

Life Journey Through Autism: A Guide for Military Families



ORGANIZATION FOR AUTISM RESEARCH

Life Journey Through Autism: A Guide for Military Families

by



Organization for Autism Research

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Board of Directors' Message

November 19, 2019

Hello, my name is Greg Smith, and I am a member of the Organization for Autism Research (OAR) Board of Directors, a proud parent of a child with autism, and a retired Air Force member.

I was on active duty when my daughter came into this world. She was born prematurely, and we were fortunate to have a lot of caring people provide immeasurable help as my wife and I grappled with the many questions we faced with regard to our daughter's issues. As I look back on those times, I feel very blessed. So, when I was asked if I would be interested in joining the Board of OAR, I saw it as an opportunity to give back a little of what I had received in the way of support. OAR has afforded me the chance to fulfill my desire to give something back, and for that I am very thankful. My involvement with OAR has allowed me to stay engaged in the broader autism community and to be in tune with the greater struggle faced by families dealing with autism. When I consider this disorder in light of my background, there is an extra special place in my heart for those who support and defend our country and our way of life.



We know our military families face additional hardships when it comes to dealing with this disorder. These hardships are manifested in many ways, to include military members deploying, which means that, in many cases, a spouse has to handle the many issues that arise on the "home front" on their own. There is also the issue of separation from extended family members, which further highlights the need for additional support. In spite of these and other hardships, our military families keep getting up each day and doing the best they can to take care of their families. They demonstrate a strong "sense of duty" and focus. I am honored to have been a member of this honorable profession, and have nothing but respect for the people who have served and those who are still serving.

Because of the sacrifices that our military families make on a regular basis, the Board is honored to support them with this updated publication, *Life Journey Through Autism: A Guide for Military Families* and the associated website, *Operation Autism*. These resources are but small tokens of our support from the heart. The website and guidebook are there for you to use, and the Board looks forward to your feedback on ways to make them even better.

We salute your tenacity in dealing not only with autism but also the attendant military issues. OAR will continue to do what we can to support you. In closing, I echo the sentiments expressed by our Executive Director, "thank you for your service to all the men and women serving in the Army, Air Force, Navy, Marines, and Coast Guard and all their reserve components today."

Sincerely,

Gregory L. Smith
Member, Board of Directors
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Nearly ten years after its initial launch, this 2019 update of *Life Journey Through Autism: A Guide for Military Families* was made possible by the generosity of The Schiff Foundation.

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Introduction

Autism presents parents and families with many challenges under normal circumstances. Autism in a military family magnifies many of those challenges and adds a few more that are unique to the demands of military life and service, further complicating an already complex neurobiological disorder. These include war, extended family separation, frequent moves, varying access to specialized healthcare, and other stressors that complicate and often work against effective treatment for children with autism.

Autism Prevalence

Autism affects an estimated 3.5 million children and adults in the U.S. based on the most recent prevalence figures (1:59 - 2018) from the U.S. Centers for Disease Control and Prevention (**CDC**).

This guide and its companion website, *Operation Autism*, located at www.operationautism.org, are designed to give families the tools and access to information they need to navigate their unique life journey through autism. More specifically, the goals of this guide are to provide:

- An understanding of autism and related intervention and treatment
- Strategies for addressing the challenges of autism from the time of diagnosis through adulthood
- An overview of the Department of Defense (**DoD**) and service policies related to having a child with autism
- Information on autism treatment options and coverage within the military healthcare system
- Practical information and tools to guide the child's education
- Tips and advice relative to transitions, such as permanent change of station (**PCS**) moves, new schools, and more
- Helpful online resources for military families affected by autism

Overview

This guide is intended to be a flexible, convenient reference tool supporting its online companion, *Operation Autism*. It offers information about autism and autism treatment for parents of newly diagnosed children. It also discusses early childhood developmental milestones and describes the warning signs of autism for parents who may be concerned about their child's development.

Next, the guide recognizes the many challenges autism presents from the time of a child's diagnosis through adulthood. It provides an overview of the policies that are relevant to military service members who have dependents with special needs, and offers guidelines for navigating the military healthcare system and accessing needed

treatments and services. The guide also addresses the topic of educating children with autism, another area that is often more difficult when compounded by the complexities of military life.

The guide concludes with a discussion of transitions—some related to autism, others unique to military life—and offers strategies for effectively countering some of the possible associated stresses and negative effects. Finally, the Appendices provide a combination of more in-depth and practical tools, tips, and resource materials.

Introducing *Operation Autism*

Operation Autism (www.operationautism.org) features five main content areas and a resource directory that provides information on schools, services, and supports available at or near military installations across the U.S. and some overseas locations. The website also provides templates and tip sheets that you can reproduce and use in your family's journey through autism. The content areas on the website correspond to and expand upon chapters in this guide, including *Autism 101*, *Raising Your Child With Autism*, *Healthcare*, *Education*, and *Transitions*. Refer to the *Operation Autism* website for further details, resources, and time-sensitive updates.



About Autism, which provides basic information about **autism spectrum disorder (ASD)**, is oriented toward the parent of a newly diagnosed child with autism. The remaining content areas and the resource directory provide general information for parents across the board.

Raising Your Child With Autism addresses post-diagnosis topics, including action(s) to be taken immediately after the diagnosis, the autism learning curve, treatments and interventions, sources of support, and continuity of care. The section on *Healthcare* provides an overview of the key policies and programs governing healthcare within DoD that are related to having a child with autism. *Education* provides useful information for educational success, as well as information on Individual Education Programs (IEPs). Finally, *Transitions* offers practical advice and tips on how to prepare the individual with autism and the family for a range of transitions, including new duty stations, PCS moves, schools, and more.

The *Resources* section of the website offers a more comprehensive listing than the *Resources* section of this guide. For example, it includes information and links to DoD and military sites, national autism organizations, training resources, and pertinent sections of OAR's main website.

Icons

Throughout the text, you will see text boxes with icons that highlight important facts, direct you toward additional information in the Appendices, or point to online resources on *Operation Autism* and other websites. Look for the following icons:



The *Operation Autism* icon denotes a cross-reference to the *Operation Autism* website.



The computer icon denotes a reference to another online resource.



The sun icon denotes a reference to an Appendix in the back of this guide.

Glossary

The Glossary that begins on [page 61](#) defines terminology and acronyms commonly used in autism treatment, special education, and the military. Throughout the text, terms defined in the Glossary are marked in bold print the first time they appear within a given section.

Federal, Military, and Autism Resources

Refer to the list on [page 67](#) to learn more about military and autism organizations and resources that may provide support to you, your child, and your family. The list is not all-inclusive, but it represents a good start as you start exploring options. Visit the websites listed to obtain information about the organizations, the resources they offer, and available support groups. All of these groups have good information, but review with a critical eye, and always check with your child's primary care provider if you are not sure. By doing so, you will, in effect, build your own, tailored resource listing as you go.

You will find other national resources—as well as resources at the state and local levels—by using the *Resources* page on *Operation Autism* and similar listings on the sites and resources you consult.

Appendices

The Appendices that begin on [page 71](#) offer supplementary information to what you will find within this guide. These appendices simply amplify the discussion.

About Autism

What Is Autism?

Autism is a complex neurodevelopmental disorder that affects a child's ability to communicate and interact socially. It is described as a spectrum disorder, which means that it manifests itself across a wide range of behaviors from mild to severe and, therefore, requires varying degrees of support.

Although some studies have demonstrated early predictors of autism in infants as young as 6 months of age, children are typically diagnosed by the age of 3. The symptoms of autism involve two major areas of development: social communication/interaction and restricted, repetitive patterns of behavior. Specifically, autism impacts a child's ability to:

- Engage in reciprocal social interactions with others
- Communicate with others in developmentally appropriate ways
- Transition or adapt flexibly to changes in routine

While most of us show some mild form of these characteristics, it is their excessive and persistent presence in individuals with autism that substantially affects their quality of life and dictates the need for supports. Complicating diagnosis is the fact that these characteristics vary significantly among different children with autism—and even within the same child across time. In short, no two children with autism are the same.

According to the American Psychiatric Association's *Diagnostic and Statistical Manual, Fifth Edition (DSM-5)*, a person must display the following characteristics in order to be diagnosed as having an **autism spectrum disorder (ASD)**:

- Persistent deficits in social communication and social interaction across multiple contexts
- Restricted, repetitive patterns of behavior, interests, or activities
- Symptoms that are present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life)

When diagnosing individuals with autism, clinicians must indicate the severity level of the disorder to help determine the amount of support a given individual needs, as follows:

- Level 1 Autism—Needs support
- Level 2 Autism—Needs substantial support
- Level 3 Autism—Needs very substantial support

Individuals with level 1 autism typically have higher adaptive skills and, therefore, require fewer and less intensive supports than those with level 2 autism. Individuals with level 3 autism experience the greatest challenges in adaptive behavior and, therefore, require very substantial supports.

How Has “Autism” Terminology Evolved Over Time?

Until 2013, when the DSM-5 was published, “autism spectrum disorder” referred to an umbrella of disorders, including autistic disorder (classic autism), Asperger syndrome (AS), pervasive developmental disorders-not otherwise specified (PDD-NOS), Rett Syndrome, and Childhood Disintegrative Disorder. Since then, these disorders have been folded into the broad term autism spectrum disorder, which ranges in severity of deficits based on the level of supports required, as mentioned earlier.

Despite the changes in the official terminology, some individuals with autism who have greater adaptive skills self-identify as having “Asperger Syndrome” or being “aspies.” Often, these are individuals who were diagnosed with “Asperger Syndrome” under the earlier diagnostic criteria of the DSM. Some of them resist being called persons with autism, while others embrace being called “autistic.” Finally, many members of the autism community, including self-advocates and highly regarded professionals, describe autism as a “culture.” As part of a growing neurodiversity movement, they focus on initiatives that help society as a whole become more accepting of neurological diversity rather than on efforts to “cure” them of their differences by means of various interventions.

Common Characteristics

Autism is a lifelong disorder that may affect a person’s ability to socially communicate with others and manifests in the form of restricted and/or repetitive patterns of behavior, interests, or activities. When looking at the often excessive behaviors of individuals with autism, it is important to recognize that what may appear as willful disobedience or noncompliance is more accurately a reflection of the neurobiological nature of the disorder.

Common characteristics of the disorder include the following:

Social Communication and Social Interaction

- Literal interpretation of others' words
- Difficulty establishing and maintaining relationships
- Tendency to speak bluntly without regard for the impact of words on others
- Inappropriate facial expressions, gestures, or eye contact
- Limited imaginative or pretend play
- Limited ability to initiate, respond to, or maintain conversation
- Abnormal voice inflection and cadence
- Overgeneralization of social behaviors across all contexts and environments
- Difficulty understanding or taking on others' perspective

Restricted/Repetitive Patterns of Behavior, Interests, or Activities

- Stereotyped or repetitive behaviors (e.g., lining up toys) or speech (e.g., echolalia)
- Highly restricted interests and fixations
- Rigid thinking patterns
- Difficulty adapting to transitions or sudden changes in routine
- Difficulty switching from one activity to the next
- Hyper- or hyposensitivity to everyday sounds, textures, smells, lights, and/or movement

Causes and Prevalence Rates

What Causes Autism?

You'll hear a number of theories about the causes of autism, some with some very vocal adherents, but the short answer is: *There is no definitive answer*. This lack of clarity contributes to a considerable amount of speculation and conflicting theories among both parents and scientists about the cause or causes of autism. However, scientists strongly suspect a genetic cause, or perhaps a genetic predisposition that is triggered by something in the environment.

Though much about autism remains a mystery, researchers have made a few observations:

- Some individuals are genetically more susceptible to autism than others. For example, individuals who have siblings with autism are more likely to have autism than individuals who do not have siblings with autism.
- Individuals with autism seem to demonstrate differences in typical brain development, including size, structure, shape, and connectivity.

The effort to find the causes of autism continues with investigations into a number of theories related to our genes, environmental factors, and the immune system.

What About Autism and Vaccines?

Most discussion about the cause or causes of autism, especially in media reports, invariably touches on the subject of vaccines and autism. Indeed, a number of parents of children with autism believe that there is a link between autism and the MMR vaccine (injection of a mixture of three live attenuated viruses for immunization against measles, mumps, and rubella), and that the vaccine, in fact, causes the onset of autism.

Despite the strongly held beliefs of proponents of the vaccine theory, there is no scientific evidence that the MMR or any vaccines cause autism. There is a correlation in time, however. The age for autism diagnosis is normally between years 1 and 3, whereas children are vaccinated around the age of 2. With no other explanation for the onset of autism, this correlation often leads parents to link the development of autism symptoms to the effects of the MMR vaccine.

As a result of those concerns and the advocacy of many parents and parent groups, ongoing research is examining environmental factors as these may relate to autism. At present, however, there is no evidence that a link between autism and vaccines exists, and it is important to note that vaccines help protect and strengthen the body's immune system and, therefore, prevent many otherwise serious diseases.

What Is the Prevalence Rate of Autism?

Autism is found in all cultures and across all socio-economic groups. In the past 40 years, the prevalence rate of autism has skyrocketed. In 2018, the Centers for Disease and Control Prevention (CDC) estimated that 1 out of every 59 children in the United States have autism.

Why the increase? No one knows for sure. Some epidemiologists point to an increasing awareness of the disorder as a key contributing factor. In addition, the diagnostic criteria for autism has changed with time, reflecting the latest research evidence, and the revised criteria are broader and therefore have contributed to the increased number of children being diagnosed with autism. Others view the impact of environmental factors (e.g., toxins) as a contributing cause. As more research is conducted, this question may soon be answered.

According to the CDC (2018), boys are four times more likely to be diagnosed with autism than girls. Some experts have theorized that this ratio is misleading, however, pointing to the fact that girls are more likely to develop compensatory social mechanisms to mask their symptoms and, therefore, end up being misdiagnosed or fail to be diagnosed at all.

Early Warning Signs

If you suspect your child has a developmental delay or autism, the first step is to gather information and become more educated.



Go to the [Operation Autism](#) website to access online resources.

The following list of symptoms represents the broad range of the autism, and is not meant to be a checklist to determine whether or not a child has the disorder.

<p>At 4 months</p> <ul style="list-style-type: none">• Cannot hold head steady.• Does not coo or make sounds.• Does not watch things as they move.• Does not bring things to mouth. <p>At 6 months</p> <ul style="list-style-type: none">• Makes no eye contact during parent interaction.• Does not coo or babble.• Does not smile at parents.• Does not try to grab things within reach.• Does not respond to peek-a-boo game.	<p>At 12 months</p> <ul style="list-style-type: none">• Does not crawl.• Does not attempt to speak.• Does not point, wave, or grasp.• Does not respond when name is called.• Fixates on a single object.• Oversensitive to textures, smells, sounds.• Has strong resistance to change.• Loses skills previously gained, including language and motor movement. <p>At 24 months</p> <ul style="list-style-type: none">• Does not initiate two-word phrases.• Does not walk steadily.• Does not follow simple instructions.• Loses skills previously gained.
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Trust your instincts. If your child manifests several of these symptoms and your intuition suggests that “something is just not right,” discuss your concerns with your pediatrician or primary care provider (PCP), and ask specifically whether your child should receive a developmental screening. Be proactive.

It is important for a child with autism to be diagnosed as early as possible. Studies have shown that the earlier a child is diagnosed, the sooner a treatment program can be started, and the better the results for the child in the long term. Be suspect of a “wait-and-see” approach. If your PCP suggests you wait to see how your child progresses and you still have concerns about your child’s development, pursue further evaluation. The American Academy of Pediatrics recommends that PCPs check children’s progress against developmental milestones during every “well baby visit,” with additional developmental and autism-specific screenings at regular intervals.

Obviously, if after examining and observing your child, your doctor shares your concerns, the doctor should refer your child for screening by a developmental specialist.

The Diagnostic Process

To arrive at a diagnosis, clinicians rely on behavioral observation, generally quantified through the use of standardized diagnostic scales, such as those listed below. In general, diagnosis is a two-step process: (a) screening, and (b) a comprehensive diagnostic evaluation.

A properly conducted screening will determine if a more thorough evaluation for autism is necessary. It will also help identify or rule out any other problems or conditions that may be present, and serves as the necessary first step toward helping your child receive the appropriate treatment. Examples of specialists who conduct developmental screening include neurologists, child psychologists, neuropsychologists, psychiatrists, developmental pediatricians, and speech-language pathologists (SLP).

What Screening Tools Are Used to Determine Autism?

Ultimately, when conducting an evaluation, healthcare professionals are looking for a constellation of social, communication, and behavioral developmental differences that are consistent with a diagnosis of autism. Unfortunately, the variability that is observed among individuals with autism in combination with the lack of a medical/laboratory test or distinctive physical sign that can be used to identify autism can make diagnosis difficult.

In order to bring more clarity to the diagnostic process, specific tests are given to rule out other developmental differences and help definitively diagnose autism and gauge its severity. In general terms, the majority of children with autism receive their diagnosis between the ages of 2 and 4, after parents begin noticing delays or differences in social interaction as well as verbal and nonverbal communication.

Several tools may be used to screen for an autism diagnosis, including the following:

- **Modified Checklist for Autism in Toddlers, Revised With Follow-Up (M-CHAT-R/F)** is a brief checklist of yes/no items for early detection among children 16 to 30 months of age.
- **Autism Diagnostic Interview-Revised (ADI-R)** is a semi-structured interview with the child's parents used by a trained specialist to help make a definitive diagnosis.
- **Autism Diagnostic Observation Schedule-Generic (ADOS-G)** is a structured interview with directed activities also used by a trained specialist to help make a definitive diagnosis.

- **Childhood Autism Rating Scale (CARS)** uses a 15-point scale to evaluate a child's relationship to people, body use, adaptation to change, listening response, and verbal communication.
- **ThinkAsperger's** is a brief screening tool in a portable mobile app format that aids in the informal detection of autism for parents, teachers, and medical professionals.

After the Diagnosis

If your child is diagnosed with autism, this is the beginning of a much different journey than what you had probably planned for you and your family. It is a journey that will require the best of your ability to cope and your resourcefulness to navigate the road ahead. But just as there are sure to be challenges, there will just as surely be moments of hope and accomplishments. The *Raising Your Child With Autism* section that follows provides information that will help you adjust to the diagnosis and offers tips for taking other helpful first steps.

Raising Your Child With Autism

An autism diagnosis often creates significant changes to your child's and family's future plans. From the moment you hear your child's diagnosis, you face a range of treatment decisions requiring knowledge that may exceed your education, background, or life experiences. This need for specific, individualized information and treatment for persons with autism is dynamic and lifelong, and this is where this guide and *Operation Autism* come in to support you along the way.

In this section, we will specifically look at issues surrounding the diagnostic process, advocacy, treatment options, and how to keep all relevant data and documentation organized and up-to-date.

Diagnosed With Autism

Receiving an autism diagnosis for your child is no doubt an emotionally charged and life-changing event. You may feel surprised, overwhelmed, or you may, in fact, be relieved by your child's diagnosis. Through it all, it's important to know that life holds many possibilities for your child and your family. Most significantly, there are things you can do to enhance the quality of your child's life.

It is often helpful to shift the focus from the label of autism to treating the symptoms that initially raised the concern. Although it isn't possible to accurately predict how much progress your child will make, research shows that intervention and treatment can improve your child's development and quality of life.

Given the main characteristics of autism, it is of primary importance that you and your child's intervention team work to prioritize your child's individual needs and address them through a balanced treatment program. You may start by focusing on improving your child's communication and social interaction and reducing the presence of any problem behaviors. Next, you may identify other symptoms and developmental milestones (e.g., dressing, toileting) that can be targeted directly with intervention.

So, allow yourself some time to accept your child's diagnosis, but be ready to take action as quickly as possible. On your family's journey ahead, every day is an opportunity for you to positively impact your child's prognosis.

Your Life as Your Child's Advocate Begins

While a diagnosis of autism prompts a range of emotions and complexities, it also brings clarity and purpose in terms of understanding what is going on with your child, resulting in three positive developments. That is, the diagnosis:

1. **Can alleviate guesswork and uncertainty.** Receiving the diagnosis can provide a name for the cluster of symptoms you may have seen, as well as validate your concerns. Having the diagnosis may better equip you to discuss your child with other family members and trusted friends, as well as with your child's teachers and pediatrician.
2. **Starts the process of accessing direct and related services.** The services your child needs are rarely provided without a diagnosis. Children with autism require high-quality, intensive, and evidence-based intervention in order to make positive progress.
3. **Clarifies your role as the principal advocate for your child.** The responsibility for taking the first action step will in all likelihood rest with you. So, it is critical that you become knowledgeable about autism and understand your child's and family's needs, as well as the services available.

One of the greatest challenges following your child's diagnosis is sifting through the vast array of information available about autism and treatment options. As you begin this process, you are sure to find conflicting opinions (and sometimes high emotions) about the best methods or treatment to use. Some sources are excellent; others less so. To help you navigate these new waters, always look for evidence of efficacy in the form of documented research studies published in reputable scientific journals. If you are researching a potential treatment and you cannot find mention of that kind of evidence, you should be suspicious. While this sounds like a daunting task, this guide will provide the basic information you need to be an informed advocate for your child.

Becoming an Informed Advocate

To make informed treatment decisions for your child, you will need to gather information from a variety of sources, including the Internet, mass media, professional journals, conferences, workshops, and educational providers.

During your search, it is important to keep the following in mind:

- Beware of those who claim to have "cures." Cures for autism simply do not exist.
- Be critical of news articles that sensationalize research findings but omit key details of the study, such as its limitations, applicability, or design. Online and mass media sources are not always accurate.
- Professional research journals are the most credible sources of current research, though they may be more difficult to access and understand. They are the

primary source of information that often undergo a peer review process before being published.

- Focus on evidence-based treatments and seek support from a qualified professional when deciphering information and making decisions.



For additional tips on how to be a savvy information consumer, see OAR's guidebook *Life Journey Through Autism: A Parent's Guide to Research*.

researchautism.org/resources

Taking Care of Yourself

An autism diagnosis doesn't just affect the child. It affects you and the entire family. Just as a flight attendant instructs everyone on a plane to "put on your own mask first before assisting others" in the case of a cabin pressure emergency, you too should first take care of yourself and get the support you need. Self-care is extremely important, yet often neglected. You deserve to lead a fulfilling life and have your needs met as well. In order to take care of someone, you must first be able to take care of yourself.

So, consider choosing one or several of the following options:

- Join a support group to help you find ways to cope with the different stressors you face. Search local listings and visit a session to see if it is a right fit for you.
- Create a support network of caregivers. This can include your immediate family, grandparents, and neighbors.
- Set aside a couple of hours each week to do things for yourself that you enjoy, such as reading, gardening, or exercising.
- Join parent training programs. Parent training programs are typically implemented in the family's home and community, but they may also be provided at the park, grocery store, or shopping center.
- Use counseling services provided by appropriately trained counselors or psychologists; they may help to reduce stress as well as provide family support.
- Use respite care to get some time away from the child with autism (and any siblings). Many families can access respite care through state service agencies. Service providers may also offer respite as a separate service and can help identify people to stay with the child while you have a night out. Occasionally, extended family members can be "hired" as respite workers. Remember that TRICARE's Extended Care Health Option (ECHO) allows for provisional coverage, which includes respite care. (Additional details on ECHO may be found in the *Healthcare* section of this guide.) TRICARE's Exceptional Family Member Program (EFMP) also offers non-medical respite hours.

Remember: By renewing your internal resources, you may not only feel less stress, you may also find yourself better able to meet your family's needs.

Intervention and Quality of Life

In preparation for your child's future, you have already taken an important first step by seeking out information. If you learn as much as you can, visit schools and facilities offering intervention, talk to professionals and other parents, and consider all your options, you'll be able to make an informed decision about the treatment options that most suit your child's needs.

In the following section, we will take a closer look at who and what is typically involved in interventions for individuals with autism.

The Intervention Team

Intervention invariably involves more than one treatment and multiple providers—an intervention team. The American Academy of Child and Adolescent Psychiatry recommends that several types of professionals and services be involved in taking care of a child with autism under the direction of one certified and experienced professional who develops, organizes, advocates for, and watches over the child's specific program. The team may include some or all of the following professionals: developmental pediatrician, child psychiatrist, neurologist, board certified behavior analyst (**BCBA**), child psychologist, special and/or general education teacher, occupational therapist (**OT**), physical therapist (**PT**), and/or speech-language pathologist (**SLP**). Parents and, when appropriate, the children themselves, are also important members of the intervention team.

Components of a Treatment Program

Your child's treatment program should include the following components to varying degrees.

Early Intervention

Most experts agree that early intervention is associated with positive prognostic outcomes, so it is important to get your child started with an intervention program as soon as possible.

Intensive Intervention

Your child's treatment program should be of sufficient intensity and duration. Various professional sources vary widely with regard to the type, intensity, and duration of treatment. What is important is that the treatment plan is designed to fit your child's specific needs and symptoms. Your child's developmental specialist can recommend the optimal treatment plan for your child, which may include occupational, speech and language, and physical therapy, **ABA**, and medications. Treatment should not stop there. Engage in meaningful learning opportunities throughout the day.

Family Involvement

One way to increase the intensity of your child's treatment program is for you and other family members to be actively involved. Parent training programs, in which a treatment provider teaches you how to implement intervention procedures, are highly recommended. The goal is not for you to become or replace a therapist, but to help maintain or increase the intensity of a given treatment. Further, once you have received training, you will likely be able to train other family members, babysitters, teachers, and peers, which is particularly important and beneficial if your family relocates. Finally, including other members of your family, such as your child's siblings, may help them learn how best to interact and play with their sibling with autism, thereby further optimizing learning opportunities and the treatment program. While the involvement of siblings can be important, it is critical to be sensitive to their needs and not make unreasonable demands on them.

Intervention in Natural Environments

Generalizing skills to new environments and/or new people is challenging for many children with autism. There are two ways to improve **generalization**. The most preferable is to implement intervention programs directly in natural environments (e.g., home, school, and community). By teaching children in natural environments where they live, learn, and play, generalization training is essentially built into the intervention.

When teaching in the natural environment is not feasible for some reason, your child can be taught skills in a non-natural environment (e.g., therapy room or special education classroom). In such situations, it is important to ensure that a systematic plan for generalizing skills to the natural environment is in place before a new skill is introduced.

Intervention With Typically Developing Peers

Treatment programs that are primarily implemented in natural environments typically include opportunities for children with autism to interact with their typically developing peers. For example, if included in general education classrooms, children with autism may have numerous opportunities to talk with classmates. However, being physically close to peers and having opportunities to interact is often not sufficient. The social deficits inherent in autism often necessitate interventions that specifically structure interactions and teach children with autism how to interact with their peers. These interventions can take place in the classroom, on the playground, during play dates, or within community-based after-school activities.

Interventions Implemented With Fidelity

Fidelity of implementation refers to whether interventions are implemented correctly. As such, it is critical to ensuring your child receives a high-quality treatment program. Even the most well-researched treatments are largely ineffective if they are

not implemented with fidelity. This is similar to a medication not working properly if not taken as prescribed.

Continuity of Care

Continuity of care refers to the extent to which intervention programs are coordinated across the members making up the intervention team without lapses in treatment. Ideally, all of your child's therapists would work for one agency. Unfortunately, that doesn't happen much in the case of autism in general, and is even less likely to occur in the case of a military family and autism. Continuity of care also extends to maintaining care and services when moving from one duty station to another. The *Transitions* section of this guide deals with those issues in more detail.

It is far more likely that your child's treatment team will be made up of a number of therapists with different backgrounds and approaches to intervention and working for different service agencies. Therefore, it is critical that the members of your child's team of treatment providers work together and maintain open lines of communication. For that reason, a "lead" therapist or agency is often selected to oversee the child's overall program and coordinate interventions across therapists and service providers. Your child's primary care manager or case manager may fill this role.

Treatment Options

A treatment that is successful for one child may not be as effective for another, so it is important that the intervention team accurately and regularly measure your child's progress to ensure that the course of treatment is appropriate, effective, and rooted in evidence-based practices. Measuring effectiveness does not need to be a long or frequent process. Think of this as the primary tool you have to benchmark your child's development and document progress. Measuring effectiveness will help you determine whether you should continue or discontinue a given treatment.

How effectiveness is determined varies greatly based on the treatment and skill being considered. While some treatments by their nature take longer than others to yield improvements, do not be reticent to bring up any questions you may have to your child's team. Time is of the essence in autism intervention, and you should be committed to only those treatments that are producing meaningful changes in your child.

Finally, by law, your family must be included in the assessment of your child. In addition, treatments that are selected should be sensitive to your family's culture and ethnicity, fit within your family's daily routines, and be practical so that you and your child are able to participate in all aspects of the intervention correctly.

Types of Treatments

There are two types of treatment options: evidence-based therapies and alternative therapies. At first glance, it may not be clear which treatment fits in which category, but the distinction is important.

Evidence-Based Treatments

Evidence-based treatments are most often recommended by research and medical professionals; however, there is no one, single approach, and treatment for autism is highly individualized. The most effective treatments are those that:

- Have demonstrated support in the research literature;
- Are generally behaviorally based;
- Are provided early and at the right level and intensity for the child's needs;
- Specifically target your child's areas of strength and need;
- Match the context of your family system; and
- Are administered within the context of an integrated intervention team, under the direction and supervision of a qualified, competent team leader.

From a simple Google search, you will quickly discover that there are many treatment options available. They run the gamut from being well founded in science to the other extreme, lacking in scientific support and bordering on quackery. In between are interventions that seem to have helped some children and that some parents swear by, even if the support is anecdotal, not evidence-based.

What's a parent to do? Since an Internet search will yield a vast array of options, many of them ineffective, if not harmful, parents must turn to more solid sources of information as a guide when selecting the best treatment for their child. Parents should build their child's intervention plan around treatments that have a solid basis in science (i.e., are "evidence-based"). In the end, it rests upon your family to choose what treatments best fit your needs and the needs of your child. The following are some of those most frequently used in integrated intervention approaches.

Applied Behavior Analysis (ABA)

ABA is an intensive intervention for autism. It is a science based on the principles of learning, with a focus on improving lives. The central theory behind ABA is that behavior can be learned and modified by changing environmental conditions, such as through motivation, shaping, and prompting procedures. Goals target both increasing and decreasing specific behaviors. Behavior that is reinforced (rewarded) is more likely to be repeated than behavior that is not reinforced. Behavioral intervention may help children "learn to learn," so they eventually begin to learn and develop skills on their own and become less dependent on therapists and intensive teaching. ABA can be implemented as a focused treatment to address a narrow range of targets (e.g., toileting, self-help skills, problem behavior) or a comprehensive treatment, where the

behavior analyst designs and oversees a range of behaviors targeted for change. The most extensive research support for ABA services is in the area of autism.

In ABA, a wide variety of treatment methods are used, from highly structured programs using discrete trial training (**DTT**) to parent-driven naturalistic behavioral programs such as pivotal response training (**PRT**). Treatment intensity typically ranges from a few (5 or less) to 40 hours per week, and should be administered by a Board Certified Behavior Analyst (BCBA), a professional who is credentialed by the Behavior Analysis Certification Board (BACB) (see www.bacb.com).

Be advised that waiting lists for BCBA's can be long because the demand for them is great. When looking for ABA services, it is important to make sure that the training and experience of the potential provider fit your child's area of need. Your child's developmental specialist can help you identify the right fit for your child. The Association for Behavior Analysis International provides guidelines to help consumers select professionals qualified to design and oversee ABA interventions: bit.ly/ASATonline.

Although many in the research community agree that ABA services are evidence-based, you may find that some representatives from the Defense Health Agency disagree. One reason is that two recent large reviews (Cochrane, 2017, Hayes, 2018) found limited evidence for the effectiveness of early intensive behavioral interventions, including some ABA interventions. The American Psychological Association (APA), National Institutes of Health (NIH), and National Professional Development Center (NPDC) on Autism Spectrum Disorder maintain that ABA is evidence-based, as studies have shown positive gains in areas of academic, readiness-to-learn, social, communicative, motor, behavioral, and adaptive skills.

Developmental Approaches

The developmental approach to intervention for children with autism is based on theories that link development of cognition and communication with emotion. As such, developmental interventions look at the whole child (e.g., sensory, motor skills) and the family (e.g., deployment, moving), and guide other treatments, such as speech and language, educational, occupational therapy, and behavioral services, so that the entire team is working toward developmental progress.

Picture Exchange Communication Systems (PECS)

One of the main areas affected by autism is the ability to communicate. PECS helps get basic language underway, and provides a way of communicating for children who have limited or no verbal communication. Briefly, PECS uses ABA-based methods to teach children to exchange a picture (or set of pictures in a sentence) for something they want, such as an item or an activity. This approach enables a child with autism to communicate more easily. As a result, the child may experience less frustration and demonstrate fewer problem behaviors.

Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH)

TEACCH is a structured teaching approach based on the idea that the environment should be adapted to the child with autism, and not the other way around (the child adapting to the environment). The goal of the TEACCH approach is to provide the child with the necessary skills to understand their world and other people's behavior. Because TEACCH tends to build upon skills most children with autism already have, some families see it as a more congenial approach than the more structured interventions associated with ABA.

Speech and Language Therapy

Communication challenges are at the heart of an autism spectrum diagnosis and, in many cases, contribute to behavior problems. As a result, a quality intervention program should include methods to improve communication. Including a Speech Language Pathologist (SLP) on your child's team is often necessary. Some speech-language therapists who work with children with autism incorporate the principles of ABA into their practice to encourage positive behavior and help the children develop increasingly greater communication skills; however, SLP can also be used with benefit without ABA.

Occupational Therapy (OT)

Many children with autism benefit from working with a registered/licensed occupational therapist (OTR/L). An OT is a trained and licensed healthcare professional who collaborates with the family, the individual (when appropriate), and the intervention team to set intervention goals related to activities of daily living (e.g., dressing, self-care), functional and academic tasks (e.g., use of a computer, writing, cutting with scissors, care of personal belongings), education, work, play, leisure, and social participation. The OTR/L evaluates performance to determine what interferes with desired performance of a given skill and subsequently builds an individually tailored treatment plan.

Physical Therapy (PT)

Children with autism may have challenges with physical coordination and gross-motor skills and, therefore, may not be as physically active as their typically developing peers. In addition, their limited ability may lead to limited interest in physical activities, which can reduce opportunities to engage in fun interactions with other children, which can otherwise serve as valuable opportunities to learn and develop age-appropriate skills. Further, if a child's coordination is very impaired, safety may be a concern. To address such issues, a physical therapist can design a regimen that will help a child develop muscle strength and physical fitness while at the same time addressing issues related to gross-motor coordination and skills.

Alternative Therapies

Alternative therapy generally refers to interventions or treatments that differ from and are used instead of (or along with) conventional treatments like physical therapy. Examples include music therapy, hippotherapy, and nutritional therapies. Alternative therapies have emerged as part of a growing assortment of treatments used with individuals across the autism spectrum. However, parents must be aware that effectiveness has often not been established for a particular intervention. Focus primarily on evidence-based treatments, and be wary of misinformation or claims that certain methods lead to drastic improvements. Many families who have chosen to use alternative therapies see them as fun, motivational, and potentially helpful treatment approaches for their child, even though little scientific evidence exists on the efficacy of treatments such as those briefly described below.

Treatment Types With Limited Scientific Evidence

Some popular, non-evidence-based treatments available to children with autism include the following:

Animal Therapy	Treatments include horseback riding, also referred to as <i>hippotherapy</i> , which proponents claim draws on the multi-dimensional movement of the horse to help organize the child's sensory input; and dolphin/dog/cat/bird-assisted therapy, a mode of treatment that purports to improve a child's cognitive skills by "relaxing" their brain.
Art Therapy	This form of therapy uses the artistic techniques of drawing, painting, and modeling to reportedly help enhance cognitive, communication, and social/emotional skills through tactile and sensory stimulation.
Auditory Integration Training	This refers to a series of auditory treatments designed to normalize auditory processes in individuals who, it is hypothesized, experience distortions in hearing or are hypersensitive to sounds.
Craniosacral Therapy	This non-invasive massage technique is based on a belief in a person's innate ability to heal themselves through the use of specific massage techniques focused on the head and spine. Proponents claim this allows for the release of tension and the dissolution of energy blocks.
DIR/Floortime	DIR/Floortime (developmental, individual-difference, relationship-based approach) is a developmental intervention focusing on relationships to improve social, emotional, and intellectual capacities. DIR/Floortime is a popular intervention commonly used with other therapies.

Music Therapy	Often used to help children with motor, speech, and fluency problems, this kind of therapy uses music to increase behavioral, social, psychological, communicative, physical, sensory-motor, and/or cognitive functioning.
Play Therapy	Play therapy introduces the elements of play and develops and extends the variety of play activities the child typically engages in to increase their cognitive abilities, language development, and social skills.
Rapid Prompting Method (RPM)	This prompting technique is used by some parents or educators to help individuals with limited verbal skills communicate through pointing or writing. While the method has some strong proponents, many professionals do not recommend the practice as it has not been scientifically proven. The method may be subject to unconscious bias from facilitators.
Vision Therapy	Vision treatments include the “Irlen” method which, according to supporters, addresses a type of visual-perceptual processing problem related to sensitivity to lights, glare, patterns, colors, and contrast through the use of colored filters worn as glasses to reduce or eliminate perceptual sensitivity and sensory overload.

Evaluating Treatment Options

Given the lack of scientific support for alternative therapies, you may want to consider these therapies as recreational activities. That is, while art and horseback riding may be motivational and lead to short-term gains for your child, you are not likely to see measurable cognitive or behavioral changes as a result because they do not always address the core symptoms of autism.

To decide which form of therapies to include in addition to your evidence-based treatment program, work with a qualified professional (such as a developmental pediatrician or an experienced behavior analyst) who can help you identify the right treatment supports. You might also seek information and opinions from other healthcare providers, autism groups, and fellow parents. Also discuss therapies you are considering with your child’s current treatment professionals. They may be able to advise you on its safety, use, and effectiveness. Then, working as a team, you and the therapists should talk about the areas of your child’s development an additional therapy might improve. Finally, it’s important that your inquiries go beyond the therapies themselves, to include evaluation and careful scrutiny of any facilities involved before beginning any program.

In addition to a therapist or treatment facility, an independent professional organization associated with the type of therapy you are considering is another possible source of

reliable information, such as the websites for the American Speech-Language-Hearing Association (www.asha.org), the American Academy of Pediatrics (www.aap.org), the American Occupational Therapy Association (www.aota.org), the American Physical Therapy Association (www.apta.org), and the BACB (www.bacb.org). If this kind of organization or information does not exist on a given therapy, it's probably best to consider it as recreational.

What Does My Child Need and How Do I Get It?

Social-communication deficits are perhaps the most limiting aspect of autism. In terms of quality of life, it is particularly important to establish a functional communication system that your child can use to interact with others and to benefit from other forms of intervention and treatment. Some programs are effective at teaching children to use expressive language, but leave the child's vocabulary limited to labeling objects. This is not sufficient for the give-and-take of human communication. Instead, it is critical that treatment programs put a communication system in place that teaches children to use it competently with their parents, siblings, other family members, peers, teachers, and other people in the child's community. Addressing areas of deficits early, consistently, and thoroughly is likely to have the most meaningful impact on an individual's quality of life.

How to Access Services

There are a number of ways to access the services that you need for your child.

1. Check the agency in your state that coordinates and offers services for individuals with developmental disabilities, including autism. Learn how services are provided and how you can secure the services that your child needs.
2. Contact the educational system in your state to find out if it provides the services necessary for your child to make meaningful progress, as mandated by federal law, the Individuals With Disabilities Education Act (IDEA). This can include contacting your local education agency (LEA), school district, and the Exceptional Student Service office or school liaison on base.
3. Search for funding resources that are not provided by the public school system. Insurance coverage for autism treatment is increasingly available in many states, and TRICARE now has funding available specifically for autism. Finally, many service providers and therapists accept private payment for treatment.
4. Identify autism treatment providers in your area. If you utilize TRICARE, the Tricare provider directory at www.TRICARE.mil lists TRICARE-authorized providers who treat autism. You may be able to connect with local support groups who can provide a resource list and/or make some recommendations. Further, the Behavior Analyst Certification Board (BACB) website (www.bacb.com) includes a



registry that allows you to search for a behavior analyst by name, country, zip code, city, or state. Many other organizations, including the American Academy of Pediatrics, the American Speech-Language-Hearing Association, and the American Physical Therapy Association, have similar directories.

5. Contact providers, assess their ability to provide what your child needs, and determine how you can access their services (e.g., by the state, insurance coverage, or private pay).

Finally, stay actively involved in your child's treatment program and continually assess and advocate for what your child needs. Generally, therapists and service providers respond positively to parents who participate in their child's program, offer to assist with continuity of care, and are friendly and appreciative.

How to Select Therapists

After selecting a therapy, contact therapists to gain further information about the therapy itself, the therapist, the facility, and the providing agency's philosophy toward and experience with treating children with autism. Ask for a brief consultation with the therapy provider in person or by phone to be able to ask further questions.

Example questions include:

- What are the benefits and risks we can potentially see from this therapy?
- Will the therapy interfere with any of the child's daily treatments/activities?
- How, and how often, is progress monitored?
- Do you have any current or former clients who can serve as references?
- Can you provide research studies about the effectiveness of the therapy?

Once you have selected a therapy, prepare your child for the initial visit by explaining what can be expected to happen in terms they will understand. Observe very closely during the initial visit, and after each of the following few visits, evaluate your child's comfort level with the therapy and the provider to gauge your child's progress. If you are not satisfied or comfortable with the treatment, discuss modifications, pursue different options, or discontinue the therapy. If you decide to discontinue the treatment, remember to share that information with your child's other treatment providers in case they need to make decisions or adjustments to the treatment they are otherwise providing your child.



For more information, visit Appendix A: Finding Providers on [page 71](#).

Comorbid Conditions

A final consideration to keep in mind as treatments and interventions are chosen is that some children with autism have underlying medical or comorbid conditions that can affect their ability to respond, or respond as well as expected, to evidence-based

treatments. Therefore, medically addressing comorbid conditions such as seizures/epilepsy, anxiety, gastrointestinal issues, and attention deficits may optimize other treatment programs.

While there are presently no FDA-approved medications that improve social-communication skills in individuals with autism, two are approved to treat aggression and irritability. It is best to consult with a qualified developmental pediatrician or psychiatrist who can evaluate your child's needs, prescribe medication, and monitor your child's health and overall progress while on the medication. Keep in mind that no medication can "cure" autism; the primary goal of using medication is to remove pain and/or discomfort; make attention more available; diminish irritability; and/or reduce seizures so that children can more fully benefit from behavioral, educational, and therapeutic interventions.

Creating a Record System

Raising a child with autism often entails keeping track of important records that help track the child's progress over time, including diagnostic materials, evaluations, progress reports, Individualized Education Program (IEP), special education procedures and safeguards, general paperwork, etc. To avoid getting overwhelmed and/or losing important documentation, creating an organizational system to help keep track of your documents is critical.

The key to effectively managing your documents is to create a system that works for you. Generally, there are two basic steps to keeping everything organized and easily accessible:

Step 1: Establish a system that works for you and your family.

Step 2: Set up an easy way to maintain the system.

See Appendix B ([page 73](#)) for instructions on how to create and maintain a record system.

Conclusion

For all children with autism, it is important to remember that comprehensive, socially valid and research-supported educational methods lie at the center of any effective package of interventions. Alternative therapies are often supported with anecdotal reports and testimonials, but lack scientific support. Anecdotal evidence should never be confused with researched efficacy. Taking the time to do your homework and selecting the right therapy and provider are key to ensuring your child receives sound treatment. The selection process will be most effective if parents fully consider their child's strengths and needs. You are expected to do your own research and draw conclusions about the appropriateness of a therapy for your child, as you know your child best. It may feel time-consuming, but it is time well spent to ensure your child's progress.

Autism and Military Healthcare Services

From frequent moves to the need for specialty care, military families with dependents on the spectrum often face obstacles in terms of access to and continuity of quality healthcare. Fortunately, the Department of Defense (DoD) has a number of programs and benefits in place to help you overcome these obstacles.

The Exceptional Family Member Program (EFMP) is used by the DoD to support and categorize military families with dependents who have specific medical diagnoses or need specialty care. This program is available to active duty family members.

TRICARE is the healthcare program used by eligible DoD beneficiaries, which generally includes eligible active duty family members, military retirees and their eligible family members, and family members of Reservists who are utilizing TRICARE Reserve Select or TRICARE Retired Reserve. You can access this benefit by using military treatment facilities (MTFs) for care when space is available and, in many cases, can also use TRICARE to see TRICARE-authorized civilian providers. To provide additional support to military families with family members on the autism spectrum, other programs are either required or available, including:

The Extended Care Health Option (ECHO) is a supplemental benefit for special needs active duty military families who have a dependent with a qualifying diagnosis. In most cases participation in ECHO requires registration in the EFMP.

The Autism Care Demonstration (ACD) is the TRICARE program under which eligible military family members with an autism diagnosis can access applied behavior analysis (ABA) services.

This section describes these principal healthcare benefits to which military families with special needs are entitled, or may be entitled.

TRICARE

TRICARE is the healthcare system the DoD provides for active duty and retired uniformed service members, their families, and survivors. In military hospitals, clinics, and healthcare facilities worldwide, active duty service members from any of the seven uniformed services have priority for care. Through TRICARE, family members of uniformed personnel have access to comprehensive healthcare, including family members with disabilities. As outlined in the following, TRICARE combines military healthcare facilities (military hospitals and clinics) as well as TRICARE-authorized civilian healthcare providers to provide care to all eligible beneficiaries.

Each service determines the eligibility status of TRICARE beneficiaries, and this status is maintained in the Defense Enrollment Eligibility Reporting System (**DEERS**).

Regional TRICARE contractors provide support beyond what is available at military hospitals and clinics, and are your go-to resource for information and assistance.

Effective January 2018, TRICARE is now divided into two regions across the United States, with each region having its own TRICARE contractor. The hope in consolidating the regions is to minimize some of the challenges associated with permanent change of status (**PCS**) moves and to improve continuity of care among military dependents. For example, from getting a diagnosis to a pathway to care, both regions have set up specific autism web pages and developed flyers, giving step-by-step information for families whose children are or may be on the autism spectrum.

DEERS

The Defense Enrollment Eligibility Reporting System (DEERS) is a military database that lists everyone who is eligible for TRICARE benefits, including autism services. Keep your DEERS record up-to-date, especially with each PCS move.

DEERS enrollment is a prerequisite for eligibility for autism services under TRICARE.



TRICARE East

Managed by Humana Military

Region includes: Alabama, Arkansas, Connecticut, Delaware, the District of Columbia, Florida, Georgia, Illinois, Indiana, Iowa (Rock Island Arsenal area only), Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Mississippi, Missouri (St. Louis area only), New Hampshire, New Jersey, New York, North Carolina, Ohio, Oklahoma, Pennsylvania, Rhode Island, South Carolina, Tennessee, Texas (excluding the El Paso area), Vermont, Virginia, West Virginia, Wisconsin.

Website: www.tricare-east.com

TRICARE West

Managed by Healthnet Federal Services

Region includes: Alaska, Arizona, California, Colorado, Hawaii, Idaho, Iowa (except the Rock Island Arsenal area), Kansas, Minnesota, Missouri (except the St. Louis area), Montana, Nebraska, Nevada, New Mexico, North Dakota, Oregon, South Dakota, Texas (areas of Western Texas only), Utah, Washington, and Wyoming.

Website: www.tricare-west.com

TRICARE Overseas

Managed by International SOS

Region includes: any geographical areas and waters outside of the United States.

Website: www.tricare-overseas.com

TRICARE Plans

The TRICARE health plan and special program options available depend on who you are and where you live. In addition to consolidating the regions, TRICARE also changed its plan options. As of 2018, families need to enroll in the plan of their choice during the open enrollment period in November–December every year. As is common with many health plans, you will then be locked into the plan you choose for the following calendar year. Once the plan is in effect, it can only be changed if there is a qualifying, life-changing event (such as marriage, birth, or relocation).

The TRICARE website at www.TRICARE.mil offers the best tool for comparing plan options and receiving the most up-to-date information. Since details regarding specific plans and eligibility may change, you should consult the TRICARE website for more details on different options, especially for Retiree and Reserve options. The two plans available for active duty families are briefly described below.

TRICARE Prime

Active duty family members on TRICARE Prime will receive their primary care at their assigned MTF. This includes specialty care, if available at the assigned MTF, or at an MTF within an hour's drive. If specialty care is not available through the MTF or within the one-hour travel radius, the MTF will refer the family to local network providers. If no network providers are available for a specific specialty, TRICARE sometimes approves care with an out-of-network provider at no cost to the family.

TRICARE Prime
TRICARE Prime is the only option for active duty service members. This restriction does not apply to family members or retirees.

TRICARE Prime families need referrals and authorization for most care that is not provided by their primary care manager (PCM). If a family uses the MTF and referrals for specialty care, there are usually no deductibles, no cost shares, and no co-pays. If families choose to see an out-of-network, but participating, provider without a referral and authorization, they will be charged a point-of-service fee.

Families on Prime are eligible for reimbursement for travel if the provider is outside of a certain radius through the TRICARE Prime Travel program. Families who are stationed more than 50 miles from an MTF are eligible for TRICARE Prime Remote, which allows families to use approved civilian providers with no out-of-pocket costs. TRICARE Prime families no longer need a referral to use an authorized urgent care clinic.

TRICARE Select

Active duty family members on TRICARE Select are not required to have a PCM, but may use civilian providers as their PCM. While you can choose in-network or out-of-network providers, out-of-network providers have a higher cost share. Families on

TRICARE Select do not need referrals for specialty care through a specialty MD, but they do need a referral and authorization for ABA services. No referral is needed to use an approved urgent care clinic, and no POS deductibles or cost shares apply when urgent care is provided by a TRICARE network provider or a TRICARE-authorized (network or non-network) Urgent Care Center (UCC) or Convenience Clinic (CC).

The program does have deductibles, cost shares, and co-pays. For active duty and retired family members, there is a catastrophic cap on how much a family has to pay in a year. Once the family hits that cap, their care (including prescription drugs) is largely free for the family for the remainder of the calendar year. These costs are subject to change, so check TRICARE's website for the most recent cost sheets related to your plan.

TRICARE and Mental Health

If you are on either of the TRICARE plans, you do not need a referral or authorization for outpatient, office-based mental health services, except for psychoanalysis. Any services other than office-based outpatient do require a referral. However, you may need prior authorization from your regional contractor for certain services.

The Exceptional Family Member Program (EFMP)

EFMP, a Service run program, serves service members within DoD who have children with special needs, including autism. EFMP is mandatory for all active duty service members who have family members with special needs, and enrollment is required immediately upon identification of a family member's qualifying special need.

EFMP serves two major functions: a personnel function for administrative and management purposes, and a function that provides a range of family support. The personnel function is standardized and mandatory across all services, but the family support function is not. Both functions are discussed in greater detail below.

Personnel Function

Each military branch implements EFMP differently, and even some of the program's goals vary from branch to branch. However, the main goal is to ensure that family members with special medical or mental health needs are not sent to assignments where the MTF or facilities in the surrounding area cannot meet their medical needs. This is not to say that the service member will not be sent to such assignments, but the families should always be in a location that can meet their exceptional family member's needs.



A Note about the Coast Guard

Members of the Coast Guard who are part of the Department of Homeland Security are covered under a program through the Office of Work-Life called the Special Needs Program.

To that end, EFMP maintains documentation of a family member's special needs and uses that information to make personnel assignments consistent with the needs of the family and the availability of required services. For specialty care, each branch sets its own standards for what a workable radius is for monthly or weekly care. For example, if an EFM has a bimonthly appointment with a specialty doctor that is a two-hour drive away, this might still be considered supporting the family. If a family does not feel their current assignment meets their EFM's needs, they can put in a request for an EFMP move.

While EFMP has kept a number of families from being in locations that cannot support their loved ones, there are some realities to the program with which families and service members must contend. Since the EFMP impacts where families are placed, once enrolled in EFMP, the service member may be limited in terms of which assignments are offered to them. Although EFMP is designed not to impede a Service Member's career, some families find that enrollment in EFMP can affect career progression, as the service member is not always able to take assignments that would keep their career moving forward. To avoid this issue, the service member could go on an assignment separately, but in some branches, the family would then only be eligible for one basic allowance for housing. Ultimately, families may appeal decisions if they feel their loved one would be supported in locations they have otherwise been denied.

Family Support

The program includes case management, supplying information regarding a family member's specific needs to agencies that provide managed care support. However, EFMP typically does not contact providers or support agencies directly; families are responsible for doing that themselves. When considering available medical care in an area, EFMP offices may take into account waitlists (which can extend into years at some locations), quality of care, or the number of providers available. This service is not meant to hurt the service member's chances of being promoted, but rather to ensure the family members have access to the care and services they need. Many children with autism need weekly therapies and mental healthcare—some of the most difficult care to access when moving to a new area.

EFMP is not required to take into account area schools or the special education needs of families. This issue has continually been brought up by advocates across branches, as families are sent to areas where the schools that cannot support their children's educational needs or behavioral issues resulting from their autism. Refer to the *Education* section of this guide for information on how to manage school transitions during PCS moves.

EFMP Enrollment

The process for enrolling in EFMP differs slightly across branches, but to ensure access to proper care, enrollment is mandatory if the child or family member is identified as having a special medical or educational need, including autism. Each installation has an EFMP office that processes enrollments. The required forms are as follows:

- DD Form 2792, Exceptional Family Member Medical Summary—for medical issues only
- DD Form 2792-1, Exceptional Family Member Special Education/Special Education/Early Intervention Summary—for educational issues

Please note that enrollment primarily supports the personnel function (see above). For therapeutic intervention and EFMP family support, you must contact the appropriate staff (the procedure varies, depending on the branch of military service). When relocating, it is highly recommended that families hand carry all documentation relating to their EFM to ensure that services can resume as quickly as possible.



Find an EFMP Office

For contact information on EFMP offices in special locations, visit *Operation Autism's* resource directory or follow the Military Installations link on the DoD Military OneSource website.

Informing Your Command

Having a child with autism impacts the family, parental roles, and the amount of time one or both parents will need to dedicate toward the child's development and treatment regimen.

It is important, therefore, to inform supervisors and leaders in your command about your child's diagnosis and its implications with respect to your duty assignment and responsibilities. If you anticipate needing to take time off or modify your schedule, be sure to make your request as early as possible to allow the best opportunity for your command to react and adjust schedules as necessary.



Tell Your C.O.

Please see Appendix C on [page 77](#) for tips on how to effectively communicate your family's unique needs to your Commanding Officer and other leaders within your command.

EFMP by Branch

The following is a brief summary of how EFMP works in each service. For the most recent updates regarding the EFMP, check the website for your branch, or contact your EFMP office.

Air Force

Airmen go through a screening process any time they are up for relocation, and if any of their answers indicate they have an EFM, they will be directed to enroll in EFMP. The Air Force requires updating of EFMP information for any relocation. Once the active duty sponsor enrolls a family member in EFMP, they are Q-coded, which simply means that EFMP will be involved in all assignments unless the Q-code is removed. Once family members are enrolled in EFMP, they will remain enrolled for at least five years from the last appointment they had for specialty medical care. Even if the EFM is no longer receiving specialty care, certain diagnoses will keep them in EFM status.



The Air Force EFMP program is divided into three subprograms, all with different functions.

- EFMP-Medical (EFMP-M) works at the member's current base to gather all medical and educational information on the EFM that would be relevant when considering a move. A face-to-face meeting is also set up for base medical personnel to meet with the EFM before a potential PCS.
- EFMP-Assignments (EFMP-A) work to ensure airmen are assigned in locations that support both the accomplishment of the mission and the well-being of families.
- EFMP-Family Support (EFMP-FS) offers family support and community to EFMP families. This can include family-friendly activities, support groups, and coordination with the base's school liaison officer to ensure clear communication with local school districts and resources for families so they know their children's educational rights.

Army

The Army primarily uses its EFMP program to ensure families are only sent to locations where the EFM can be supported. This does not mean, however, that the soldier may not be sent somewhere unaccompanied. The Army relies on families to self-identify as EFMP or, when going overseas, EFMP screening is implemented. If special medical needs are identified in this process, families will be required to enroll in EFMP. If a family member is enrolled in EFMP, the soldier's record will be flagged as EFMP when assignments are considered. Sponsors are responsible for keeping all enrollment information current and providing updates whenever there are changes.



Navy

The Navy EFMP program is one of the few that categorizes EFMs based on the severity or type of special needs. Upon identification of a special need (by self-identifying, during a suitability screening, or identified by the MTF), sailors enroll with their EFMP office or electronically using the Navy Family Accountability and Assessment System. Upon enrolling, EFMs are categorized into one of the following groups:



- Category I—for monitoring purposes only
- Category II—to pinpoint to specific geographic locations
- Category III—no overseas assignments
- Category IV—major medical areas in CONUS
- Category V—homesteading
- Category VI—temporary enrollment; update required in 6–12 months

For some of the more severe categories, the Navy will only send families to assignments considered capable of caring for that category of need. Sailors can talk to their detailer regarding other options for assignments. It is important to keep EFMP category and other information up-to-date so that assignments can be coordinated to meet the family's needs.

Navy EFMP also offers EFMP liaisons and EFMP coordinators. EFMP liaisons are located at Fleet and Family Support Centers, where they provide information, referral, and system navigation to families with special needs. They also link families with available military, national, and local community resources, provide non-medical case management, and develop and maintain Individual Service Plans (ISP).

EFMP coordinators are located at the MTF, where they oversee the identification and enrollment of eligible service members and their families. They also provide enrollment forms, offer help with completing the necessary forms, review completed forms for accuracy, and forward the enrollment package to the Central Screening Committee. Families need to update their EFMP enrollment every three years or with any change of status.

Marine Corps

The Marine Corps uses EFMP both when considering assignments and for family support. To enroll in EFMP, the active duty sponsor should visit their local EFMP office or email enrollment questions to headquarters. Once enrolled, families go through an update process every three years. The Marine Corps relies on self-identification or suitability screenings to identify a family member with a special need.





How EFMP Coordinators Can Help

The Marine Corps provides a detailed listing of the ways EFMP coordinators can help families at www.usmc-mccs.org/services/family/exceptional-family-member/

Marine Corps families are assigned a family case worker, who provides information and support at least quarterly. The Marine Corps EFMP also works to review all PCS orders to ensure families will have access to necessary medical care and educational supports within reasonable distances based upon frequency of required care; support families before, during, and after a PCS move to ensure a seamless transition; identify family members who are eligible to be considered for priority housing and/or housing

accommodations/modifications, in accordance with appropriate federal law; and endorse eligible family stabilization requests, when appropriate, to support unique care requirements.

The Marine Corps uses four enrollment categories, or “Levels of Need,” as guidelines when making assignment decisions, with Level of Need 1 considered least severe and Level of Need 4, the most severe.

Coast Guard

The Coast Guard does not have EFMP, but they do have a similar program called **SNP**, or the Special Needs Program. SNP is implemented through the Coast Guard’s Office of Work-Life programs. SNP is a comprehensive, coordinated, multidisciplinary approach to community support, housing, medical, educational, and personnel services for Coast Guard families with special needs. Efforts are made by SNP to ensure that sponsors with a dependent family member(s) with special needs are assigned to duty stations where access to, and availability of, medical and community special needs services are validated. Like EFMP, SNP is mandatory for active duty members if a qualifying need is identified in one of their family members. For enrollment and updates to enrollment, families should contact their Office of Health, Safety and Work-Life family resource specialist.

Respite Care by Branch

Military branches typically offer some form of respite care or reimbursement through their EFMP. However, respite care through EFMP is dependent on available funding and eligibility standards, which vary by branch, and there may be long waitlists for care. Basic information on each branch’s respite care options and enrollment is included below for 2019.



For updates on respite care, visit *Operation Autism’s* “Healthcare” section.

Air Force EFMP:

- Offers up to 40 hours per month
- Includes siblings

The Air Force offers respite hours to qualifying families through Child Care Aware. Whether or not a family qualifies for respite depends on severity, level of needs, and disability. For more information and to start the enrollment process, call the EFMP respite line at Child Care Aware or visit their website.

Army EFMP:

- Offers up to 25 hours per month
- Does not include siblings

Army EFMP respite care was reduced in 2018, and eligibility standards were tightened. Only certain levels of severity qualify for care. For more information on Army EFMP respite, contact their local EFMP office.

Navy EFMP:

- Offers up to 40 hours per month
- Includes siblings

Navy EFMP offers respite through Child Care Aware. For more information or to enroll in the Navy EFMP respite program, contact the EFMP respite line at Child Care Aware or visit their website at www.childcareaware.org.

Marine Corps EFMP:

- Offers up to 20 hours per month
- Does not include siblings
- Does not include adult EFMs

The Marine Corps offers respite reimbursement for Levels of Need 3 and 4, not respite care. Each installation sets its own procedures for reimbursement for care. To inquire about reimbursement for respite care, contact your installation's EFMP office.

Coast Guard:

- Offers respite through a program called The Coast Guard Mutual Assistance Respite Care Program
- Offers short-term care while families work to get their own care in place
- To be eligible for respite, the family member must be diagnosed with a profound disability or a serious or terminal illness that requires ongoing care and attention and must be enrolled in the Coast Guard special needs program (SNP).

ECHO

ECHO is a supplemental benefit for active duty (or activated National Guard/Reserves if activated for more than 30 days) military families with special needs. ECHO offers certain services and supplies that are not available through the basic TRICARE program and will cover up to \$36,000 a year in qualifying expenses.

In order for families to qualify for ECHO, their dependent with special needs must:

- Have a qualifying diagnosis (as determined by the regional managed care support contractor)
- Be enrolled in EFMP

Registration in ECHO takes place via the TRICARE Managed Care Support Contractor (MCSC) in your region. Supplies, equipment, and services covered by ECHO are listed on the *TRICARE.mil* website. A referral from doctors or therapists showing the need for said supplies or equipment is required. If families have difficulty getting referrals approved, they may contact their region's information line for more guidance. ECHO also offers case management for some conditions/disabilities; this may be requested by calling the region's information line. Note that case management may also be available to non-ECHO families with complex medical needs.

What Benefits Can ECHO Offer My Family?

Active duty families must be registered in ECHO for their children to receive ABA services through the Autism Care Demonstration (ACD) discussed in the next section. However, ECHO itself does not pay for ABA services. For any month that the ECHO benefit is used, families must pay a cost share that is prorated based on the active duty member's rank. ABA services are not considered ECHO services, and therefore are separate from the ECHO cost share.

ECHO's financial assistance may be used for a variety of services and equipment, including:

- Assistive services (e.g., qualified interpreter)
- In-home respite care services (please see section below)
- Home healthcare (please see section below)
- Medical and rehabilitative services
- Training for assistive devices
- Special education
- Transportation in limited circumstances
- Institutional care when a residential environment is required
- Equipment
- Durable equipment, including adaptation and maintenance
- Assistive technology devices

What Is Included in ECHO Home Healthcare and ECHO Respite Care?

In addition to addressing the needs of the EFM, ECHO addresses the needs of the caregiver. In most cases, this involves rest or time away from the “care environment.” ECHO’s additional benefits include ECHO respite care and ECHO home healthcare. Respite care provides relief for caregivers of EFM, including family members with autism.

ECHO Respite Care:

- ECHO respite does not cover siblings and is not to be confused with EFMP respite, which is offered through some of the military’s branches.
- ECHO beneficiaries qualify for 16 hours of respite care a month, which are to be administered in the home by a TRICARE authorized home health agency. During respite hours, the caregiver may leave the home.
- Respite care is authorized only when the beneficiary is receiving some other ECHO benefit during the same month (use of ABA qualifies a beneficiary for the respite benefit).

ECHO Home Health Care (EHHC):

- EHHC includes extended home healthcare and respite care for caregivers of an EFM who is homebound.
- Under EHHC, licensed or registered nurses provide skilled home healthcare for more than 28 hours a week.
- Under EHHC, respite care may allow for a maximum of eight hours, five days per week, which may be used as a sleep benefit.
- Respite care under EHHC is not to be used during the same month as ECHO’s respite care.
- Members should speak to their regional contractor or TRICARE area office to determine their eligibility and maximum monthly limit for EHHC benefits.

Will ECHO Benefits Follow My Family From One Location to Another?

Yes, ECHO benefits automatically transfer when a family’s active duty sponsor is reassigned, and stay with the family regardless of moving between contractors.

The Autism Care Demonstration

Once you are enrolled in EFMP and registered in ECHO, you may be eligible for services under the Autism Care Demonstration (ACD) benefit—a program under TRICARE that allows families to access ABA services for their children diagnosed with autism. As of 2019, to qualify, children need to have an autism diagnosis given by a diagnosing specialist (consult your insurer for a full, updated list of accepted specialists). If a general physician or PCM gave the initial autism diagnosis, the child can still start ABA services, but will need a diagnosis from a qualified specialist within a year.

TRICARE requires the administration of three outcome measures in order to receive prior authorization for ABA services. These measures are the Vineland Adaptive Behavior Scale, Third Edition (Vineland 3), the Social Responsiveness Scale, Second Edition (SRS-2), and the Pervasive Developmental Disability Behavior Inventory (PDDBI). ABA services may start after the initial assessment and submission of the PDDBI. To continue ABA services and receive reauthorization, the PDDBI and two additional outcome measures must be submitted in regular intervals. The PDDBI is required every six months. The Vineland 3 and SRS-2 are required within the first year of the initial autism diagnosis and every two years in conjunction with the two year referral for continued services. These measures are not diagnostic and are meant to measure progress or lack thereof, in addition to scoring the severity level of focused skills. The Vineland 3 and SRS-2 may be administered by either the specialized autism diagnosing provider or in some cases by the ABA provider. See TRICARE's website for a full list of qualified professionals able to administer these measures. These measures are used as one component of several to determine if the current/proposed treatment plan is appropriate for the child or needs to be modified. Families may contact the regional contractors if they are experiencing TRICARE issues that are keeping them from receiving ABA services for their children diagnosed with autism.

To find an ABA provider, ask the child's PCM for a referral for ABA services. The regional contractor will issue an authorization with a local ABA provider. Families can also search for ABA providers using the Provider Directories on the Health Net Federal Services (HNFS) or Humana Military websites. Note: The ACD is available overseas in limited locations; contact your regional call center for more information.

The ACD has been extended through 2023. It is expected to undergo significant changes in the coming years in order to make the program more comprehensive and centered around the family. These pending changes include case management, integration of speech and occupational therapies as part of comprehensive treatment plans, increased access to respite care, and a stronger focus on outcomes.

Medicaid Waivers

Section 1915(c) waivers, also known as HCBS waivers, allow states to provide home- and community-based services (HCBS) to individuals in need of long-term care. While not military-specific, in certain states services accessed through Medicaid waivers may be established more quickly than military-specific services. The waivers may also cover a more extensive range of services than military-specific services alone. Medicaid waivers do not transfer when moving to a new state, and eligibility, services provided, and waiting lists for these waivers all vary by state.

Transitions

For children with autism, who often crave routine and “sameness,” the frequent moves that characterize the lives of most military families can pose particular challenges. This resistance to change often leads to anxiety and disruptive behaviors. But if given ample time to anticipate, understand, and practice dealing with anticipated changes, most children can learn to successfully cope with transitions. In this section, we will look at ways to help children with autism do just that.

What Do We Mean by *Transitions*?

The term *transition* can refer to minor changes such as taking a different route to school or having to reschedule an appointment, as well as more significant, life-changing events, such as starting a new school year or moving to a new community.

What is unique to children with autism is that the “size” or significance of the transition is generally not correlated with the intensity of the challenging behavior they exhibit. As a result, minor changes in daily routine can lead to highly disruptive meltdowns.

Tips for Successfully Managing Change

Here are some things you can do to help your child better handle both expected and unexpected changes:

- Establish and maintain a daily routine using visual supports (e.g., timers, photos, videos, and mobile apps for portable, picture-based schedules) and organizers (e.g., calendars, checklists, daily schedules).
- For consistently difficult transitions, consider verbally or pictorially walking your child through the upcoming transition, including what reward they will earn at the end (e.g., in 2 minutes we are turning off “Thomas the Tank Engine,” but if you do so nicely, you will get “X”).
- Rehearse new settings or changes to routine.
- Identify and prepare for possible changes in advance.
- Have a contingency plan for meltdowns. Be sure this plan can be implemented consistently by all involved and across different settings.
- Ask other caregivers, neighbors, and teachers to provide support.



Go to *Operation Autism* for a list of free online parent training resources related to transitions. operationautism.org/transitions/

In the following sections, we will look at some of the more common transition challenges for children with autism as well as challenges that are more unique to military families.

Relocation

Moving can be a difficult transition for anyone, but it's especially challenging for children with autism as it entails significant and sudden environmental changes. Here are some tips on how to prepare for the transition.

3-Step Planning Process

Step 1: Collect Information About the New Location

Begin collecting information on the new location as soon as you learn that a move might be on the horizon. Here are some suggested places/organizations to research.

Local School Districts

Review the websites of local school districts, looking specifically for information on autism services and other programs that might be relevant to your child. Follow up with a call to the school district's special education office to learn more about the types of educational placements available, training and support available to teachers of students with **autism spectrum disorder (ASD)**, and the district's approach to addressing behavioral issues. Once you have found a potential school, pay a visit and ask critical questions.

Do not assume that the services and supports established in your child's Individualized Education Program (**IEP**) will naturally and smoothly follow, despite the provisions of the Individuals With Disabilities Education Act (**IDEA**). It is not uncommon for military families to have to seek command and legal support as they battle to protect and ensure the continuation of their child's educational rights.

ABA Service Providers

Get a list of **ABA** providers from the regional contractors. Call the ABA providers and ask questions about the types of services that are available (clinic vs. home-based) and the credentialing of staff members. Enlist the regional contractor's support for identifying available providers and resources. If your child is assigned a case manager, make sure to notify them as soon as you are aware you will be moving. The case manager can make contact at the new location and assist with a smooth transition.



Community-Based Support Services

Contact state developmental disabilities councils and vocational rehabilitation agencies as needed to help obtain services for your child.

Step 2: Gather Information About Your Child

Ensure you have handy all the information that you will need on your child as you settle into the new location. On moving day, have a designated spot for the records and take them with you to prevent their misplacement or prepare for any unanticipated delays due to movers. Examples of records you might want to have on hand include a copy of a signed IEP, medical documentation of disability, and any information on allergies and/or other medical conditions. Be sure to include safety plans to address the medical conditions.

Step 3: Get Ready for the Transition

Once you know that the request for orders is coming, start making definitive arrangements for the transition to the new installation. This includes contacting the organizations you researched earlier to make final plans for your child's arrival and arrange to start services. You will want to contact the following:

- Exceptional Family Member Program (EFMP)
- School liaison officer
- Local school district special education office
- Primary Care Manager
- Case Manager (if one is assigned)
- Therapy providers
- Community-based service providers (e.g., vocational rehabilitation, intellectual/developmental disabilities agencies)

One Last Tip: Take Advantage of Word of Mouth

Other parents and families can be excellent sources of information about resources and services. If you are not able to meet up in person, social media networks offer great ways to connect with other military families with children with autism. For instance, you could join the closed Facebook group for military families at the new installation.

Timeline Tools

The following tools were developed by the military as guidelines for general moves, but they are also helpful in your particular situation, as a way to make the transition for your child with autism as smooth as possible.

Plan My Move

<https://planmymove.militaryonesource.mil/>

This online moving tool provided by Military OneSource generates a personalized checklist based on the parameters of your move. The checklist can be customized based on your role and the circumstances of your move, including whether you need continued EFMP services.

For an expanded checklist tool that can help prepare for you and your child for the autism-related tasks associated with moving, see Appendix D.

MilitaryINSTALLATIONS

<https://installations.militaryonesource.mil/>

MilitaryINSTALLATIONS works hand in hand with *Plan My Move*, providing maps and contact information for programs and services, links to comprehensive location overviews, and points of interest for military installations worldwide.

Military Kids Connect

<http://militarykidsconnect.dcoe.mil/>

This online space is designed for children ages 6–18 to help them deal with some of the anxiety and challenges caused by a permanent change of station (PCS) move and change of schools through connecting with other children and engaging in age-relevant activities.

How to Prepare for the Move

Here are some autism-specific strategies you can use to help your child anticipate and prepare for moving day.

Use Social Stories™ to Prepare for Moving Logistics

As soon as you get your orders for a new duty station, begin a **Social Story** with your child. A Social Story is built around an event, places your child as the main character, and uses pictures and words that your child can understand. You can use your child's name or simply use "I," as if the child is reading the story in the first person. If possible, work together with your child to create a storybook, complete with lots of pictures and maps, that can be read frequently prior to your move. This will ease some of the anxiety tied to moving: flying in an airplane, having the movers box up your child's belongings, moving into a new house, and having a new room. Be sure to discuss and have pictures of the new sights, sounds, people, and smells that will be associated with your move.

Use Visual Schedules to Help Anticipate the Event

If your child thrives on a daily routine, it may help to have a picture schedule and calendar in place. At the same time each evening, have your child cross off another day on the calendar with a big "X." This will help them understand the concept of days and "see" the moving day getting closer. Use the picture schedule to depict upcoming moving events: the day the movers will come, when you will move into temporary lodging, when you will get on an airplane or go on a long car ride, etc.

Share Information Cards With People Who Are Unfamiliar With Autism

Amid all the stress of traveling during a PCS, you may encounter strangers who do not know what autism is. Have a few information cards on hand that explain autism, just in case you find yourself in the middle of a sensory-based meltdown in front of unsuspecting, and possibly judgmental, onlookers.

Carry Proof of Your Child's Disability

At least three months prior to your PCS, get a letter from your child's physician verifying and specifying your child's disability. You may need this for an airline, hotel, or other event that occurs during your move.

Use Your Child's Preferences to Your Advantage.

If your child has a preference for a certain color of cup, type of plate or eating utensil, don't forget to pack these items. Several weeks prior to your trip, make a list of items your child cannot be without on a daily basis. You will thank yourself later!

Practice, Practice, Practice!

If your PCS involves staying in a hotel or temporary lodging facility, you may want to prepare by staying one night in a nearby hotel for practice. If your child is a picky eater or if the thought of eating out in a restaurant every day is daunting, you may want to request a room with a kitchenette so you can make your own meals.

Travel

You've spent countless hours helping your family anticipate and prepare for the transition of moving into a new home and community. For the big moving day, here are some helpful suggestions for keeping your child occupied and happy while traveling.

By Car

Plan smart, and be strategic while on the road:

- Use a behind-the-seat organizer to store your child's belongings. If this is within your child's reach, you will be able to focus on your driving and maintain an organized car.
- Take frequent rest stops. Allow your child to run around outside if it is safe to do so. If your child needs a visual cue to know when the next stop will be, use timers.
- If you know your child enjoys playgrounds, research playgrounds along your route in advance. Tell your child that the next stop will be at a playground so they will have something to look forward to.

- Try to plan your trip around times of the day that are routine nap times or bed times for your child.
- Get a map and draw a line along your route. Show your child each city and state you are passing through. Use a line to show your child where you are “now” and how far you have to drive before you get to your destination.
- Make a customized activity bag. Give your child a couple of items at a time so that the novelty does not wear off too quickly.
- Pre-load a tablet device with games and kid-friendly television shows and movies.
- Bring headphones with a variety of music, to include calm instrumental songs for relaxation, kid-friendly tunes, and any other favorites.
- Bring sensory toys, such as vibrating massagers or weighted blankets.
- Carry a handy bag of maintenance items, such as hand sanitizer, flushable wipes, medicine, extra headphones and chargers, etc.
- Even with all of these preventive strategies, you can’t ensure a perfect trip. Consider your child’s needs and set realistic goals for how far you travel each day. Break the trip up if possible. Trying to rush travel can lead to more stress and anxiety and increase the chances for something to go wrong or for you to forget something. Take some deep breaths and relax.

By Plane

When traveling by plane, you don’t have the same flexibility in terms of accommodating your child’s needs as you do when traveling by car. Below are ideas for how to make the experience go as smoothly as possible.

Things you can do in preparation for the flight:

- Try to minimize the number of connecting flights. It is easier to find a direct flight if you book early.
- If this is your child’s first time on an airplane, be sure to discuss the sights and sounds of the airplane ride in your Social Story.
- Contact the airport where you will be departing from, explain your child’s diagnosis, and request a time to come to the airport to do a “dry run” of what your child should expect. Take pictures while you are there and add them to your Social Story.
- If there is a layover at an airport, research the airport in advance to see if there is a child’s indoor play area. If available, let your child run around, climb, play, and slide in order to get some energy out and be ready to sit for the next leg of your trip.
- Some airports have a USO lounge for military personnel and their families that provide free amenities, including snacks, Internet access, and TVs. To be admitted, be sure to have your military and/or dependent ID cards handy.
- If your child is a picky eater or has food allergies, and if your airline will be serving a meal during the flight, contact the airline in advance to ask if they offer special meals or have an alternate meal option. Do not forget to plan for favorite snacks ahead of time as well.

Tips on what to do on the day you travel:

- Arrive at the airport in plenty of time for your flight. Explain to the airline at check-in that your child has autism and request bulkhead seating (at the front of the economy section). Provide proof of diagnosis. The front seat will give you a little extra leg room and will likely put you close to a restroom. If looking out the window will be interesting for your child, request a window seat. On the other hand, if your child becomes anxious at the thought of being in the air, request an aisle or an inside seat. If the flight will not be full, request a row to yourself.
- Go through the security checkpoint early to avoid the crowds. Give the security guard an information card that explains autism and increases their understanding of why your child may not follow the instructions.
- Board the airplane at the first call for special boarding. Traveling with a child with autism requires extra time to find your seat and get comfortable. This will also give you extra time to briefly talk to the airline attendant(s) about your child's special needs. Give them an information card if necessary.
- Children with autism often have difficulty coping with the "popping" of their ears as the airplane ascends and descends. Give your child gum, hard candy, chew toys, or a drink during this portion of the plane ride; this encourages swallowing and reduces the effects of their ears popping.
- Bring earplugs or noise-canceling headphones for your child.

Preparing for emergencies in case your child wanders away:

- If you have a child who is a frequent wanderer, it may greatly benefit you to invest in a type of personal locator in the form of a watch or attachable belt unit.
- A less expensive way to track your child is to get a military-style dog tag or a bracelet made with your child's information (name, age, parents' names and contact information, allergies, and other pertinent information, such as specifying if your child is nonverbal).
- Another option is to print the same information on a laminated index card and attach it to your child's shirt or shoelace.
- For an older, verbal child, teach the child their name, age, parents' names, and a phone number to call. Role-play a scenario in which your child accidentally gets lost. Discuss the information booth typically found at airports and how your child can locate one. Write key words down for your child on an index card, such as "Information" and "Lost."
- Carry a recent photo of your child to show to security personnel in case your child wanders.

Extended Separation

Military duty often requires service member to be away from home for extended deployments for training or combat operations. Depending on your child, the immediate impact of such absences may vary from near-calamitous to barely notice-

able. Nevertheless, there are some things you can do to help mitigate the effect, including:

- Create a “countdown calendar” with your child to mark the days until you or your spouse is to be deployed. If possible, include dates on the calendar for emails, Skype, phone calls, and the eventual return. Reverse the process when a parent deploys, and create a “Homecoming Calendar” to mark the time until the deployed parent returns.
- Develop a series of short videos of the soon-to-be-deployed parent and show them to your child on a regular basis.
- Encourage siblings, extended family members, or even neighbors, to, at times, fill in for the deployed parent (e.g., during a trip to the doctor).

Independent of the impact on the child with autism, the impact of deployment on the parent who remains behind is significant. Some recommendations for how you, as the stay-at-home parent, can best deal with the challenges of deployment include:

- If you know a deployment is pending, plan ahead. Determine what additional help you are going to need and prioritize your needs. See if your child’s school has an after-school program they can attend. Recruit volunteers from your community of faith, extended family, and neighbors to help out when you most need it.
- Learn to accept the fact that despite your best efforts, there will be days that are “less than perfect.” All that can be expected of you is your best effort, and on days when that does not seem to be enough, do what you can and move on.
- Network with other parents—both inside and outside of the military. Other parents are often great sources of ideas and strategies to make each day go as smoothly as possible.
- Find time to take care of yourself. Whether it is regular exercise, reading for pleasure, meditation, carpentry, or anything you prefer, the more you can work the activity into your daily or weekly schedule, the better you will be able to deal with stressors associated with a pending or current deployment.

Adulthood

IDEA, the federal law governing special education services, requires IEP teams to help youth with disabilities plan and prepare for a specific kind of transition—the transition from school to adulthood. This type of transition planning must be in effect when your child turns 16, though some states mandate an earlier age. Through this process, youth with autism and their families develop a plan for life after high school and start to make decisions about employment, college, independent living, and community involvement. Along the way, youth



Suggested Reading

OAR’s *Life Journey Through Autism Series: A Guide for Transition to Adulthood*.
researchautism.org/resources

with autism participate in instruction, activities, and experiences that help them gain the skills they will need to achieve their goals for the future.

The transition from school to adult life is often challenging and complex for military dependents with autism, particularly if deployments or relocations occur during this period. Here are some tips for making it easier:

- Inform members of the IEP team and adult service providers about the work experiences your child participated in during high school.
- Ask for contact information and letters of recommendation from individuals who worked with your child in the community and at school. This information can be helpful to develop job applications and future plans.
- Help your child think about their strengths, skills, interests, and goals for life after high school. Support your child in communicating this information to the new IEP team.
- Be sure to make contact with the local office of the state vocational rehabilitation agency (the organization tasked with helping individuals with disabilities find employment) and the state developmental disability council (the organization that supports self-determination and inclusion for individuals with developmental disabilities).

Leaving the Service

Regardless of why you are leaving the service, this move is a major life transition for you, your family, and your child with autism. At this time, it is important to determine which of your child's current healthcare services can continue or may be transferred after your change of status. Even if you are no longer eligible under **TRICARE**, you will want to ensure continuity of care, whether within the TRICARE system or not. Be sure to include a liaison with TRICARE as one of the items on your personal Separating From Service Checklist.

Education

The often complex and transitory nature of military life can be challenging in terms of establishing and maintaining the educational program of any child. But for a child with autism, transitioning from one familiar school, teacher, and classroom setting to another presents a particular challenge due to the core characteristics of the disorder. Fortunately, there are steps you can take to ease the transition and continue to support your child's development.

By law, all students, regardless of disability or the professional status of their parents, are entitled to the same legal rights to a free and appropriate education (**FAPE**). In the following, we will take a look at educational options as they pertain particularly to a student with autism, with a major emphasis on the Individuals With Disabilities Education Act (**IDEA**) and its protections for children with disabilities.



For more details on education, refer to OAR's guidebook, *Life Journey Through Autism: Navigating the Special Education System*.
researchautism.org/resources

IDEA: A Brief Legislative History

Congress passed the Education of All Handicapped Children Act in 1975 and reauthorized it in 1990 as the Individuals With Disabilities Education Act (**IDEA**). This is not a **TRICARE** or Department of Defense (**DoD**) program, but is available to all citizens of the United States. The legislation is actually an extension of the civil rights movement and guarantees that all students with disabilities will be provided a **FAPE**. It also states that students with disabilities should be placed in the least restrictive environment (**LRE**), where they can make progress toward achieving the goals established in their Individualized Education Program (**IEP**). The intent of the law is to ensure that children with disabilities are educated with children who are not disabled to the maximum extent possible.

IDEA also sets forth the requirements for an educational team, of which families are critical members along with school staff, who are required or requested to participate. No **IEP** decision should ever be made without your participation. Finally, this law stipulates that students with disabilities must have an **IEP**, which describes the student's current level of functioning, their goals for the year, and how these goals will be supported through special services and supports.

Because the challenges associated with autism affect many key aspects of development, the impact of the disorder on education, learning, and overall participation in the educational setting is often profound. Therefore, children with **autism spectrum disorder (ASD)** are considered to have a disability under the **IDEA** guidelines and,

therefore, are legally entitled to an IEP in order to access a FAPE. However, the presence of a diagnosis does not automatically mean that a student is eligible for an IEP. Every student must be determined “eligible” by their educational team, and the process of determining eligibility can take up to 60 days.

IDEA Components and Your Child’s Rights

IDEA is a federal law pertaining to developmental services for children 0–3 years old (Part C – Infants and Toddlers with Disabilities) and educational services for children 3–21 years old (Part B – Assistance for Education of All Children With Disabilities).

Part C

Under Part C of IDEA, local authorities are required to provide a free evaluation when parents of children 3 years old or younger express concern about their child’s development. While this free evaluation will not provide a diagnosis, it will establish what services and therapies may help the child and, therefore, is an important start.



For a list of Part C coordinators by state, go to www.ectacenter.org/contact/ptccoord.asp.

Once referred to an Early Intervention Services (EIS) agency for an evaluation, a service coordinator will be assigned to your family. The coordinator will gather information from your family, help arrange the appropriate assessments and evaluations for your child, as well as help you to create an Individualized Family Service Plan (IFSP). The IFSP describes the child’s strengths and weakness as well as family concerns. The plan also lists services to be provided, to include who will provide the services, where, how often, and for how long.

An eligibility meeting will be held after the appropriate assessments and evaluations have been performed to see if your child qualifies for EIS. If your child is found to be eligible, then you and your support team (including your EIS service coordinator) will write an IFSP.

It is important to note that military families living on a base where there is a DoD school will receive services from the Educational and Developmental Intervention Services (EDIS) and from the local Military Treatment Facility (MTF). All other military families need to contact their local EIS agency.

Part B

Part B of IDEA establishes guidelines for educating children with disabilities between the ages of 3–21. A referral to evaluate your child can be made by you, a teacher, doctor, or child development program. If your child is deemed eligible for special education, an IEP will be created. Your child’s IEP will be evaluated and modified on a yearly basis, with an extensive review performed every three years.

In summary, IDEA governs the way school districts must find, evaluate, develop, and implement special education programs. IDEA requires specific procedures from the identification of a student who may require special education through implementation and ongoing evaluation of that student's educational program. That process includes the following steps:

1. Identification of the student by the school or the family
2. Initiation of an evaluation to determine eligibility
3. Meeting to determine the student's specific eligibility
4. Development of the IEP
5. Implementation of the IEP
6. Documentation and ongoing review of the IEP
7. Formal annual review and revision of the IEP
8. Determination every three years by an educational team whether a new evaluation needs to be conducted

Evaluation and Eligibility

Obtaining initial eligibility can be time-consuming, but it is important for clearly establishing your child's specific areas of strength and need. The IEP data will be updated annually with information based your child's performance at that time. IEPs must be more comprehensively updated in tri-annual evaluations (every three years when the educational team determines if a new evaluation is required).

Once the evaluation is complete, the educational team convenes to discuss evaluation results and assign an educational diagnostic category, such as autism spectrum disorder (ASD), emotional disturbance (ED), or specific learning disability (SLD). Some states assign multiple diagnostic categories where appropriate. Remember, you are a part of the educational team and must be included in all of these decisions. Even though you are part of the educational team, you may not always agree with the evaluation or placement decision. In that case, further discussion should occur.

What Assessments Will Be Used in My Child's Evaluation?

Typically, a meeting takes place before evaluations are conducted, at which the educational team determines which assessment tools will be helpful in understanding how and why a child demonstrates the difficulties they do at school. Such a meeting is not required; however, Prior Written Notice (PWN) about any requests for evaluations or changes to your child's IEP must be given. Parents must give informed written consent before the school district conducts any assessments. The educational team may use assessments that measure cognition, academics, social-emotional domains, and areas relevant to related services (occupational therapy [OT], physical therapy

[PT], and speech-language pathology [SLP]). The school psychologist, social worker, classroom teacher, and/or SLP are some of the educational professionals who conduct educational assessments. In addition, an audiologist may complete hearing tests, and the classroom teacher will give input about your child's academic progress and classroom behavior.

You will also be asked to provide input to each specialist throughout the process. Then, one person on the evaluation team will coordinate all the information, and the team will meet to make recommendations to the IEP team. Some school districts include evaluations that have been conducted by outside sources (e.g., if you've already had a diagnostic team conduct a cognitive assessment and an autism diagnostic evaluation of your child). You should always feel comfortable asking the team questions about different assessment tools, how they will be conducted, and what the results will mean for your child. Also, if you have heard of an assessment that you think would be helpful to your child and the team, ask the team about that assessment.

What Should I Bring to Team Meetings Regarding Evaluation and Eligibility?

To be an effective advocate on behalf of your child, please bring the following to evaluation/eligibility meetings, as appropriate:

- Evaluation tools you would like to provide to the educational team
- Reports generated by other service providers (e.g., primary care provider (PCP) documenting a medical diagnosis of autism, private SLP's progress reports)
- Materials for recording meeting notes and documentation (e.g., paper, pen, laptop)
- Friend or family member to provide support or help take notes

What's the Individualized Education Program (IEP)?

Once your child is determined eligible for special education, they have specific rights governed by IDEA legislated by Congress. According to IDEA, students with special needs:

- Must be provided with a free and appropriate public education (FAPE)
- Should be placed in the least restrictive environment (LRE), and
- Must have an Individualized Education Program (IEP).

The IEP is a blueprint for all educational programs and supports that will be in place for your child in school for the following year. You will participate in the development of an IEP, which should be tailored to the abilities and needs of your child, with a multidisciplinary team (MDT) of education professionals or educational team. The educational team either must or can consist of special and general education teachers, SLPs, OTs, school psychologists, and, of course, you—the parents.

Finding the Best Educational Placement for Your Child

What Are the Different Types of Educational Placements?

It is important to understand the four main types of placements that exist and how they work so that you can better participate in your team's discussions about your child.

The intent of IDEA and its accompanying LRE requirements is that a student should participate in the general education environment as much as possible without interfering with that student's ability to access a FAPE. Each of the following types of special education placements has its supporters and critics. However, the most important thing is determining what is best for your child, keeping in mind that it may change over time. In that connection, it is important to remember that special education is a collection of services, not a specific physical place.

General Education Setting

In the general education setting (also known as "inclusion class" or "mainstream placement"), a student is in a regular class with their grade-level peers. In this scenario, the general and special education teacher should work together to develop accommodations and modifications to provide the student with access to the general education curriculum. While in the general education setting, the student may receive instruction from the general or special education teacher or may receive assistance from a paraprofessional if designated in the IEP.

When a general education placement is the best match for a student's needs, the student participates in a more complex, natural setting that affords almost continuous opportunities for **generalization**—that is, applying new skills to different people, environments, and settings—which is critical for students with autism. When appropriate, related services such as OT, PT, and SLP may be provided. These services will be determined by the IEP team and documented in the IEP.

Special Education Placement

Some students' educational needs are too complex and intense to be adequately met in the general education setting, so these students thrive best when receiving specialized attention in a more controlled setting. In such cases, students complete grade-level work in targeted subject areas in a setting frequently called the "resource room" provided by a special education teacher, who works with a small group of students and utilizes instructional methods that will foster meaningful progress for those students. Related services (OT, PT, SLP) may also be provided in the resource room setting or in a different room outside of the general education environment. The child's IEP designates what percentage of the school day should be spent in the resource room vs. the general education classroom.

Self-Contained Educational Placement


Placement in a self-contained classroom means that the student is removed from the general education classroom for all academic subjects to work in a small, controlled setting with a special education teacher and paraprofessionals. Students in a self-contained class work at various academic levels with different textbooks and curricula, using a variety of research based teaching strategies and materials. While some students continue to access some general education settings (e.g., lunchroom, recess, and/or special classes like art, music, and library), other students are “100% self-contained,” meaning that they are never, or very rarely, included in the general education setting. Some self-contained educational placements require a student to go to a school outside your neighborhood.

For a student who has autism and whose team has determined partial inclusion in settings that include so-called “specials” and recess, the inclusion must be carefully planned. For example, the lunchroom is one of the most problematic settings in the school for many students with autism due to their primary impairment in social skills. Therefore, occasions when they may be included for social participation need as much planning and support as might be required for inclusion in an academic period of the school day.

Out-of-District Placement

An out-of-district educational placement refers to a school specifically designed to address targeted areas: specific disability groups, special types of learning needs, special behavioral or emotional needs, and/or some combination of these.

When an out-of-district placement is the best match for a student, that student typically has access to highly specialized educational programming in the presence of structure, routine, and consistency. Therefore, similar to a self-contained educational placement, generalization must be carefully considered, as access to the “general” population by the school may be limited or nonexistent.



Find the Right School

The [Operation Autism](#) website lists a number of resources you can use in your search to identify the right educational placement for your child.

Which Educational Placement Is Right for My Child?

This is the final question faced by the educational team, and several considerations are critical to making the best decision for your child. These include:

1. In which educational placements can my child access the educational supports, modifications, and services required for them to meet the annual goals/objectives set forth in the IEP?

2. In which placements will my child have the most access to the general education setting?
3. In which settings will my child find the “just right challenge”? Meaning, which setting will provide enough of a challenge to help propel my child’s development but not so much challenge that their development is either stunted or, worse yet, set back?
4. In what setting does my child learn best, and in what setting is my child the least productive?
5. Does my child have friends and/or a meaningful social support network in the general education setting?
6. Has the general education setting been dangerous or unfriendly for my child?
7. Where will my child be most comfortable?
8. How much will my child be integrated into the general education setting?
9. How is a child who is having a “meltdown” or significant behavioral difficulty supported?
10. How does the classroom setting support any sensory issues my child may have?
11. Will my child be taught explicitly and allowed to practice the skills needed for living productively in the community and coping with its complex demands?

If you are concerned about the proposed educational placement for your child, ask to have the meeting rescheduled to give you time to evaluate the proposal. In the meantime, speak to your child’s teachers, other parents, special education personnel, advocates in your area, and, most important, your child, and try to gauge what setting would be the most productive and beneficial place for your child to learn.

Although IDEA sets forth a process by which the general education setting must be ruled out before considering other educational placements, ultimately, your child should be in an educational placement that will allow them to access a FAPE. In addition, your child may require a “more restrictive” setting now, but there may come a time when a less restrictive setting is a better match. Your child’s placement is not set in stone. The IEP team will discuss educational placement every year when conducting the annual IEP review, and you can always request an IEP meeting to review your child’s placement if you become concerned that it is no longer a match.

Once the IEP team has made a determination for educational placement, it is only just the beginning, as you will need to work closely with the teachers to ensure that they know all about your child. They may well know about autism spectrum disorder, but they won’t know about your individual child. It is your job to be an advocate for your child and teach the school what they need to know.

The Individualized Education Program (IEP)

What Is an IEP?

The IEP ...

- Is a blueprint for all educational programs and supports for your child for the following year.
- Specifies the educational placement for your child.
- Outlines goals that the IEP team will intermittently discuss to assess your child's progress.
- Must undergo at least yearly review and revision to determine goal achievement and to review your child's performance.

What Does the IEP Contain?

An IEP must include the following components:

- **Present Levels of Performance (PLOP)**—This section captures a description of your child's current abilities, skills, strengths, and weaknesses across academic, social, physical, and functional domains, and serves as the baseline for measuring your child's progress.
- **Annual Goals**—These must be written objectively and measurably while specifying the performance changes expected in the following year; they may touch upon various skills, including academic, social/emotional, communication, motor, etc.
- **Benchmarks or Short-Term Objectives**—These should contain incremental and sequential steps needed to move toward meeting each of the annual goals. In addition to academic or communication-related skills, short-term objectives can also target challenging behaviors.
- **Supports**—These include special education and related services that your child needs (e.g., SLP, OT, PT), and any program modifications or individual accommodations that need to be made in order for your child to reach academic achievement (e.g., visual schedules).

Your child's teacher is responsible for reporting back to the IEP team on your child's progress toward meeting the academic, social, and behavioral goals and objectives outlined in the IEP. The teacher will also be asked for input about developing new goals for your child in subsequent and review IEP meetings. Remember, you are a valuable part of the IEP team. If you have suggestions for goals, accommodations, etc., you should bring them up at the meeting.

IEP Meetings

Who Is on the IEP Team?

Your child's IEP team includes several people. By law, it includes, to the extent applicable:

- You, the parent
- Your child at age 16 and older (at age 16, children must attend; however, it may be appropriate for them to participate earlier)
- A translator, if needed
- The evaluator, such as a school psychologist
- At least one general education teacher
- At least one special education teacher
- A school district representative

You are welcome to invite advocates, such as a family member or friend, to provide support or help you take notes. The team may also invite additional people with knowledge about the student (OT, PT, SLP, an ABA therapist, etc.)

What Should I Do to Prepare for the IEP Meeting?

You do not need to be a special education lawyer to be an effective advocate for your child in the IEP process. Prepare and plan ahead.

- Know your rights as a parent and team member according to the law.
- Be familiar with your child's current evaluation data and performance at school.
 - Review recent work samples from school.
 - Review the IEP if one already exists to determine if it needs updating.
 - Observe your child at school.
- Prepare a list of goals and services you wish your child to receive.
- Consider inviting an advocate (friend or family member) for support.

What Should I Bring to the IEP Meeting?

Bring any documentation that may help inform the IEP team's decisions, including:

- A photo of your child if they are not with you (IEP meetings tend to be somewhat impersonal, and your child's photo will serve as a reminder)
- Materials to take notes and document the discussion (paper and pen, laptop, etc.)
- Recent IEP and assessments or reports from school or other service providers
- Bring or refer to any articles or other research that may help the team better understand your child's needs
- Demonstrate a positive attitude. A good approach is to "expect the best but prepare for the worst"

What Should I Do After the Meeting?

- Review and clarify your notes for future reference.
- Confirm action items and who is responsible for doing what.
- Work cooperatively with your child's teacher to ensure that the IEP is implemented effectively, as written.
- File all materials away (see the previous chapter for tips on how to stay organized).
- Prepare for the next IEP meeting.

What Happens to My Child's IEP When Transferring Schools?

When children with disabilities move to a different school district, the new district must provide services that are comparable to the services outlined in the previous IEP. The new district can conduct an evaluation to develop a new IEP, but must provide comparable services in the meantime.

Creating a Partnership With the School

Teachers today are busier than ever before, due to an increasing number of students, many with special needs or at-risk status, and increasing demands for accountability, including teaching to strict state standards in core subjects like reading and math. For these reasons, it is important to build and cultivate strong relationships with your child's teachers.

A vital first step in creating a strong relationship with the teacher is to reach out to discuss your child and how autism affects their everyday life. For example, you can provide information about your child's sensitivities and behavioral challenges; areas where your child struggles; and which adaptations have been successful in the past. Such an exchange of information can take the form of in-person meetings, telephone calls, e-mails, audio tapes, or journal exchanges.

By providing teachers with information on your child's abilities and autism, and working with them to make best use of resources such as OAR's *An Educator's Guide to ASD (Level 1 Supports)* or *An Educator's Guide to Autism*, you can make their job just a little easier, and they will love you for it.



Make the best use of resources such as OAR's Educator Guides. researchautism.org/resources

Glossary

Commonly Used Abbreviations, Acronyms, and Terms Related to Autism, Special Education, and the U.S. Military

A majority of the following terms are referenced in the text of this guidebook; however, we have also included other common terms you may encounter as a military family impacted by autism.

504 Plan—refers to **Section 504 of the Rehabilitation Act** and the **Americans With Disabilities Act**, which specifies that no one with a disability may be excluded from participating in federally funded programs or activities, including elementary, secondary, or postsecondary schooling. A 504 Plan spells out the modifications and accommodations that eligible students need to have an opportunity to perform at the same level as their peers.

ABA (Applied Behavior Analysis)—the process of applying experimentally derived principles of behavior in an attempt to improve socially important behavior. For people with autism, ABA seeks to:

- a) increase positive behaviors
- b) teach new skills
- c) maintain behaviors
- d) transfer behavior from one situation (or response) to another
- e) restrict or narrow conditions in which interfering behaviors occur
- f) reduce interfering behaviors

Autism Care Demonstration (ACD)—a program under **TRICARE** that allows families to access medically necessary and appropriate ABA services for their children with autism.

Autism Spectrum Disorder (ASD)—a complex neurodevelopmental disorder characterized by deficits in social communication and social interaction in addition to the presence of repetitive behaviors or interests.

ADA (Americans With Disabilities Act)—prohibits employers, state and local governments, employment agencies, and labor unions from discriminating against qualified individuals with disabilities. It affects access to employment, state and local government programs and services, and access to places of public accommodation, such as businesses, transportation, and nonprofit service providers. See www.ada.gov for more information.

AS (Asperger Syndrome)—a neurodevelopmental disorder that was formerly part of the official diagnosis of autism spectrum; now an outdated diagnostic term that was used between 1994 and 2013. Individuals formerly diagnosed with AS continue to identify themselves as “having Asperger’s” and require limited supports for independent living.

BCaBA (Board Certified Assistant Behavior Analyst)—an autism professional certified by the Behavior Analyst Certification Board. BCaBAs may conduct descriptive behavioral assessments, interpret the results, and design ethical and effective behavior analytic interventions, as well as design and oversee interventions in cases similar to those they encountered during their training. The BCaBA obtains technical direction from a **BCBA** for unfamiliar situations, and may assist a BCBA with the design and delivery of introductory-level instruction in behavior analysis. It is strongly recommended that the BCaBA practice under the supervision of a BCBA.

BCBA (Board Certified Behavior Analyst)—an autism professional certified by the Behavior Analyst Certification Board. This is a higher certification than BCaBA. BCBAAs conduct descriptive and systematic behavioral assessments and provides behavior analytic interpretations of the results. BCBAAs also design and supervise behavior analytic interventions and develop and implement appropriate assessment and intervention methods for use in unfamiliar situations and in a range of cases. It is strongly recommended that a BCBA supervise the work of BCaBAs and others who implement behavior analytic interventions.

BIP (Behavior Intervention Plan)—a set of strategies to support children with inappropriate classroom behaviors by suggesting the learning and practicing of new, appropriate behaviors. BIPs are also known as Behavior Modification Plans.

CDC (Centers for Disease Control and Prevention)—one of the major operating components of the Department of Health and Human Services in the federal government. The CDC identifies and defines preventable health problems and monitors diseases by performing data collection, analysis, and distribution. It also actively monitors epidemiological and laboratory investigations. Within the CDC, the National Center for Birth Defects and Developmental Disabilities (**NCBDDD**) monitors autism. See www.cdc.gov for more information.

DEERS (Defense Enrollment Eligibility Reporting System)—military database that lists everyone who is eligible for TRICARE benefits.

DoD (Department of Defense)—the federal department charged with coordinating and supervising all agencies and functions of the government relating directly to the armed forces, national security, and the military.

DHHS (Department of Health and Human Services)—A federal agency charged with coordinating and supervising all agencies and functions of the government related to public health, wellbeing, and provision of essential human services. See www.hhs.gov for more information.

DIR/Floortime (Developmental, Individual Differences, Relationship Approach, also referred to as Floortime)—a development-based system of autism intervention focusing on social and communicative development.

DTT (Discrete Trial Training)—behavior analytic intervention that involves the repetitive presentation of discrete instructional directions.

Due Process—protects the rights of parents to have input into their child’s educational program and to take steps to resolve disagreements. When parents and school districts disagree, either party may ask for an impartial hearing to resolve the issues. (**Mediation** must also be available.)

ECHO (Extended Care Health Option)—a supplemental program to the TRICARE basic program that enhances accessibility to additional interventions for children diagnosed with autism. It provides eligible active duty family members with an additional financial resource for obtaining an integrated set of services and supplies designed to help reduce the disabling effects of the beneficiary’s condition (such as moderate or severe mental retardation, a serious physical disability, or an extraordinary physical or psychological condition) such that the beneficiary is homebound.

ECTAC (Early Childhood Technical Assistance Center)—supported by the U.S. Department of Education’s Office of Special Education Programs, ECTAC serves all 50 states with an array of services and supports to improve systems and outcomes for children with special needs from birth to age 5 and their families.

EDIS (Educational and Developmental Intervention Services)—established to implement specific portions of **IDEA**. It delivers early intervention services (**EIS**) to eligible infants and toddlers in domestic and overseas areas, and medically related services (**MRS**) to school-age children in special education programs in DoD schools overseas.

EFM (Exceptional Family Member)—a family member with a physical, developmental, emotional, or mental disorder requiring specialized services.

EFMP (Exceptional Family Member Program)—a mandatory enrollment program for all active duty service members with family members with special medical and/or educational needs. Each branch manages its own EFMP with specific goals and services.

EIS (Early Intervention Services)—usually refers to **IDEA** services for children 0–3 years of age.

ESDM (Early Start Denver Model)—autism intervention for toddlers and preschoolers that entails an individualized set of objectives emphasizing relationships, shared control, and positive emotion.

FAPE (Free and Appropriate Public Education)—a requirement under **Section 504 of the Rehabilitation Act** of 1973 mandating that public schools provide access to general education and special education settings and services for students with disabilities. It requires that those children receive support free of charge as provided to children without disabilities. It also provides access to general education services for children with disabilities by encouraging that support and related services be provided to children in their general education setting as much as possible.

FBA (Functional Behavioral Assessment)—strategy of looking beyond the obvious interpretation of a negative behavior to determine the function it may be serving for the child. Understanding the reason behind the inappropriate behavior helps eliminate or change the behavior.

Fidelity of Implementation—the delivery of instruction/intervention in the way it was designed to be delivered. Fidelity of implementation also addresses the integrity with which screening and progress-monitoring procedures are followed and implemented.

Generalization—the ability to select and use a learned skill in a setting different from the one where it was originally learned.

IDEA (Individuals With Disabilities Education Act)—federal program that provides funds to states and local school districts to support education for children with disabilities, age 3 to 21. IDEA also provides guidelines and protections for children with disabilities to ensure that they have access to a free and appropriate public education (FAPE).

IEP (Individualized Education Program)—written statement for a child, 3–21 years of age, with a disability that is developed, reviewed, and revised annually in accordance with IDEA.

IFSP (Individualized Family Service Plan)—a written statement for an infant or toddler 0–3 years of age with developmental needs and their family.

Impartial Hearing Meeting—a meeting between parents and the school district. Each side presents a position and a hearing officer decides what the appropriate educational program is, based on requirements by law.

LRE (Least Restrictive Environment)—IDEA’s guiding policy on inclusion. It requires school districts to educate students with disabilities in general education classrooms with their nondisabled peers in the school they would attend if they did not have a disability, as much as possible.

MDT (Multidisciplinary Team)—team of professionals meeting the needs of a specific child. The MDT for a child with autism may include the following: **OT** (occupational therapist), **PT** (physical therapist), **SLP** (speech-language pathologist), special

education teacher, general education teacher, guidance counselor, school principal, ESL (English-as-a-second-language) teacher.

Mediation—a meeting between parents and the school district with an impartial person called a mediator. The mediator helps both sides come to an agreement that each finds acceptable

MTF (Military Treatment Facility)—a medical hospital or clinic administered by the Department of Defense (DoD).

NCBDDD (National Center for Birth Defects and Developmental Disabilities)—a division of the CDC that strives to identify the causes of birth defects and developmental disabilities, help children reach their full potential, and promote health and well-being among people of all ages with disabilities.

OT (Occupational Therapy)—therapy provided by a licensed occupational therapist that develops physical skills that aid in daily living. OT focuses on sensory integration (also called sensory processing); balance and coordination of movement; and fine-motor and self-help skills, such as dressing, tying shoes, and eating with a fork and spoon.

PCM/PCP (Primary Care Manager/Provider)—the person who oversees care for your child.

PCS (Permanent Change of Station)—the official relocation of an active duty military service member, along with any family members living with them, to a different duty location such as a military base.

PDD-NOS (Pervasive Developmental Disorder-Not Otherwise Specified)—now an outdated diagnostic term that was used between 1994 and 2013, PDD-NOS is a diagnosis on the autism spectrum that shares some of the central features of autism, yet does not meet all the criteria for an actual diagnosis of autism spectrum disorder.

PECS (Picture Exchange Communication Systems)—a modified applied behavior analysis (ABA) program designed for early nonverbal symbolic communication training that teaches children to exchange a picture for something they want, such as an item or activity. PECS is not designed to teach speech, but speech is encouraged indirectly, and some children begin to spontaneously use speech while enrolled.

PRT (Pivotal Response Treatment)—a naturalistic, child-directed intervention based upon the principles of ABA.

PT (Physical Therapy)—therapy provided by a licensed physical therapist, who evaluates, diagnoses, and treats disorders of the musculoskeletal system. The goal of physical therapy is to improve gross-motor skills and restore maximal functional independence by using a range of interventions, to include exercise, heat, cold, electricity, and massage.

Section 504 of the Rehabilitation Act (for children)—a national law that protects the rights of individuals with disabilities in programs and activities that receive federal funds, including public schools and institutions of higher learning. The Section 504 regulation requires a school district to provide a “free appropriate public education” (FAPE) to each qualified child with a disability who is in the school district’s jurisdiction, regardless of the nature or severity of their disability. (See also **504 Plan** and **FAPE**.)

SLP (Speech-Language Pathologist)—a specialist in the study of human communication, its development, and its disorders, including speech, language, voice and swallowing disorders, and other communicative deficits.

Social Stories™—a simple method of teaching or maintaining social, daily living, or behavior management skills. These narratives address specific situations by teaching the student appropriate behaviors and responses (e.g., how to cope with changes in routine, how to get along with peers, or how to work in a classroom). They provide an explanation of detailed social information as well as desired responses instead of problem behaviors. See *carolgraysocialstories.com* for more information.

SPD (Sensory Processing Disorder)—a neurological disorder causing information received through the senses to be processed abnormally in a way that may cause distress or confusion. SPD is its own diagnosis, but it can be linked to other neurological conditions, including autism.

Special Needs Program (SNP)—the Coast Guard’s equivalent to EFMP. SNP is implemented through the Coast Guard’s Office of Work-Life programs. It is a mandatory comprehensive, coordinated, multidisciplinary approach to community support, housing, medical, educational, and personnel services for Coast Guard families with special needs.

Specialized ASD Provider—a TRICARE authorized provider who is board certified or board eligible in behavioral developmental pediatrics, neurodevelopment pediatrics, child neurology or child/adult psychiatry. Or, a doctoral-level licensed clinical psychologist or board-certified doctor of nursing practice (DNP).

TEACCH (Treatment and Education of Autistic and Related Communication—Handicapped Children)—a structured teaching approach based on the idea that the environment should be adapted to the child with autism, and not the other way around. See www.teacch.com for more information.

TRICARE—the regionally managed healthcare system for active duty and retired members of the uniformed services and their families. See www.tricare.mil for more information.

Resource Listing

This list includes reliable “first-stops” for information on autism and military resources in general. For an expanded list, please visit *Operation Autism* online.

Federal Links

Centers for Disease Control and Prevention—Autism Information Center

<https://www.cdc.gov/ncbddd/autism/families.html>

A comprehensive resource with autism facts; definitions; data and statistics; information about screening and diagnosis, treatment, and research; downloadable materials; and links to other websites.

Learn the Signs. Act Early.

<https://www.cdc.gov/ncbddd/actearly/index.html>

A CDC campaign and tool that aims to educate parents about childhood development, including early warning signs of autism and other developmental disorders.

Military Links

Military Child Education Coalition (MCEC)

<https://www.militarychild.org/>

Worldwide non-profit organization whose mission is to ensure inclusive, quality educational opportunities for all military-connected children affected by mobility, transition, deployments, and family separation.

MilitaryINSTALLATIONS

<https://installations.militaryonesource.mil/>

Official DoD source for installation and state resources available to active duty, Guard, and Reserve service and family members.

Military Kids Connect

<https://militarykidsconnect.dcoe.mil/>

Website where military kids, tweens, and teens can share their experiences and learn healthy coping strategies for the challenges unique to life as a military dependent.

Military OneSource

<https://www.militaryonesource.mil/>

Service provided by the DoD for active-duty, Guard, and Reserve service members and their families to provide support for any issue, including education, relocation, parenting, and stress. Military OneSource provides useful tools for military families with children on the spectrum.

TRICARE

<https://tricare.mil/>

Official website for **TRICARE**, the healthcare program that provides civilian benefits for military personnel, military retirees, and their dependents, including some members of the reserve component.

The National Resource Directory

<https://nrd.gov/>

Connects wounded warriors, service members, veterans, their families, and caregivers to programs and services that support them.

Autism Links

Organization for Autism Research (OAR)

<https://researchautism.org/>

Non-profit organization responsible for creating Operation Autism and this guide. OAR uses applied science to answer questions that parents, families, individuals with autism, teachers, and caregivers confront daily. OAR also creates and distributes free resources on such topics as sibling support, assessment, peer education, transitioning to adulthood/college, and more. All of OAR's resources may be digitally downloaded or ordered in hard copy.

Association for Science in Autism Treatment

<https://asatonline.org/>

Not-for-profit organization committed to improving the education, treatment, and care of people with autism. Advocates for the use of scientific methods to guide treatment and combat inaccurate and false information about autism and its treatment.

Autism Society of America

<http://www.autism-society.org/>

Promotes community involvement of individuals with autism through education, advocacy, and public awareness. The website lists state and local chapters and provides resources for parents.

Autism Speaks

<https://www.autismspeaks.org/>

Provides general information about autism, research, and resources for support; offers resources for parents and educators.

Behavior Analysts Certification Board (BACB)

<https://www.bacb.com>

The BACB credentials professionals in behavior analysis services, including ABA. Families can search for **BCBAs** in their area using the tool provided on the BACB website.

Center for Parent Information and Resources (CPIR)

<https://www.parentcenterhub.org/the-parent-center-network/>

Previously, National Information Center for Children and Youth with Disabilities (NICHCY), CPIR provides a directory to Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs) in the United States.

The National Professional Development Center on Autism Spectrum Disorder (NPDC)

<https://autismpdc.fpg.unc.edu/national-professional-development-center-autism-spectrum-disorder>

Develops free professional resources for teachers, therapists, and technical assistance providers who work with individuals with autism. Resources include Autism Focused Intervention Resources and Modules (AFIRM), a series of free online modules on planning, using, and monitoring evidence-based practices.

The Southwest Autism Research and Resource Center (SAARC)

<http://www.autismcenter.org>

Non-profit, community-based organization dedicated to autism research, education, and resources for children and young adults with autism and their families. Serves as a satellite site for national and international projects, and provides up-to-date information, training, and assistance to families and professionals. SAARC is piloting telemedicine as a way to provide therapy to families who live in areas that lack high-quality autism services. Military families are encouraged to contact SAARC about participating in the telemedicine project.

Appendix A

Finding Providers

Often you will be stationed in a location with a lot of private therapists and other services that may be difficult to find. Below are some tips on how to find these other providers.

Which Types of Providers Might Be Able to Assist My Child?

- Speech-language pathologists (SLPs) (www.asha.org)
- Occupational therapists (OTs) (www.aota.org)
- Physical therapists (PTs) (www.apta.org)
- Behavioral specialists¹ (bacb.com/)
- Psychologists (www.apa.org)
- Respite care providers (archrespice.org)

Where Should I Look?

- TRICARE Online Directory at www.TRICARE.mil (for military beneficiaries)
- OAR's *Base-by-Base Resource Directory on the Operation Autism* website
- A local phone book or online yellow pages
- Internet
- Pediatricians' offices; they usually have a list of community resources
- Local school district; ask one of their SLPs (or OTs, PTs, psychologists, etc.) if they know of any private providers in their field
- Local Chamber of Commerce
- County's or state's early Intervention program (usually on the state's Department of Health & Human Services [DHHS] website)
- The state's Developmental Disabilities Council
- Local child development centers
- Local or state autism support groups

¹ These may include Board Certified Behavior Analysts (BCBAs), Board Certified Assistant Behavior Analysts (BCABAs), and Registered Behavior Technicians (RBTs) who are credentialed by BACB, BICC, and QABA.

Appendix B

Creating a Record System

Which Documents Should I Keep and How Long Should I Keep Them?

- **TRICARE, Insurance or Other Funding-Source Paperwork:**
 - Documentation provided to or from a given funding source until the given issue is resolved and you have documentation of the resolution
 - Notes from conversations with insurance representatives (note the date, time, and name of the person with whom you've spoken)
- **School Documentation:**
 - Each final, signed **IEP**
 - Your notes, copies of notes taken by school personnel, and documentation of Prior Written Notice
 - Evaluation reports (e.g., psychological, speech-language, OT, educational assessments)
 - Special education eligibility and evaluation summaries
 - Other paperwork (e.g., notice of action refused, written requests you have made)
 - Report cards and progress reports
 - Notes from important conversations with school personnel
- **Therapy Documentation** (this section refers to private, not school-based, therapies):
 - Evaluation reports
 - Progress reports
 - Including graphs of important data
 - Home program documentation (when applicable)
 - Other paperwork
 - Any formal letters provided by therapists
 - Notes from important phone conversations
- **Other Medical Documentation:**
 - Medical evaluations
 - Diagnostic evaluations are particularly important and helpful
 - Other paperwork
 - Referral documentation
 - Formal letters provided by medical personnel
 - Notes from important conversations with medical care providers
 - Information on specific medical procedures (e.g., asthma plan, seizure plan, feeding procedures)
- Keep a record of documents for as long as you can, especially while your child is school age. Though it may be rare that you will need old documentation, it is better to be "safe than sorry."

- As a general rule, evaluations are valid for about three years (some assessments differ). If you believe the information in an evaluation report is no longer accurate for your child, it is important to obtain a current evaluation.

How Do I Set up My Record System?

The system consists of two basic elements:

- **Reference**—This includes all information that is current and may be helpful/necessary at key times (e.g., IEP meetings, new evaluation). Examples include the current IEP, current evaluations, and current progress reports.
- **Archive**—This includes all information that you should keep but will not need to quickly reference.

Keep it as simple as possible. Your organization system will mirror the categories of documents you should keep (TRICARE, school, therapy, medical, other). Most likely, your archival system will stay in your home whereas the reference system will be portable, ready for you to bring to your child’s next IEP meeting, accessible within seconds.

Below is a more in-depth look at each system.

The Reference System

You will need:

- One 3-inch, loose-leaf 3-ring binder or a portable file case
- 10 notebook dividers (clear tab if possible) or 10 file folders
- 3 different-colored pens
- A 3-hole punch
- One loose-leaf folder or an additional file folder
- Documentation for the current academic year. (You may find it helpful to run the system based on the school year calendar as opposed to the IEP and replace the IEP when needed. For example, some children have an IEP running from November to November even though the academic year begins in August/September.)
 - Current IEP
 - Most recent school and private therapy evaluations
 - Progress reports and report cards for school and private therapies
 - Any current notes or other paperwork (see “What Documents Should I Keep?”)
 - Any current funding source documentation

Steps:

1. Write or print each of the following section headings as a folder tab. You will see a one-letter prefix for each section, as follows:

S = School → T = Therapy → M = Medical

Use a different color to label each of the following tabs/headers:

S - IEP
S - Evaluation
S - Progress
S - Other
T - Evaluations
T - Progress
T - Home Program
T - Other
M - Evaluations
M - Other

2. Insert tabs into the dividers or, if using files, label the folders.
3. If using a 3-ring binder, make sure all documentation has been punched with the 3-hole punch.
4. As you move through your stack of paperwork, sort documents behind the corresponding divider (or in the corresponding folder).
5. Place your now categorized and organized stack of dividers and paperwork into the notebook (or the files into the file case).
6. The additional folder is used to keep TRICARE and funding source documentation.

The Archival System

You will need:

- One hanging “box bottom” file pocket (at least 3 inches wide) for each year since your child was diagnosed
- Pen (or use a printer)
- Clear tabs and inserts (typically come with the hanging file folders)
- All documentation and paperwork since your child’s diagnosis
- Something in which to place the hanging pocket files (e.g., file cabinet, file box)

Steps:

1. Label each file pocket with one academic year (e.g., 2019–2020).
2. Sort through the paperwork you have accumulated since your child’s diagnosis. Place each document in the corresponding year’s file pocket.
3. In future years, you will be able to easily lift the documents from the reference system (leaving the dividers in the notebook) and place them in a new file pocket. The archival system is a bit simpler than the reference system, but you won’t be accessing it nearly as often.
4. When you receive the results of an updated evaluation of your child, place the old evaluation in the file pocket year that corresponds with the evaluation date (i.e., an evaluation completed in April 2018 will go in the archive file labeled 2018–2019).

How Do I Maintain the System?

Maintenance is easy once you have established a routine system, as outlined below.

1. As you receive new evaluations, place the old evaluation in the archive system file pocket for the year during which the evaluation occurred. Place the new evaluation in the reference 3-ring binder behind the appropriate School, Therapy, Medical Evaluation, or TRICARE divider.
2. When you receive the final IEP, place the previous IEP in the corresponding archive file pocket for that year. Place the new IEP in the 3-ring binder behind the School-IEP divider.
3. At the beginning of each school year, remove the contents of the 3-ring binder (reserving the dividers and any evaluations that are still current), and place them in the corresponding file pocket. Place the dividers and current evaluations back in the notebook.

It will take a few hours to set up this system, but after that it will only take minutes to maintain—besides, the financial cost is minimal. There are many possible variations on this system, so feel free to tweak it to make as useful as possible to you.

Appendix C

Communicating With Commanders

Having a child with special needs can pose challenges within your command and cause stress within the family. Autism is still not widely understood, so it should come as no surprise that the members of your unit or leaders in your chain of command² may be unaware of the demands associated with raising a child with autism.

As a result, it is incumbent upon you to inform and educate them in order to successfully balance two competing priorities—fulfilling your duties as a member of the military and at the same time your role as parent.

This section offers a four-step approach to promoting better communication and understanding of your situation among the leaders and fellow service members within your command by explaining the disorder and the type of support and consideration you may be requesting.

Step 1. Inform Your Immediate Leader/Supervisor

When you need to request leave or time to go to an IEP meeting or a medical appointment with your child, be sure to explain what's going on and why it's important. Also be prepared, when possible, to compensate in part for times when you need to be absent.

Step 2. Speak to the Commander/Commanding Officer or Command Representative

Your immediate leader/supervisor may not have the authority to grant leave or respond from the command perspective to approve the support you are requesting. Therefore, once you have taken care of Step 1, speak to the responsible leader or the designated command representative. In most cases, your immediate leader/supervisor will make the leader at the next level aware of your situation. Even so, you should still discuss your personal family situation with the designated command representative, frequently the senior enlisted member for enlisted service members, and quite possibly the commander/commanding officer.

Approach this appointment as if the person you are meeting knows nothing about your child's autism diagnosis or autism in general. Come prepared to explain what autism is, how it impacts your family, and what support or consideration you antic-

²Since command structures and terminology differ among the branches of service, we will use the terms *chain of command* and *command* interchangeably to refer to your immediate superiors and those in your chain of command who are responsible for you, and by extension, your family.

ipate needing from the command. Think of this as an information briefing so don't expect final resolution of anything from this meeting.

Things to Consider:

Come prepared. For example, you might want to bring a meeting outline or topic list and a folder with a 1–2 page autism information sheet. (You might include some information downloaded from OAR's *Operation Autism* website.) Don't expect the commander to review this in your presence, but also don't hesitate to point out some of the more relevant pieces of important information as they pertain to your child and your family's situation. Be sure to discuss the level of confidentiality regarding the situation that you desire. Finally, keep a record of any meeting like this for your own reference and possible future use with a new command representative or commander.

Explain your child's therapies. Time permitting, provide an overview of what therapies your child receives, how often, what days of the week, and what times. Explain that there will be days and certain appointments when your presence and participation will be important to your child's treatment plan and development, including the need to follow through with supporting programs at home.

In addition, help your command understand that a child with autism will likely have more medical appointments than a typically developing child. This means you may need to take leave to attend some of these appointments. (Review any family medical leave policies prior to this meeting and get clarification on these policies as they pertain to your situation, if necessary.)

Share your child's goals and behaviors. If you have a very supportive command and feel comfortable sharing your child's IEP and/or goals, include a copy in the information folder. This will give your command a better idea of the extent of your child's strengths and weaknesses and a better sense of what you are experiencing at home.

If your unit has command or social functions that include families, you may want to describe any specific behaviors that your child may exhibit during such activities. For example, if your child becomes overstimulated in loud and crowded environments, describe what you or your spouse may do to help your child adjust, including leaving a function early.

Discuss your commitment. Let your command know how much you value your family and your commitment to your child(ren). Mention that you want to ensure your child receives excellent care so that they can live the most productive and independent life possible. At the same time, let the command representative know that you expect and want to "carry your own pack" and that you can best do that with the assurance that your child's and family's needs are fully considered and supported.

If you have an impending deployment, explain any additional family supports you may need to have in place before you deploy. This may require you to request extra leave time before a deployment. These should also be delineated in your family care plan. When the command is attuned to your family's needs, it will be better positioned to help your family seek out support services, such as a chaplain or the Exceptional Family Member Program (EFMP) coordinator. Many re-assignments are made as usual even if your family is enrolled in EFMP. If compassionate re-assignment is something your family wishes to prioritize to ensure that your child receives the services they need, also discuss this with command.

Step 3. Take Action

Look for opportunities to increase understanding of autism within your command and local community. Organize an awareness campaign in your unit, on base, or in your child's school during National Autism Awareness Month in April. Make yourself a one-person awareness campaign by joining OAR's *RUN FOR AUTISM* team, or get your unit or squadron involved in your autism awareness efforts by organizing a base run in support of OAR. Be sure to check with your command's ethics advisor regarding the use of base facilities or personnel to support a private organization. If approved, this can be a great way to promote unit cohesiveness outside of the work arena while simultaneously raising funds for an excellent cause.

Step 4. Keep the Lines of Communication Open

If you believe your child's needs are not being fully met at your duty station due to a lack of services and resources, keep your command informed. You may find this support invaluable if you need to consider other options, such as requesting Permanent Change of Station (PCS) reassignment to a duty station with more appropriate resources. But be realistic. There are limits to what your immediate command may be willing or able to do.

Even though it may not be easy to approach your command about your personal, family situation, it is important both for you and the command. As your child's best advocate, you need to speak up; and as a member of the command, your leaders need to know about things that affect your ability to perform your duty to the fullest extent possible. The greater understanding that results from your efforts will serve to assist other service members and their families within your command in similar circumstances in the future.

Appendix D

Plan My Move: Expanded Autism Checklist

The [Plan My Move](#) checklist tool provided by Military OneSource is an excellent place to start organizing your transition plans for moving to a new base, home, or community. To make the best use of your checklist, organize the tasks from highest to lowest priority. Then, develop a realistic action timeline or calendar for completing the tasks. Be sure to give yourself sufficient buffer time for those inevitable delays.

Visit this URL to access the Plan My Move tool and generate your full checklist: planmymove.militaryonesource.mil/

Here are some autism-specific suggestions to expand your Plan My Move checklist. It is recommended that you break them up further into discrete tasks with target deadlines.

School

1. Research and select schools from the local area or on base.
 - Narrow down search for educational placements using OAR's Resource Directory or Military OneSource's Education Directory.
 - Contact and visit 1–2 schools to ask questions regarding special education supports and programs.
2. Request copies of any school paperwork from your current installation, including any Exceptional Family Member Program (EFMP) paperwork.
3. Gather key documents such as report cards, evaluation reports, the most recently signed Individualized Education Program (IEP), Functional Behavior Analysis (FBA), and Behavior Intervention Plan (BIP).
4. Update your *school safety plan* covering topics such as asthma, seizures, feeding, allergies, challenging behaviors, including "running."

Paperwork

1. Remind your service member to complete all out-processing paperwork from your current installation.
2. Gather and fill out all necessary paperwork.
3. Gather copies of important documents.
 - Gather evaluation and progress reports from service providers outside of school (OT, PT, SLP, ABA, etc.).
 - Request formal letters about your child's progress from doctors and service providers to help orient new service providers.

- Gather healthcare items (medical documentation of disability, allergies, and other medical conditions, referral records, etc.) ahead of schedule in anticipation of delays and to ensure continuity of care.
4. Remind your service member to request a sponsor at your new installation.
 5. Review the check-in procedures at your new installation.
 - Contact the EFMP office at the new location to ensure continuity of care and anticipate any waitlists or gaps in service upon arrival.

Family

1. Work with your service member to tell your family about your upcoming move.
 - Develop **Social Stories™**, visual supports, and calendars to prepare your child for the move.
 - Establish and maintain a schedule to review social stories, visual supports, and calendars about the move with your child.
2. Reach out to and connect with support groups and other resources at your new installation.
3. Look into child care options.
 - Find and re-establish respite care set up through EFMP/ECHO.
4. Identify local health care options.
 - Research and contact therapy providers for continuation of services. The **TRICARE** online provider directory is your best source for TRICARE authorized providers. OAR's Resource Directory also includes a list of ABA providers accepting TRICARE near many bases.
5. Look into local community resources and assistance.
 - Research and connect with community-based service providers (vocational rehabilitation, disabilities agencies) about local resources.

Household Goods

1. Schedule a time for the movers to pick up your items.
2. Pack a "First Week" box.
 - Pack a box with your child's comfort items, sensory toys, and familiar belongings for travel. Be sure to include anything your child cannot be without on a daily basis.
 - Store all important documents and paperwork in a safe place for easy access.

Housing

1. Decide where you'll be living.
 - Capture screenshots from Google Maps, download photos from real estate listings, or take your own photos of the new home/base/community to develop social stories and help your child anticipate the new environment.

2. Do your own move-in inspection.
 - Prepare your home environment in ways that are important for your child to maintain routines and familiarity.
 - Check with your base housing office.

Financial

1. Research cost of living or pay at your new installation.
 - Update budget with costs for new therapists or service providers.

Transportation

1. Pick a travel date.
 - Obtain a letter from your child's physician verifying and specifying your child's disability in case of an incident.
2. Make hotel reservations.
 - Practice staying with your child in a nearby hotel to better anticipate challenges on moving day.
3. Plan transportation to your new installation.
 - Have your child carry a safety ID card during travel if needed.
 - Prepare a travel box with maintenance items (e.g., hand sanitizer, flushable wipes, medicine, extra headphones and chargers), and toys.



Autism presents parents and families with many challenges under normal circumstances. Autism in the context of a military family magnifies many of those challenges and adds a few more that are unique to military life and service.

This guide and its companion website, *Operation Autism*, are designed to give these special families the information and tools they need on their unique life journey through autism. More specifically, it offers:

- An understanding of autism and related interventions and treatments
- Strategies for addressing the challenges of autism from the time of diagnosis through adulthood
- Information on autism treatment options and coverage within the military healthcare system
- Practical information to guide your child's education
- Tips and advice on major transitions, including moves, new schools, etc.
- A structured plan for creating and maintaining a record management system

For time-sensitive updates and further in-depth information, visit *Operation Autism* at www.operationautism.org. This guide's online companion features five main content areas and a resource directory of schools, services, and supports available at or near military installations across the U.S. and also some overseas locations. The content areas correspond to chapters in this guide.

The Organization for Autism Research (OAR) is a national non-profit organization dedicated to promoting research that can be applied to help families, educators, related professionals, and individuals with autism spectrum disorders find much-needed answers to their urgent questions. Committed to excellence in service to the autism community, OAR funds applied research that will make a difference in the lives of individuals; provide information that is accurate, useful, and cost efficient; and offer opportunities for the autism community to collaborate and make advances together. For more information about OAR, visit www.researchautism.org.

www.researchautism.org

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ORGANIZATION FOR AUTISM RESEARCH