of \$94.72, indicating that the proposed TRICARE rate of \$68 for BCBA’s was substantially below the weighted mean reimbursement rate of commercial and public insurers, and further pointed out the fact that providers might be disincentivized to accept TRICARE patients compared with enrollees from other private health insurance

---

164. AUTISM SPEAKS, *supra* note 14. In 2014, TRICARE planned to cut autism provider reimbursement rates in half. FROM MOTHERHOOD, *supra* note 116.

165. *Pentagon Threatens Cuts to Families Dealing with Autism*, THE DEPLOYMENT DIATRIBES (Oct. 22, 2014), <https://deploymentdiatribes.wordpress.com/2014/10/22/pentagon-threatens-cuts-to-families-dealing-with-autism/>. (“A Navigation Behavior Consulting survey of TRICARE providers who work with autistic children found that 95 percent of these providers planned to cut back on the services they offer, while 22 percent intended to stop working with military children altogether, if the changes were to go through.”)

166. The DHA is an “integrated Combat Support Agency” which is responsible for, among other things, “exercising management responsibility for the TRICARE Health Plan.” *Defense Health Agency*, HEALTH.MIL, <https://health.mil/dha> (last visited Apr. 9, 2018).

167. “The Under Secretary for Personnel and Readiness is the principal staff assistant and advisor to the Secretary and Deputy Secretary of Defense for Total Force Management as it relates to readiness; National Guard and Reserve component affairs; health affairs; training; and personnel requirements and management, including equal opportunity, morale, welfare, recreation, and quality of life matters.” *About*, OFF. OF THE UNDERSECRETARY FOR PERSONNEL AND READINESS, <http://prhome.defense.gov/About/> (last visited Apr. 9, 2018). “The RAND National Defense Research Institute evaluated TRICARE’s ABA benefit at the request of the Office of the Under Secretary of Defense for Personnel and Readiness (OUSDR).” MAGLIONE ET AL., *supra* note 53 at iii.

168. “The RAND Corporation is a research organization that develops solutions to public policy challenges to help make communities throughout the world safer and more secure, healthier and more prosperous.” *About*, RAND, <https://www.rand.org/> (last visited Apr. 9, 2018).

169. Kellie Lunney, *Pentagon Delays until April Changes to Autism Coverage for Military Kids*, GOV’T EXECUTIVE (Oct. 21, 2014), <http://www.govexec.com/pay-benefits/2014/10/pentagon-delays-until-april-changes-autism-coverage-military-kids/97040/>; AUTISM SPEAKS, *supra* note 14; *see also*, *Pentagon Delays Proposed Rate Cuts for ABA*, AUTISM SPEAKS (Oct. 9, 2014), <https://www.autismspeaks.org/advocacy/advocacy-news/pentagon-delays-proposed-rate-cuts-aba>. (“Due to the outcry from military families and the media attention, the Pentagon back-peddled and postponed rate reductions.”); *see also* FROM MOTHERHOOD, *supra* note 116.

170. MAGLIONE ET AL., *supra* note 53, at 50.

plans.<sup>171</sup> According to a subsequent study on TRICARE reimbursement rates conducted by Kennell and Associates, another research and consulting firm, the DHA was dissatisfied with the results of the RAND study, and particularly with RAND's decision to analyze rates by grouping BCBA-Ms and BCBA-Ds together and placing BTs and BCaBAs together in a separate group.<sup>172</sup> Rather, according to the Kennell report, the DHA wanted rates broken up by provider type, even though RAND explained that claim data by provider type was not widely available.<sup>173</sup> Instead of requesting that RAND do further research, TRICARE hired Kennell and Associates to do a second analysis.<sup>174</sup> The resulting Kennell Report was thirteen pages long and concluded that "TRICARE was paying well above the rates offered by private insurers and that the newly proposed cuts would bring the figures more in line."<sup>175</sup> Subsequently, in April of 2016, TRICARE imposed new national reimbursement rates, reduced by fifteen percent across the board—an arbitrary measurement that did not consider commercial insurance rates—resulting in \$114 for BCBA-Ds, \$107 for BCBA-Ms (as opposed to the previous \$125 an hour for providers with doctorate or master degrees), \$67 for BCaBAs (as opposed to the previous \$75 an hour), \$40 per hour for BTs (as opposed to the previous \$50 an hour), with actual rates adjusted based on cost of living in certain locations.<sup>176</sup> These rates remained in place until the NDAA for fiscal year 2017, which reinstated the previous reimbursement rates, was signed into law in December of 2016.

---

171. *Id.*; see also *id.* at 82. "This study compared the Applied Behavior Analysis (ABA) benefit provided by TRICARE as an early intervention for autism spectrum disorder with similar benefits in Medicaid and commercial health insurance plans. The sponsor, the Office of the Under Secretary of Defense for Personnel and Readiness, was particularly interested in how a proposed TRICARE reimbursement rate decrease from \$125 per hour to \$68 per hour for ABA services performed by a Board Certified Behavior Analyst compared with reimbursement rates (defined as third-party payment to the service provider) in Medicaid and commercial health insurance plans. Information on ABA coverage in state Medicaid programs was collected from Medicaid state waiver databases; subsequently, Medicaid provider reimbursement data were collected from state Medicaid fee schedules. Applied Behavior Analysis provider reimbursement in the commercial health insurance system was estimated using Truven Health MarketScan data. A weighted mean U.S. reimbursement rate was calculated for several services using cross-state information on the number of children diagnosed with autism spectrum disorder. Locations of potential provider shortages were also identified. Medicaid and commercial insurance reimbursement rates varied considerably across the United States. This project concluded that the proposed \$68-per-hour reimbursement rate for services provided by a board certified analyst was more than 25 percent below the U.S. mean." *Id.*

172. See generally KENNEL & ASSOC., MEMORANDUM: OPTIONS FOR 2016 TRICARE ABA REIMBURSEMENT RATES (TASK ORDER NO. 1505-005) (2015), <https://health.mil/Reference-Center/Reports/. . /Kennell-Report-TRICARE-ABA-Benefit>.

173. *Id.* at 3–5; see also MAGLIONE ET AL., *supra* note 53 at 29, 59.

174. *ABA Therapy, TRICARE, and Rates*, AMVIK, <https://www.webaba.com/aba-therapy-tricare-and-rates/> (last visited Apr. 9, 2018). See also Patricia Kime, *Tricare to Change Autism Therapy Reimbursement Rates*, MILITARY TIMES (Dec. 1, 2015), <https://www.militarytimes.com/pay-benefits/military-benefits/health-care/2015/12/01/tricare-to-change-autism-therapy-reimbursement-rates/>.

175. Amy Bushatz, *Pentagon to Cut Pay Rates for Autism Specialists: Tricare Officials*, MILITARY.COM, (Dec. 2, 2015), <http://www.military.com/daily-news/2015/12/02/pentagon-cut-pay-rates-autism-specialists-tricare-officials.html>.

176. Philpott, *Access Worries*, *supra* note 13; Tom Philpott, *Autism Businesses Worry about TRICARE Cut*, KITSAP SUN (Dec. 23, 2015), <http://archive.kitsapsun.com/opinion/tricare-cuts-reimbursement-for-some-autism-services—27945e8a-979f-74f9-e053-0100007f4584-363377921.html> [hereinafter Philpott, *Autism Businesses*].

*B. Effect of New TRICARE Reduced Reimbursement Rates Policy on  
Military Autism Families*

TRICARE's attempt "to ensure beneficiaries can access treatment while ensuring the government is not overpaying" resulted in delayed therapy and lack of access to ABA for military families in many states<sup>177</sup> The results from the RAND study indicated that, if adopted, these rates might lead providers to either leave TRICARE's networks, or to prioritize ASD children from other health insurers over TRICARE-covered children. The results projected by the RAND study became a reality, as the effects of the new policy of reduced rates were felt by military families almost immediately.<sup>178</sup> "The rate cuts were significant enough that some groups of ABA providers stopped caring for military children, telling affected families they can't properly pay staff or sustain their businesses with such low fees."<sup>179</sup> "The fifteen percent reduction in rates is crippling for an agency," states Jennifer Orme, director of South Sound Behavior Therapy of Olympia Washington, which "assured TRICARE clients that services will continue despite the rate cut[ , b]ut the agency will not accept new Tricare patients."<sup>180</sup> Veronica Grant of New Jersey, "spouse of an Army lawyer assigned to West Point [received] a letter from her ABA provider in December, less than a week after TRICARE announced plans to cut rates, explaining that therapy for their twelve-year-old son, Colum, would end in January" due to "continued reduction in reimbursement rates by TRICARE," making it "cost prohibitive for [the provider] to appropriately staff programs."<sup>181</sup>

In a statement to the DOD's Military Family Readiness Council in September of 2016, advocate Karen Driscoll wrote:

In the five months since these cuts were implemented there has been a substantial reduction in access to crucial ABA services for TRICARE beneficiaries with autism, a result that was identified by DHA's own study on reimbursement rates.

....

Over the course of the last five months since the rate cuts became effective, ABA providers in many locations around the country have notified family members that they will no longer serve TRICARE members or will not accept new TRICARE patient referrals as the

---

177. Kime, *supra* note 174.

178. MAGLIONE ET AL., *supra* note 53, at 56.

179. Tom Philpott, *Families, Providers Await Vote on TRICARE Autism Fees*, DAILY PRESS (Oct. 30, 2016), <http://www.dailypress.com/news/military/dp-nws-military-update-1031-20161030-story.html>.

180. Tom Philpott, *Families Face Cuts to Autism Coverage*, COLO. SPRINGS (Apr. 12, 2016), <http://coloradosprings.com/families-face-cuts-to-autism-coverage/article/1572928>.

181. *Id.*

announced rates are no longer sufficient to meet the cost of providing ABA services under the TRICARE model.<sup>182</sup>

These reductions hurt families in low cost of living areas the most: “smaller providers collapsed under the red tape and lower rates. Because of all these changes and the surrounding uncertainty many military families’ services went on hold or disappeared. The most recent NDAA reversed these rate cuts, but for some providers it was too late and those areas are now without services altogether.”<sup>183</sup>

### III. THE PATH FORWARD—NEW TRICARE POLICY, AND LESSONS FOR THE FUTURE

#### A. TRICARE’s Conceptual Mistakes About the Insurance Industry and Providing ABA

TRICARE’s rate reductions might not seem entirely unreasonable despite a growing autism population (and its corresponding increasing need for ABA therapy). The cited studies’ central contradictions make clear the complexity of the task with which TRICARE was faced.<sup>184</sup> TRICARE is not the only insurance carrier that has made it difficult for autism families to access ABA, and in fact, at many points in the development of TRICARE’s policy of delivering autism treatment, TRICARE has followed the path paved by commercial insurance and Medicaid and made incremental attempts to enhance benefits. For example, when insurance mandates in forty-three states required private, state-licensed insurance companies to provide coverage of ABA as a medical treatment to autism families, TRICARE soon followed by ridding itself of the ECHO Autism Demo which classified autism as habilitative rather than medical and replaced it with the ABA Pilot, which clarified that ABA would be included as a behavioral health treatment for autism. Additionally, when the autism insurance reform movement in the commercial insurance context pushed for the removal of monetary and age limitations to the provision of ABA therapy under state commercial insurance mandates and fought for provision of ABA according to the continued efficacy of treatment, TRICARE similarly removed the \$36,000 annual dollar limitation cap on ABA that existed under the ABA Pilot and created the ACD, which reimburses ABA services subject to no duration of therapy or monetary limits.<sup>185</sup> “TRICARE coverage of ABA therapy has been among the best in the country with no age limits on children treated and no caps on total TRICARE costs per family.”<sup>186</sup> The problem with TRICARE, then, lies not with its

---

182. DRISCOLL, *supra* note 118.

183. FROM MOTHERHOOD, *supra* note 116.

184. Amy Bushatz, *Senators Ask DoD to Delay Tricare Autism Therapy Rate Changes*, MILITARY.COM (Mar. 9, 2016), <https://www.military.com/daily-news/2016/03/09/senators-ask-dod-to-delay-tricare-autism-therapy-rate-changes.html>. “The base rates were chosen based on a pair of studies commissioned by Tricare last year, Tricare officials said. But those studies came to different rate conclusions . . . [a]nd the rate reductions that Tricare chose after examining the studies . . . put beneficiaries at risk of being dropped by providers.” *Id.*

185. MAGLIONE ET AL., *supra* note 53 at 13.

186. Philpott, *Autism Businesses*, *supra* note 176.

---

incremental progress over the years, as autism families are familiar with and understanding of the fact that proper access is not quickly accomplished. Rather, the sense of urgency surrounding TRICARE has to do with TRICARE's most recent actions, and with two factors in particular.

First, TRICARE's changes to reimbursement rates run counter to trends and were executed without explanation. As several lawmakers and autism advocates wrote in a letter to Defense Secretary Ashton Carter in 2016: "Ironically, this . . . reduction in reimbursement rates occurs at a time when public and private insurers are increasing autism coverage."<sup>187</sup> Families are angry because "[w]hile most state and private insurers are moving towards more coverage for autism families, TRICARE is making it more difficult to access the autism services it already covers."<sup>188</sup> Second, TRICARE's latest changes reflect not only a lack of understanding of what the autism community needs and how ABA is delivered, but also indicate a lack of insight to the fact that not all insurance industry business models are created equal, and an insensitivity to the heightened struggles faced by military families to access and maintain ABA given their unique and often volatile lifestyle. In order to avoid barriers to military autism families' access to ABA in the future, it is essential that policymakers understand why they have occurred thus far in TRICARE's treatment of autism services provision. This section will identify two reasons why changes to TRICARE resulted in decreased access to therapy, namely by cutting reimbursement rates to more closely resemble the rates of other industries and lowering the profit margin per military child with autism. Furthermore, this section will attempt to elucidate such shortcomings in the hopes of identifying the misunderstanding of the fundamentals of insurance treatment of ABA that occurred, and to aid policymakers in future decision-making.

### 1. The Increased Credentialing Standards Problem

First, immediately preceding TRICARE's announcement of slashed reimbursement rates, the BACB issued new national guidelines for behavior technicians ("BTs"), who interact with the autism-diagnosed beneficiaries for multiple hours per day.<sup>189</sup> While BACB standards apply to all insurance carriers, TRICARE was the first in the industry to implement the new "Registered Behavior Technician ('RBT')" certification, requiring all BTs hired after December 31, 2014 to complete the RBT credential.<sup>190</sup> There were no RBTs credentialed in the country when the new RBT requirements were published. This was problematic for a number of reasons. First, it meant that providers had to hire, train, supervise, determine competency, and register employees with the BACB before they could serve TRICARE families, a process which takes at a minimum three months and which resulted in significant delays in provision of ABA services to beneficiaries. As

---

187. Tim Devaney, *Pentagon under Fire for Proposed Cuts to Autism Care*, THE HILL (Mar. 12, 2016), <http://thehill.com/policy/defense/272749-pentagon-under-fire-for-proposed-cuts-to-autism-care>.

188. FROM MOTHERHOOD, *supra* note 116.

189. TRICARE OPERATIONS MANUAL, *supra* note 50, at Ch. 18, § 18, 2.

190. See BHC, *supra* note 131; see also MHN, *supra* note 132.

several lawmakers wrote in a joint letter to Secretary of Defense Ashton Carter in early 2016:

DHA's proposed reimbursement rate cuts come at the same time DHA is imposing new certification requirements on all Behavior Technicians (BT) providing ABA services to TRICARE beneficiaries.<sup>191</sup> While these certification requirements will ensure that TRICARE beneficiaries obtain ABA services from qualified technicians, they also impose additional costs on TRICARE ABA service providers. Certification may extend as many as 130 additional days to the time it takes to hire, train, and credential BTs to serve TRICARE beneficiaries. When considering that BTs are typically part-time employees with high turnover rates, these certification requirements will likely exacerbate the impact of reimbursement rate reductions.<sup>192</sup>

Essentially, the problem as noted by lawmakers opposed to the rate cuts in their letters is that as therapy technicians gain new skills as a result of the newly imposed certification requirements and “perhaps expect a pay raise, TRICARE reimbursements are falling.”<sup>193</sup>

Second, “TRICARE requires more ABA provider credentialing than any other insurance, which is costly and time consuming for providers, making TRICARE patients harder to serve.”<sup>194</sup> Aggravating the reduction in reimbursement rates for providers is another fresh TRICARE requirement that ABA technicians be trained and certified.<sup>195</sup> Separate from the BACB's launch of the new RBT requirement, TRICARE issued its own additional credentialing updates for all types of ABA providers—BCBAs, BCaBAs, and BTs—requiring them to obtain a Basic Life Support (“BLS”) certification and complete a BACB online supervisory training course.<sup>196</sup> “It's a quality check most commercial insurers don't yet require, and it gives providers one more reason not to accept TRICARE children. Current ABA technicians must be certified to continue to provide therapy under TRICARE. . . . Lisa Capra, mother of an eleven-year old with autism, said the lower TRICARE fees atop the certification requirement have made it impossible to find an ABA provider for her son in the Dallas-Fort Worth area.”<sup>197</sup>

---

191. Senators Thom Tillis, Kirsten Gillibrand, Jerry Moran, and Amy Klobuchar, Letter to The Honorable Ashton B. Carter, Secretary, United States Department of Defense (Mar. 8, 2016), <https://www.gillibrand.senate.gov/imo/media/doc/TRICARE%20Autism%20Letter.pdf>.

192. Press Release, United States Senator Thom Tillis, Senators Call on DoD to Halt Cuts to Autism Therapy for Military Children, (Mar. 8, 2016), <https://www.tillis.senate.gov/public/index.cfm/2016/3/senators-call-on-dod-to-halt-cuts-to-autism-therapy-for-military-children>.

193. Philpott, *supra* note 180.

194. FROM MOTHERHOOD, *supra* note 116.

195. Tom Philpott, *Families, Providers Await Hill Vote on Tricare Autism Fees*, FLEET RES. ASSOC'N, (Oct. 27, 2016), [https://www.fra.org/fra/web/Content/Military\\_Update/Families,%20Providers%20Await%20Hill%20Vote%20on%20Tricare%20Autism%20Fees%20October%2027%202016.aspx](https://www.fra.org/fra/web/Content/Military_Update/Families,%20Providers%20Await%20Hill%20Vote%20on%20Tricare%20Autism%20Fees%20October%2027%202016.aspx).

196. *TRICARE Requires Basic Life Support Training for ABA Providers*, HEALTH.MIL (July 27, 2016), <https://health.mil/News/Articles/2016/07/27/TRICARE-requires-Basic-Life-Support-training-for-ABA-providers>.

197. *Id.*

---

---

## 2. Services Covered by Commercial Insurance and Medicaid but not by TRICARE

Furthermore, TRICARE does not allow providers to bill many services that other funding sources pay for. For instance, TRICARE does not allow for billing of RBT time when the BCBA is supervising the RBT, while other funding sources pay for both employees. Additionally, TRICARE does not cover the full cost of assessments, limiting reimbursement to four hours, while other funding sources allow for hourly billing.

### *B. Analysis and Suggestions for the Future*

By imposing new credentialing standards, TRICARE demanded more highly-credentialed employees, a change which would have improved the quality of ABA therapy provided had TRICARE refrained from slashing reimbursement rates at the same time and to the extent it did. Instead, what occurred was a decrease in profit margin per TRICARE child with autism, making these children the least-marketable clients for ABA therapy in certain areas. While provider reimbursement rates have been restored under the NDAA fiscal year 2017,<sup>198</sup> there are several substantive lessons that policymakers should be aware of going forward so that similar errors in policy in the attempt to serve military autism families do not occur.

In addition to TRICARE reducing reimbursement rates (which was counter-trend) and increasing credentialing standards (which aggravated access problems generated by the slashed rates), TRICARE highlighted another deficiency in its service of autism families: its lack of understanding that not all insurance industry business models are alike or solely based on revenues.<sup>199</sup> What mattered, but was not investigated in this case by either the RAND or Kennell and Associates studies ordered by the Defense Health Agency on which the adjusted reimbursement rates were based, was an analysis of the effect of reduced reimbursement rates on the profit margin per child with autism under TRICARE insurance as compared to the profit margin per autistic child receiving ABA under other forms of insurance, like commercial and Medicaid. While the RAND report, which analyzed TRICARE's initial suggested slash of provider reimbursement rates by forty-six percent, arrived at the correct general conclusion—that such a reduction would place military autism families in difficulty as the least desirable ABA clients due to having the lowest reimbursement rates in many states—RAND's assessment did not accurately portray the seriousness or depth of the impact these reduced rates would have on military autism families under TRICARE.

RAND's assessment focused solely on comparing reimbursement rates in the insurance industry across the board, concluding that reduced rates for TRICARE would be harmful, rather than looking at how each insurance system functions to

---

198. *California Delegation Applauds NDAA Provisions Protecting National Guard Bonuses*, THE RIPON ADVANCE, (Dec. 6, 2016), <https://riponadvance.com/stories/california-delegation-applauds-ndaa-provisions-protecting-national-guard-bonuses/>.

199. Kime, *supra* note 174.

provide ABA therapy to the autism populations it serves, calculating the profit margin per child in each of these systems and determining how it would be affected for military autism families under TRICARE with the new rates, and then comparing this data together. This is a critical difference that has to do with manner of assessment and requires an understanding that providers take into account more than just the price of reimbursement when running an ABA services business and taking on clients with different types of insurance. Providers can also be affected by insurance-imposed policies, such as heightened credentialing standards, which means providers must hire more qualified individuals or spend resources training individuals to be qualified under TRICARE but receiving less money to pay them, and also providing other services beneficial to autism families that non-TRICARE covered families' insurance will cover that TRICARE does not cover. These combined factors contributed to hardships and lack of access to ABA faced by military autism families as a result of TRICARE's latest policy moves, and thus the more unsettling oversight that DOD leadership were not asking the right questions in the first place, and failed to capture accurately how TRICARE reimbursements stack up against others in the industry.

The new TRICARE policies have gone into effect. While the NDAA fiscal year 2017 reinstated reimbursement rates to what they were prior to their reduction by 15%, there are new issues preventing timely access to care involving diagnostic, IQ, and other testing requirements to access ABA services. Under this new policy, at the initiation of services and every two years thereafter, patients must undergo diagnostic testing, IQ testing, and an assessment of adaptive functioning.<sup>200</sup> While the NDAA directs TRICARE to provide information on patient outcomes, these new DHA requirements have limitations, are not appropriate measures of patient outcomes, and will most likely result in significant delays in care. Further, the new testing requirements will require involvement of multiple specialty providers, causing parents to jump through multiple referral and authorization hoops. The level of strain these new requirements will put on the system will cause a multitude of problems for both current families and families going through the diagnostic process, putting timely access and continuity of services at risk. Additionally, under the new policy, ABA providers must conduct the Pervasive Developmental Disorders Behavior Inventory ("PDDBI") and include results with the updated treatment plan every six months.<sup>201</sup> While the PDDBI assessment is a validated tool for assessing areas of need for patients with autism, it has only been validated for patients aged two and a half through twelve years old. The PDDBI has not been validated for the youngest and older patients. While a new PDDBI for patients aged thirteen through eighteen is currently under development and will be available at a later date, DHA has not provided comment on how to address these patient groups at present, or patients outside those age groups. Essentially, TRICARE has eliminated the old problem

---

200. TRICARE OPERATIONS MANUAL, *supra* note 50. (It should be noted that this element was reconsidered by TRICARE, and while it still remains the formal policy today, TRICARE has issued direction to the regional contractors that IQ and diagnostic testing is not needed any longer—only assessments of adaptive functioning); See Defense Health Agency Component Acquisition Executive (J-4) "Deletion of Two Outcome Measures" letter, (May 17, 2017).

201. *Id.*

---

regarding reimbursement rates and introduced several new policies that have the potential to, and will very likely act as, barriers to access for military autism families. With the autism population on the rise and the already difficult time military autism families have with accessing care due to the nature of their lifestyle, TRICARE must dedicate itself to resolving these fundamental issues in provision of ABA and affording better access to these important families and defenders of the nation in the future—more needs to be done to ensure comprehensive treatment.

The rising incidence of autism has hit society like a ton of bricks, and it is not surprising that both the private and public sectors have been slow to respond—autism is a complex disability, those affected by it have a variety of needs, and societal systems and institutions have not kept pace with the increased prevalence of autism, nor with the scientific advancements in treatment. “Law is one of many disciplines that lag behind, which exacerbates the difficulty families experience in accessing proper clinical and educational interventions.”<sup>202</sup> Given that people with autism are a quickly emerging population in this country, it is incumbent upon us as a society to ensure that those with autism have an equal chance to attain their highest level of independence. For many people with autism, ABA therapy is the avenue by which this opportunity to pursue an independent life is made possible. “Recent advances in autism awareness have spurred legislatures and courts across the country to respond to the autism crisis, and a proliferation of autism-related statutes and cases has resulted.”<sup>203</sup> The changes in policy seen in the commercial insurance mandates, as well as with Medicaid in the past few years, have been largely well-received within the autism community because these changes, while incremental, demonstrate progress in the health insurance industry’s understanding of autism as a chronic medical condition not unlike others covered by health insurance, and have functioned to improve the availability of ABA to families with autism. While no one would say the commercial insurance and Medicaid reforms have been perfect successes, and while it is important to note that families with these kinds of insurance still experience barriers to accessing ABA and other treatments for autism, the particular barriers to access experienced by military families with TRICARE insurance are uniquely troubling because they have run counter to trend.

The wide range of difficulties experienced by military autism families with TRICARE insurance highlights the importance of engaging stakeholders in policy development. To avoid policy missteps in the future that do not align with industry standards and best practices, the DOD could include military families with autism or individuals with autism themselves, in addition to representatives from ABA therapy providers and others who routinely interface with this community in its endeavor to revise TRICARE policy to serve the military autism community as effectively as possible while being economically feasible. Had the DOD based their insurance policy for military autism families on the report issued by RAND rather than the one conducted by Kennell & Associates, the slash in reimbursement rates to providers would not have been as severe as the one that was issued. Had the DOD solicited the opinions of ABA therapy providers in addition to commissioning a study by RAND,

---

202. UNUMB, *supra* note 24, at 8.

203. *Id.*

providers would surely have pointed out the fact that RAND's analysis was flawed in that it reviewed and compared the reimbursement rates of the different insurance carriers without taking into consideration the ways in which the business structures of commercial insurance, Medicaid, and TRICARE differ from each other. Providers also could have lent insight on the effect implementing a policy of slashing rates simultaneous with demanding more highly credentialed therapists would have on their ability to stay in business and continue to accept and treat military autism children with TRICARE insurance. Finally, had the DOD consulted military families with autism living in different states, they would have learned of the barriers to accessing ABA experienced by these families, and been more efficient and capable of eliminating or addressing them. As it stands, TRICARE's coverage for treating autism and for ABA, specifically, is inadequate, but this is not to say that change for the better is not possible. The DOD has listened and made positive changes to improve access for these families in the past, and can continue to move forward in the ways outlined above.

#### CONCLUSION

For military families living with autism, change cannot happen soon enough. The U.S. must take action to improve the status quo, which has thus far left military families across the country struggling to secure coverage of basic treatment for their children with autism. The cause of and cure for autism are not yet known, but it is well-known and established that autism has a rapidly growing presence in the U.S. today, and that people with autism impose larger costs to society if they do not receive early intervention treatment than if they have consistent access to quality, evidence-based treatments like ABA. Denying such early intervention preventive treatments that both improve the functioning and quality of life of people with autism is a form of rationing justice to the very individuals who fight to preserve the freedoms and just society of the U.S., and also damages the nation at large, given the demonstrated nexus between the health and well-being of military families and military readiness. It is therefore to the betterment of the U.S. as a whole to take steps to improve the way TRICARE provides coverage for autism treatment, and especially ABA programs, for military autism families.