

# Toward Innovative, Cost-Effective, and Systemic Solutions to Improve Outcomes and Well-Being of Military Families Affected by Autism Spectrum Disorder

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The burdens faced by military families who have a child with autism are unique. The usual challenges of securing diagnostic, treatment, and educational services are compounded by life circumstances that include the anxieties of war, frequent relocation and separation, and a demand structure that emphasizes mission readiness and service. Recently established military autism-specific health care benefits set the stage for community-viable and cost-effective solutions that can achieve better outcomes for children and greater well-being for families. Here we argue for implementation of evidence-based solutions focused on reducing age of diagnosis and improving access to early intervention, as well as establishment of a tiered menu of services, individualized to the child and family, that fit with the military ethos and system of health care. Absence of this new model of care could compromise the utility and sustainability of the autism-specific benefit.

## INTRODUCTION

Autism spectrum disorder (ASD†) affects as many as 1 in 68 individuals (1:42 boys), or more than 4.0 million Americans [1]. Autism is a neurodevelopmental condition of genetic origins that results in lifelong disability varying in severity but is typically associated with significant impairments in social and communication func-

tioning, learning, and independent living skills, as well as potentially devastating behavioral challenges [2]. The lifetime societal cost of autism per affected individual is estimated to be between \$1.4 and \$3.6 million, depending on the person's level of disability and on the methodology used to make these projections [3,4]. The enormity of this public health challenge has been highlighted by

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†Abbreviations: ASD, autism spectrum disorder; ECHO, Extended Care Health Option, TRICARE's autism-related benefit; IDEA, Individuals with Disabilities Education Act; NDAA, National Defense Authorization Act; PCM, patient care manager; TRICARE, U.S. Department of Defense Military Health System

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the U.S. Congress in the Combating Autism Act of 2006 and 2011 and the Autism Collaboration, Accountability, Research, Education and Support Act of 2014. Autism has been prioritized for investments to accelerate the pace of clinically meaningful research via the creation of the U.S. Health & Human Services Interagency Autism Coordinating Committee [5]. Military families with a child with autism encounter a series of burdens including challenges in attaining diagnostic and evidence-based treatment services [6] and locating family-centered care and supports [7]. These families also face increased stress [8], financial strain [3], loss of revenue reflecting unfavorable spousal employment status [8], a higher rate of divorce, and lower quality of life [9].

Although the prevalence of autism in the military is not well-established, it has been estimated that more than 13,000 military dependents (most of whom are children) have a diagnosis of autism [10]. This may be an underestimate, given findings from a report that counted 8,500 cases of autism in the Army alone (the Army corresponds to only about 37 percent of U.S. military personnel) [11]. A recent report to the U.S. Congress associated with the National Defense Authorization Act (NDAA) [12] indicated that the annual number of active duty family members receiving care for autism under TRICARE (the U.S. Department of Defense military health system) nearly tripled between 2009 and 2012, from 2,292 to 6,550 users, with costs also tripling from \$31.0 to \$107.7 million yearly. Although the difficulties of raising a child with autism in military families have not been studied systematically [13], it is likely that they face the same challenges as civilian families. These usual challenges are compounded by the realities of military service: war, extended family separation, frequent moves, varying access to specialized health care, reduced spousal income, compounded financial burdens, and other challenges [14-17]. The intersection of stressors associated with military life and the additional burden of having a child with autism is easily illustrated. Frequent changes of duty stations undermine the family's ability to secure stable school environments and advocate for adequate individualized services. Children with autism often have difficulty with transitions and change in routine. Frequent moves may worsen behavioral problems, and the child may be less able to make use of available services [6,10,13]. These circumstances may significantly compromise the well-being and mission readiness of military families affected by autism.

Efforts to address these challenges have yielded two important achievements. First, the recognition by the U.S. Congress and U.S. Department of Defense of the pressing public health problem posed by autism has led to an increase in the autism-related benefits offered by TRICARE. This increase in benefits has been accompanied by better coverage of diagnostic and treatment services, and pilot demonstration projects have also been carried out [12,18]. Second, comprehensive compilations of autism-related information and resources for military parents were created

in book and web-portal form [10], and shorter up-to-date guides for families provide directives for self-advocacy [19]. Although these resources represent important pre-conditions for improvements, a greater effort is warranted in order to organize available resources into systems of health care delivery specifically tailored to the military system. The organization of resources hinges on providing tools and support to patient care managers (PCMs), who coordinate and are responsible for the primary and specialty care for military families through TRICARE. Parents deserve well-delineated paths and guidance to navigate through a maze of resources to meet the needs of the individual child and family. Although the service landscape may differ by region, a sound foundation of services should be in place across military bases and regions of the country.

In light of these various challenges, we offer an overview of how the needs of military families affected by autism could be addressed in a cost-effective, sustainable fashion. Specifically, we advocate the implementation of community-viable, evidence-based solutions that are tailored to meet the unique challenges of managing children with autism in military families. This is likely to be an iterative process. The infrastructure for health care delivery in the military must be strengthened so that proposed improvements can be tested for feasibility, acceptability, and effectiveness. Models of implementing evidence-based treatments across military bases need to be defined and evaluated. The evaluation of these implementation models will focus on quantitative outcomes at the family and child levels, as well as engagement by health care providers, service utilization patterns, and cost. The deployment of technologies such as telehealth, video conferencing for training, and mobile phone applications offer exciting possibilities to shrink distances and build the foundation of care across regions.

## TOPICS

### *Key Challenges and Possible Solutions Part 1: Reducing Age of Diagnosis and Improving Access to Early Intervention*

The distribution by age in 2012 of autism beneficiaries by the Extended Care Health Option (ECHO), TRICARE's autism benefit [12], reveal that nearly 90 percent of users are younger than 12; however, only 11.5 percent are children younger than 3. In the civilian system, only 20 percent of children receiving services are identified before the age of 3 via the birth-to-3 Individuals with Disabilities Education Act (IDEA) Part C services [20]. Although these rates are not directly comparable, they do indicate that the vast majority of children with autism are not identified and, therefore, are not served, before the age of 3.

There is a confluence of evidence indicating that early identification and treatment are two of the most important factors for improving lifetime learning, language, and in-

dependent living skills [21-25]. Because symptoms of autism are already present by 18 to 24 months [23,26] and autism can be reliably diagnosed at this age [27], the American Academy of Pediatrics recommends universal screening for autism during well-child visits at 18 and 24 months [28]. However, only 7 percent of primary care providers routinely do so in their practices [29-31]. Time restrictions, under-performing screening methods, and doubt about availability and effectiveness of early treatments contribute to inadequate screening in primary care [29-32]. This “wait-and-see” approach delays diagnosis. Indeed, the median age of diagnosis in the United States remains around 5.5 years of age [33], despite the fact that the majority of parents suspect problems by 18 to 24 months [34-36]. By age 5, children with autism may have accumulated secondary, preventable burdens such as intellectual disability, language deficits, and serious behavioral problems [6]. The median age of diagnosis is later still for those lacking resources and access to expert clinicians, including lower income, minority, and rural families [37-39].

Intervention that begins during infancy or preschool has a much greater impact on outcomes for children and families than providing services at school age [21-23]. It is also much more cost-beneficial: Every dollar spent on early intervention can save \$8 in special education later and other costs [40,41]. Many school-age children with autism currently require special education at staggering cost to the educational system. For example, several years ago, the cost of educating a regular student was \$6,556 per year, whereas the cost of educating a student with autism was more than \$18,000 [42]. Currently, this estimate is about twice as much. Programs for children with autism requiring more specialized and intensive services for severe learning delays and behavioral problems cost several times this amount [3].

There is some evidence that services required for early identification and intervention are less available in the military than in civilian life [12]. The uniformity and cohesion provided by the military health care system, however, could foster advances in this pivotal area that remain underdeveloped in the highly fragmented civilian system. One positive element in TRICARE is the central role of PCMs. Engaging and training PCMs, combined with novel tools for early screening and implementation of community-viable early treatment approaches, could reduce the age of diagnosis of autism and improve access to care in the military.

Community-based screening tools for autism and related communication delays, such as the *Modified Checklist for Autism in Toddlers (M-CHAT)* [43,44] and the *Infant-Toddler Checklist* [45,46], have been extensively researched, are now becoming available in tablet and online format, and dissemination is increasing [47]. Yet obstacles in the implementation of regular screening in the community remain, including low levels of acceptance among primary care providers and lack of clear direction for families on how to follow-up with the necessary ac-

tion after a positive screen, particularly the pursuit of diagnostic assessment and appropriate treatment [47].

These challenges are more likely to be addressed in the more uniform service setting of TRICARE than in the civilian system. Screening for autism-related delays in toddlers is conducted through primary care providers. Some screening instruments allow for the identification first of a larger number of children with language and communication delays and then move seamlessly to autism-specific screens [45]; others show that toddlers who receive a screen positive for ASD but do not have the condition almost invariably exhibit developmental delays that warrant intervention [43-44]. If systematically applied, these measures could identify a larger number of children who could benefit from early intervention than simply the population of toddlers with ASD [47].

The understandable concern of primary care providers about the unavailability of services to children who are identified stands in contrast to an emerging body of data supporting the effectiveness of community-viable, parent-mediated intervention for toddlers with autism and their families [25]. If disseminated, these intervention models could reduce costs because expert interventionists coach and support parents rather than delivering the intervention themselves. These parent-mediated interventions build on routine activities to promote maximal parent-toddler interaction [25]. Efforts are currently under way to connect education and training programs for primary care providers, early intervention providers, and families. These efforts may provide a common source of reference for information on the early signs of autism, evidence-based screening tools, and parental advocacy, as well as implementation of best practice for community practitioners.

### *Key Challenges and Possible Solutions Part 2: Promoting School Readiness for Older Children*

Although successful implementation of universal early screening and intervention will eventually result in children with autism being better prepared for entry into preschool, the vast majority of children with autism in military families in need of care now are older than 4 years of age (modal and median ages are 5 and 7 years, respectively) [12]. This distribution signifies that most resources are necessarily devoted to managing more severe and costly learning difficulties and behavioral problems. Current benefits for children with autism under TRICARE provide \$36,000 per child annually. Although reimbursable services include behavioral, medical, and habilitative services (speech therapy and occupational therapy), there is no support for PCMs. In the absence of these support services, families may not be able to take full advantage of these benefits. Thus, placing well-trained and supported PCMs as the point-of-access and guidance to families could optimize utilization of available resources. Some military bases might be close enough to non-military service providers to develop close relationships with health care providers and school systems. However, ac-

cess to such services can be limited. Other military bases are too remote, requiring more innovative approaches to service delivery such as telehealth [21].

Central to the organization of services for children with autism is a tiered menu of interventions that ensures that services match the individual child, family, and community. One size does not fit all children. Some children with autism can manage in a regular school environment with supports. Other children need more intensive language or behavioral interventions to promote their readiness for learning and success in school [6]. This individual approach is consistent with recommendations of previous reports on the educational needs of children in the military [10,12,15]. In the absence of a full menu of services and full capacity of PCMs to assist military families in determining appropriate educational and treatment services, however, identifying and meeting individual needs of school-age children with autism will be limited.

Despite these considerable challenges, work on the seeds for possible solutions is already under way. The goal should be a comprehensive package distributed through an electronic communication system that could serve as an online virtual hub of information, support, and educational resources unique to children and families with autism that can be available anywhere, any time. This system would allow families to share information and communicate with one another even during deployment worldwide. Using PCMs as the point of contact and support to families, the first step could be mobilization of assessments to identify the needs of school-age children with autism in order to put in place the necessary developmental, educational, and behavioral services. For example, through an efficient triage process and guided conversations with families, it can be determined if the child meets inclusion criteria for services integrated with regular school environments or requires more intensive treatments for serious behavioral problems. Families stationed in foreign countries could be connected with available resources on base or in surrounding communities. The goal of the PCM is to build a one-stop shop for families once their child is identified with autism, coordinating referrals, advocacy, and monitoring. To make this a reality, a full menu of tiered services and development of an effective electronic infrastructure are required. The *electronic* infrastructure could include group telehealth meetings to train PCMs and practitioners in evidence-based interventions and to engage families not yet integrated into community practice in interventions.

### ***Key Challenges and Possible Solutions Part 3: Deploying Evidence-Based Treatments for Behavioral Problems in Routine Practice***

A substantial number of preschool and school-age children with autism display behavior problems such as tantrums, aggression, self-injury, noncompliance, hyperactivity, wandering, and running away, among others [48]. These behavior problems interfere with the child's ability to

benefit from educational efforts and often require the child to be placed in a more restrictive educational setting. Children with autism and behavior problems also display prominent adaptive skill deficits in functional language (some are only minimally verbal) and self-care (including dressing, feeding, and toileting). These behavior problems and adaptive skill deficits typically interact — the presence of one often amplifies the other — thus compounding the deleterious effects of each. Untreated or inadequately treated behavior problems interfere with adaptive skill development and educational achievement and hinder the child's readiness for independent living in the future. Although there is a growing body of empirical support for managing behavior problems in children with autism [48], application of these interventions in routine clinical care has been inadequate. The journey from efficacy (demonstrating that an intervention is beneficial in a randomized clinical trial) through effectiveness (demonstrating that benefits of an intervention show positive effects in clinical practice) to actual implementation of evidence-based treatments in the community [49-52] to assessment of cost-effectiveness of community implementation remains a major challenge.

There is growing evidence that behavior problems can be reduced with relatively low-cost interventions. As an extension of the PCMs, we consider the role of PCM teams. These teams could marshal appropriate assessments and follow-up treatment algorithms for optimal clinical management of children with autism who display developmental deficits, behavioral problems, or both. The first step would be to classify the severity of these impairments or behavior problems. For example, accumulating data suggest that parent training built on the principles of applied behavior analysis is effective in reducing serious behavioral problems in preschool and young school-age children with autism [53]. Using a "train the trainer" model via telehealth, parent training interventions could be implemented in military settings. However, more severe behavior challenges, such as severe aggression and self-injury, extreme food refusal, and severe skill deficits in language and learning, may require more intensive behavioral interventions and a consultation model through establishing access to experts. Still other children may require targeted psychopharmacological treatment before they can benefit from behavioral ones [54-57]. In such cases, consultation with experts may be warranted, or the experts may actually have to deliver the intervention. Development of telehealth models for direct service to children and families, training clinicians to provide services, and clinical consultation for complex cases is under way. These efforts can be aided by use of technologies such as iPad and *in situ* video captures.

### ***Implementation Science and the Challenge of Improving Systems of Care in the Real World***

Despite the growing body of evidence supporting screening, diagnostic, and treatment strategies for children with autism, these tools and interventions are rarely im-

plemented in community settings. Moreover, when evidence-based practices are implemented, they rarely yield the same results observed in university-based studies. The transition from findings from specialty clinics and carefully conducted clinical trials is complicated and largely uncharted in children with autism. The science of implementing evidence-based practice is relatively new in the autism field and warrants careful consideration. Demonstration of efficacy of an intervention may not be sufficient to change practice or guarantee third-party payment for that intervention. Specific efforts may be needed to implement evidence-based interventions into clinical practice [58]. Cost-effectiveness analysis may be needed to persuade insurance companies and policy makers to support a given evidenced-based intervention.

Implementation science researchers have developed organizational and practitioner-level strategies to increase the probability of successful application of evidence-based interventions in clinical practice. These strategies often begin with gathering information from administrators, clinicians, and parents about the barriers and facilitators of moving an evidence-based intervention into real-world practice. To build a bridge from evidence-based intervention to clinical practice, we may need to test implementation strategies to identify methods that increase the probability of success of the proposed solutions. This dilemma of implementation is present in many fields of medicine. In the field of autism, however, there is a pressing need for synergy between clinical investigators who build the evidence base and front-line clinicians who are called upon to embrace such solutions. Factors of importance include the realities of clinical practice, culture, and level of resources, as well as pressures and incentives extant in the targeted clinical environment.

These considerations are particularly pertinent in the case of the military system of health care delivery, where mission-readiness is such an important consideration. The experience of military families adjusting to the needs of their child with autism has not been systematically studied. This information is key to operationalize a system of supports that will immediately alleviate the burden, build on assets of the family and the system, and capitalize on opportunities for cost-effective improvements. In this context, specific measures need to be developed to enhance available options and the effectiveness of PCMs on military base levels in order to promote successful implementation.

Alongside considerations associated with implementation are those associated with cost-effectiveness, without which sustainability of any improvements would suffer. Such analyses are needed to demonstrate the incremental benefits of specific interventions compared to treatment as usual. They should consider direct costs of system implementation, the benefit that accrues to recipients, and subsequent cost savings, both in direct costs such as health care utilization and indirect costs such as parental time spent on care. Without evidence that a given solution is

sustainable, its future is limited. In this regard, the military system of care compares favorably with the civilian system of care. In the civilian care system, for example, increased investments by an agency such as the federal infant and toddler system (IDEA part C) may result in savings for the public educational system. Because investments and savings may accrue to different administrative cost centers, however, it may be difficult to demonstrate the costs and benefits of an implementation effort. In contrast, TRICARE provides services for as long as the family is eligible, meaning for as long as the child (adolescent or adult) meets criteria for ASD. This administrative continuity provides an opportunity to assess the value of early intervention in young children with autism and the effect of targeted interventions for school-age children.

Taking an implementation science and health economics approach requires collecting of a wide range of data as the system is deployed. Examples of costs include implementation and utilization of existing health care infrastructure, as well as additional health care costs for autism, especially in the short run, from either more diagnosed cases or more intensive treatment for those diagnosed. Examples of benefits include reduction in health care costs for autism in the long run due to earlier diagnosis and early intervention and reduction in costs of intensive special educational services following implementation of child-specific educational and clinical interventions for school-age children.

## CONCLUSIONS AND OUTLOOK

For any family, having a child with autism presents many burdens. Military families face additional challenges due to relocation and variability of available services, periodic separation of caregivers leaving only one parent available to advocate and care for the child, and the anxieties associated with life-threatening deployment. And yet, viable and cost-effective solutions, reflecting evidence-based practices emerging in the screening, diagnosis, treatment, and implementation science research in autism, are now available. These emerging solutions can meaningfully address and, likely, considerably attenuate the pressures faced by military families in raising a child with autism. Priority should be given to reducing age of diagnosis and improving access to quality early intervention. Achievement of these objectives could promote better outcomes for children and families, but also the sustainability of the military health care system through cost savings over time. However, families of older children with autism cannot wait. The complementary priorities are solutions for achieving better supports and management and greater access to a tiered menu of child- and family-specific interventions that match level and intensity of services to the profile of challenges of each beneficiary. The solutions outlined in this perspective follow from knowledge gained from clinical practice, formal clinical trials, and emerging data from effectiveness studies. This body of research,

however, is still a work in progress. Thus, successful implementation of the proposed system of evidence-based practices in the military environment would also provide a model for the civilian care system.

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