

Life Journey through Autism: A Guide for Military Families



ORGANIZATION FOR AUTISM RESEARCH



SARRC

Southwest
Autism
Research &
Resource
Center

Life Journey through Autism: A Guide for Military Families

by



Organization for Autism Research

2000 N. 14th Street, Suite 710

Arlington, VA 22201

(866) 366-9710 (Toll-free)

www.researchautism.org

and



SARRC

Southwest
Autism
Research &
Resource
Center

**Southwest Autism
Research & Resource Center**

300 North 18th Street

Phoenix, AZ 85006

(602) 340-8717

www.autismcenter.org

American Legion
Child Welfare Foundation



**Production and distribution of the *Guide for Military Families*
was made possible through the generous support of
the American Legion Child Welfare Foundation.**

This publication is designed to provide accurate and authoritative information concerning the subject matter covered. It is published with the understanding that the Organization for Autism Research, Inc. is not engaged in the rendering of legal, medical, or other professional services. If legal, medical, or other expert advice or assistance is required, the services of a competent professional should be sought.

Copyright © 2010 Organization for Autism Research, Inc. All rights reserved.

No part of this work may be reproduced or transmitted in any form or by any means, electronic or mechanical, including photocopying and recording, or by any information storage or retrieval system, without prior written consent of the Organization for Autism Research, Inc., unless such copying is expressly permitted by Federal copyright law. Address all inquiries to the Organization for Autism Research, Inc., 2000 N. 14th Street, Suite 710, Arlington, VA 22201.

www.researchautism.org



ORGANIZATION FOR AUTISM RESEARCH

Research and resources that help families today!

January 2010

Dear Readers,

Hi, my name is Greg Smith, a member of the Organization for Autism Research (OAR) Board of Directors, parent of a child with autism and retired Air Force member. I was asked at our last Board meeting if I would be interested in writing an item to go along with the publication of our military families' guidebook, *Life Journey through Autism: A Guide for Military Families*. It is with great pleasure that I write this message.

My daughter was born prematurely when I was on active duty and there were a lot of caring people that provided immeasurable help as my wife and I grappled with the many questions that we faced with 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 been given 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 in tune with the greater struggle faced by families dealing with this disorder. 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 there are additional hardships faced by our military families when it comes to dealing with this disorder. These hardships are manifested in many ways to include military members deploying which means in many cases, a spouse has to handle the many issues that arise on the "home front" on their own. There is the issue of separations from extended families 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. There is a strong "sense of duty" and focus. I am honored to have been a member of this honorable profession and 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 see our organization produce this publication in support of our military to accompany our military families' Web site. These efforts are but small tokens of our support to the military, but these efforts are from the heart. The publication and companion Web site are there for your use and the Board looks forward to your feedback on ways to make them even better. We salute your tenacity in dealing with not only autism, but dealing with this disorder along with the attendant military issues. OAR will continue to do what we can to support you and we greatly appreciate your service to country.

In closing, I must 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



ORGANIZATION FOR AUTISM RESEARCH

Research and resources that help families today!

January 2010

Dear Readers,

I never served in the military, but have always admired those who did starting with my late father, who served in the U.S. Army in North Africa during WW II. Pop was proud of his service, but never talked much about what he did, which may in part explain why I enjoy reading military history within my passion for reading in general. I've read enough to know that it takes a special person to wear your uniforms and do what you do in service to our country. Thank you for your service and sacrifice.

On the other hand, I do have a lot of experience working with families with autism and know all too well the challenges that having a child with autism can pose for the child, you as parents, and your other children and family members. Knowing how difficult autism can be under "normal" circumstances leaves me reaching for words to describe the extra pressure autism places on a military family that has a child on the autism spectrum.

I cannot speak to the challenges that military life and its environment may pose, but I will offer four points that should serve you well in your duties as a parent of a child with autism regardless of military assignment or locations. First, as this *Life Journey through Autism* Guidebook (and the *Operation Autism* Web site: <http://www.operationautismonline.org/>) emphasizes, you must learn everything you can about autism as it pertains to your child. Only by becoming an informed and knowledgeable parent can you make the best choices on behalf of your child. You will be faced with an overwhelming onslaught of information, misinformation, opinion, theories, and research outcomes. At the end of the day, it will be up to you to make sense of all this information and make decisions in the best interests of your child.

I've learned many times over, "Life isn't fair." It's probably the same with respect to aspects of military life, and it's assuredly true with respect to caring for a child with autism. While one parent or the other may, at different times, shoulder more of the responsibility for caring for their child with autism, coordinating treatments, and working with schools and teachers to ensure the best educational environment, I cannot overemphasize the importance of working together as a team and sharing accomplishments as well as challenges.

Building on that last point, autism is difficult for the child and you without a doubt. At the same time, it is not a death sentence. Your child has potential and a future. With effective early intervention, perseverance, patience, and love, a life of yet unknown possibilities awaits. Keep the faith, and press on. As you do, keep in mind the importance of finding, supporting, and capitalizing on your child's strengths at every step along the way.

Finally, take care of yourself, and find time for R&R. I'm not talking about a week in Hawaii or some other exotic location (but don't rule it out if you can swing it!). Autism can be all-consuming as you immerse yourself in the mission to do what's best for your child. It can take its toll on your family, your marriage, and your health. R&R in this context is as basic as allowing yourself time to read a book about something other than autism, go for a walk with your spouse, or train for a marathon as many of our *RUN FOR AUTISM* runners-parents have done. Don't ask me how, but it's healthy and good. As the saying goes, you have to take care of yourself if you really want to take care of your child.

That's it. Learn. Share. Emphasize ability over disability. Take care of yourself. It has been an honor to contribute to this publication and it is my great hope that it helps you and your family find success in each of the four points. Thanks again for your service.

Sincerely,

Peter F. Gerhardt, Ed.D.

President and Chair, Scientific Council



ORGANIZATION FOR AUTISM RESEARCH

Research and resources that help families today!

January 2010

Dear Readers,

In some respects this project has been more than 40 years in the making, beginning in 1969, when I was commissioned an officer in the U.S. Marine Corps. In less than a year, I was on my way to "WESTPAC" and my first leadership assignment. Beginning then and at every stop after, the Marine Corps taught me that a leader's first and most important charge was to "take care of your men and women." This responsibility extended beyond training, combat, and military affairs to taking care of the families of the people we led as well. It's no different for today's leaders.

That sense of responsibility was re-awakened with new purpose after we founded OAR, and I met people like Karen Driscoll, a Marine wife and autism Mom; LtCol Scott Campbell, USA, another autism parent-champion; and Joe Valenzano, a Marine in earlier days and today CEO and President of *Exceptional Parent* Magazine, and advocate-champion for families that have members with special needs and disabilities. I had been looking for the opportunity to extend OAR's work to military families touched by autism. The example of these three persons moved us to from ideas to action.

In 2007, OAR's Board of Directors gave the green light to develop an initiative focused on military families touched by autism. That October, the American Legion Child Welfare Foundation awarded OAR a grant of almost \$41,000 to create the Operation Autism Web site and produce the *Life Journey through Autism: A Guide for Military Families* guidebook that you now have in your hands.

Now that the work of creating these resources is done, OAR and each of the persons who have contributed to this effort can enjoy the special satisfaction that comes with knowing that we have indeed done something meaningful for others. In this instance, it was for that special group of men and women who serve in uniform today and their families. Just like 40 years ago, it's called "taking care of our own."

The Web site and this companion *Guide for Military Families* stand as OAR's way of serving military families with children on the autism spectrum and saying "thank you for your service" to all men and women serving in uniform today. In that respect, offering these resources is our small way of returning the favor. I hope you find this *Guide* and the *Operation Autism* Web site useful.

Sincerely,

Michael V. Maloney
Executive Director



SARRC

Southwest
Autism
Research &
Resource
Center

Dear Family,

We extend our heartfelt thanks to the U.S. men and women in uniform dedicating their careers and lives to military service. And we open our arms to those living with autism spectrum and related disorders, as we recognize their extraordinary courage and needs.

Like most families living with autism, we know parents wrestle with understanding and accepting their child's diagnosis as well as navigating daily life with this mysterious neurobiological disorder that includes lack of communication; lack of social connectedness; and perseveration on repetitive tasks, sameness and routines. We also recognize military families are presented with even greater challenges in raising children with autism as they face periodic relocations, the absence of a spouse for extended periods of time and the inconsistent delivery of support services among bases and communities for their dependent family member who requires intensive intervention.

The Southwest Autism Research & Resource Center (SARRC) is proud to collaborate with the Organization for Autism Research (OAR) on the production of *Life Journey Through Autism: A Resource Guide for Military Families*, the third in a series of guides jointly produced by our organizations that strive to empower parents with accurate information. This guide provides tools for navigating the often-confusing world of autism and supports parents to be the best decision makers possible on behalf of their loved ones.

Nearly two decades ago, when our son was diagnosed with autism, we were told to *love him, accept him and plan to institutionalize him because there was no hope for individuals with autism*. That wholly unsatisfactory response was the impetus for creating the Southwest Autism Research & Resource Center (SARRC).

Founded in 1997, SARRC's mission is to advance discoveries and support individuals with autism and their families throughout their lifetimes. Our nonprofit is squarely focused on helping affected individuals and their parents with the complicated day-to-day issues associated with the disorder. We provide diagnostic assessments, intervention services, school and classroom support, life skills development and vocational training for young adults and adults, and education, training and support for parents, relatives, professionals, diagnosticians, interventionists, educators and physicians. At the same time, we continue to search for answers through our robust research program.

In recent years, we've spent more time with our affected military families to learn about their experiences, including the process and timing of diagnosis; early intervention training and support; base and area school support and integration; and the issues associated with supporting a child as they transition to adulthood. We hope to be of even greater support in the near term as SARRC replicates its programs, expands its tele-diagnostic and tele-therapeutic services and makes continued progress toward building meaningful futures for our children as they enter adulthood—futures that include friends, jobs, homes and communities that accept, support and value them.

Together in this journey,

Denise D. Resnik
SARRC, Co-Founder



Board of Directors

James M. Sack Chairman McLean, VA	Madeline Millman Vice Chairman Englewood, NJ
Peter F. Gerhardt, Ed.D. President Arlington, VA	Dean Koocher Treasurer White Plains, NY
William Donlon Hicksville, NY	Lori Lapin Jones Great Neck, NY
Anthony Ferrera Hillsborough, NJ	Gloria M. Satriale Chester Springs, PA
Lewis Grossman Port Jefferson Station, NY	Edward Schwallie Manasquan, NJ
Lisa Hussman Ellicott City, MD	Gregory L. Smith Lorton, VA

Staff

Michael V. Maloney
Executive Director

Peter F. Gerhardt, Ed.D.
President & Chair, Scientific Council

Alyssa Kruszyna
Assistant Director, Research and Programs

Lily Matusiak
Director, *RUN FOR AUTISM*

Julia Hornaday
Coordinator, *RUN FOR AUTISM*

Sarah Schuyler
Coordinator, *RUN FOR AUTISM*



Scientific Council

OAR's Scientific Council is comprised of 16 leading autism and medical professionals and serves as an expert information resource for all OAR matters concerning issues of research. In that regard, the Council assists OAR's Board of Directors in developing its research strategy, near term priorities, and long-range research objectives. The Council also provides program guidance and oversight for OAR's research competition and plays a central role in ensuring the highest quality reviews for prospective OAR research proposals.

Peter F. Gerhardt, Ed.D.
Founding Chair and President
Organization for Autism Research

Michael Alessandri, Ph.D.
Executive Director, UM-NSU CARD
Director, UM Marino Autism Research
Institute Clinical Professor, Department of
Psychology, University of Miami

Glen Dunlap, Ph.D.
Professor, Department of Child and
Family Studies
University of South Florida

Michael Fabrizio, M.A., BCBA
Clinical Services Director
Families for Effective Autism Treatment
(FEAT) of Washington

Joanne Gersen, Ph.D., CCC-SLP
Executive Director, Eden II Programs
Staten Island, NY

Gerald P. Koocher, Ph.D.
Professor and Dean, School for
Health Studies
Simmons College

Suzanne Letso, M.A., BCBA
Co-founder and Chief Executive Officer
Connecticut Center for
Child Development

Michael Londner, M.D., MPH, MBA
Inova Health Systems
Falls Church, VA

James A. Mulick, Ph.D.
Professor, Department of Psychology
College of Social and Behavioral Sciences
Ohio State University

Brenda Myles, Ph.D.
Ziggurat Group
Dallas, TX

Samuel L. Odom, Ph.D.
FPG Child Development Institute
University of North Carolina at Chapel Hill

Shahla Ala'i-Rosales, PhD., BCBA
Assistant Professor
Department of Behavior Analysis
University of North Texas

Luke Tsai, M.D.
Visiting Professor
Human Development and Child Studies
Oakland University

Ann Wagner, Ph.D.
Chief, Neurodevelopmental Disorders Branch
Division of Developmental
Translational Research
National Institutes of Mental Health

Mary Jane Weiss, Ph.D., BCBA
Director, Research and Training
Douglass Developmental Disabilities Center
Rutgers, the State University of NJ

Patricia Wright, Ph.D., MPH, BCBA
National Director of Autism Services
Easter Seals, Inc.



Southwest
Autism
Research &
Resource
Center

2010 Board of Directors

Officers

Howard Sobelman, Board Chair
Partner, Snell & Wilmer L.L.P.

Joseph Cooper, Board Vice Chair
Executive Vice President
Corporate & Product Development,
Medicis Pharmaceutical Corporation

Mary Martuscelli, Board Treasurer
President, Arizona, JPMorgan Chase, N.A

Cheryl Walsh, Board Secretary
Owner/President, WalshCOMM

John Napolitan
Retired Executive Vice President,
Morrison Homes, Inc.

Stephanie Papadopoulos
Parent

Sergio Penaloza
Director, Video & MTC Technology
Cox Communications

Joe Ray
Principal/Creative Director, Estudio Ray

Larry Reese
Vice President, Human Resources
Blood Systems, Inc.

Board Members

Rose Arck
Principal, ACS Realty Services, LLC

Joe Blackburn
President, Everest Holdings

Jane Christensen
Healthcare Management Consultant

Karen Donmoyer
Co-founder FRIEND Playground Program

Danielle Feroletto
President/Partner, Small Giants

Sue Glawe
Vice President Community Relations
Blue Cross Blue Shield of Arizona

Lisa Frace
Associate Vice President for
Planning/Budget
Arizona State University

Kathy Hancock
Executive Director, Fennemore Craig

Tom Kelly
President & Chief Operating Officer
Schaller Anderson, Inc.

Louis Kirby, II, M.D.

Mike Reina
Director of Marketing
Southern Wine & Spirits

Denise D. Resnik, SARRC Co-founder
Denise Resnik & Associates, Inc., President

Kay Snell
Autism Society of America, Tucson Chapter

Scott Sutherland
Vice President, Market Manager
Bonneville International Corporation

Leo V. Valdez
Senior Vice President/Manager,
Hutchinson, Shockey, Erley & Co.

Christine K. Wilkinson, Ph.D.
Senior Vice-President & Secretary
Arizona State University

Staff

Jeri Kendle, Acting President, Director of
Vocational & Life Skills Academy

Raun Melmed, M.D.
Medical Director, Co-Founder

Daniel Openden, Ph.D., BCBA-D.
Vice President, Clinical Services Director

Christopher Smith, Ph.D.
Vice President, Research Director

Acknowledgments

This publication is a product of the collaborative effort between the Organization for Autism Research (OAR) and the Southwest Autism Research & Resource Center (SARCC) with support from the American Legion Child Welfare Foundation. OAR and SARCC are dedicated to providing practical information to those living with the challenges of autism—individuals, families, and educators and other professionals.

OAR Project Team:

Peter F. Gerhardt, Ed.D., President & Chair, Scientific Council
Michael V. Maloney, Executive Director
Sarah Schuyler, Lead Project Intern
Danielle Kruglak, Project Intern
Kate Rice, Project Intern

SARRC Project Team:

Denise D. Resnik, Co-founder
Daniel Openden, Ph.D., BCBA-D.

Writers:

Katie C. Alexander, MS, OTR
Erin M. Clemens, OTR/L, CIMI
Marilyn Gilbert
Capt. Joseph McBreen, USN/MC

In addition to the members of the Board of Directors, Scientific Council, staff and writers, special thanks goes to the following people for their contributions to the content and editing of *A Guide for Military Families*:

LtCol Scott Campbell, USA; Karen Driscoll; Christine Erdie-Lalena, M.D., FAAP, LtCol, USAF, MC; Capt. Matthew Fitzgerald, USA; Joshua Feder, M.D.; Isabel Hodge; Becky Hunter; and LtCol James Phelan, M.D., USAF.

OAR would like to offer a special thank you to Dorothy Wolden, Principal/Owner, of Creative Intuition in Chandler, AZ, for donating her creative talent and services for the cover design.

Table of Contents

	<i>Page</i>
INTRODUCTION	1
Overview	1
Introducing <i>Operation Autism</i>	2
Icons	3
Federal, Military, and Autism Resources	3
Appendices	4
Algorithms	4
WHAT IS AUTISM?	5
Common Characteristics of Autism Spectrum Disorders	6
What Causes Autism?	7
How Many Children Have Autism?	8
How is Autism Diagnosed?	9
RAISING A CHILD WITH AUTISM	13
Diagnosis Autism: Your Child Still Has a Life to Live	13
Your Life as Your Child's Advocate Begins	14
Treatment Options: What Do I Need to Know?	15
Evidence-Based vs Complementary Therapies	16
Evaluating Treatments	21
Want to Know More about Treatments?	23
What Does My Child Need and How Do I Get It?	26
Continuity of Care	29
How Do I Access Services for My Child?	29
It is a Life Journey	30
DoD AND HEALTHCARE	33
TRICARE	33
Exceptional Family Member Program (EFMP)	35
EFMP: Understanding How It Works in Each Service	37
EFMP Enrollment	40
ECHO	40
Autism Demonstration Project	42
Command Support	43
AUTISM AND EDUCATION	45
IDEA: A Brief Legislative History	45
IDEA: Understanding Your Child's Educational Rights	46
The Individualized Education Program (IEP)	48

AUTISM AND EDUCATION (<i>continued</i>)	
Determining the Right Educational Placement for Your Child.....	49
Creating a Partnership with the School	54
The Parent’s Role in the Six-Step Plan for Inclusion	55
Note for Military Families, from Wrightslaw	56
TRANSITIONS	59
Tips for Successfully Managing Change	59
Military Transitions.....	60
Other Transitions	61
OAR’s Transition Resources	63
GLOSSARY	65
RESOURCE LISTING	73
Federal	73
Military	73
Autism	74
APPENDICES	
Appendix A: If You Suspect Your Child Has Autism	77
Appendix B: New to Autism?	79
Appendix C: Become an Informed Consumer of Information	81
Appendix D: Keeping It All Organized.....	87
Appendix E: Finding Other (Non-Military) Providers.....	91
Appendix F: Caring for Siblings of Children with Autism	93
Appendix G: Establishing Support for Yourself	99
Appendix H: Finding a Sitter for Your Child with Autism	101
Appendix I: Where to Start on Base	103
Appendix J: Communicating with Commanders	107
Appendix K: Developing Objective and Measurable IEP Goals for Learners with ASD and Preparing for IEP Meetings.....	111
Appendix L: Communicating with Teachers.....	117
Appendix M: Daily/Weekly Journal for Teach Communication	121
Appendix N: Tips for Permanent Change of Station (PCS) Moves	123
SAMPLE FORMS	129
ABOUT OAR.....	131
FAST FACTS	132
ALGORITHMS: THE MILITARY FAMILY AND AUTISM	133
Navigating the Military Funding System.....	135
Establishing Services	136

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.



Autism Prevalence

Autism affects an estimated 1.7 million children and adults in the U.S. based on the most recent prevalence figures (1:110 - 2009) from the U.S. Centers for Disease Control and Prevention (CDC). Military sources indicate that there are more than 13,000 military dependents with autism.

Military sources indicate that more than 13,000 military dependents, the majority of them children, have some form of autism. Their families face all the emotions and challenges that accompany having a child diagnosed with autism, compounded by the realities of military service: 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. These families need help navigating these uncharted and difficult waters.

This Guide and its companion Web site are designed for these families. The purpose of these resources is to give each family the tools and access to information that it needs on its 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 your child's education
- Tips and advice relative to transitions such as permanent change of station (**PCS**) moves, new schools and more
- Links to additional resources relative to autism and military families

Overview

This Guide is intended as a flexible reference tool that serves a variety of interests and purposes. 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, this Guide recognizes the many challenges autism presents from the time of a child's diagnosis through adulthood. It provides an overview of those policies that are relevant to military service members who have dependents with special needs. In addition, it offers some guidelines for navigating the military healthcare system and accessing required treatments and services. The Guide expands to the topic of educating children with autism, another area of great challenge that is often more difficult when compounded with the complexities of military life.

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

In addition to serving as a personal reference for military parents who have a child with autism, this Guide serves as a companion resource for *Operation Autism*, a Web site that offers added information and tools for military families impacted by autism.

Introducing *Operation Autism*

Operation Autism, located at www.operationautismonline.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 also some overseas locations. The content areas correspond to chapters in the Guide and include: *Autism 101*; *Raising a Child with Autism*; *Autism & Military Healthcare*; *Autism & Schools*; and *Tips for PCS Moves & Other Transitions*. *Autism 101*, which provides basic information about Autism Spectrum Disorders, is oriented toward the parent of a newly diagnosed child with autism. The remaining content areas and the resource directory provide information for parents across the board.



Raising a Child with Autism addresses post-diagnosis topics, including: immediate action after the diagnosis, the autism learning curve, stress, sources of support, and continuity of care. The section on *Autism & Military Healthcare* provides an overview of the key policies and programs governing healthcare within the Department of Defense (DoD) that are related to having a child with autism. *Autism & Schools* provides useful information for educational success, as well as information on Individual Education Programs (IEP's). Finally, *Tips for PCS Moves & Other 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 and permanent change of station moves, schools and more.

The *Search for Resources* section of the Web site offers a more comprehensive listing than the Resources section of this Guide. It includes information and links to DoD and military sites, national autism organizations, specific autism topics of interest, and pertinent sections of OAR's main Web site.

Icons

Throughout the text, you will run into images with text boxes that will highlight important facts, point you toward additional information in the Appendices, or provide to online resources on *Operation Autism* and other Web sites. Look for the following icons:



The light bulb icon denotes an autism fact or tip for families touched by autism;



The *Operation Autism* icon denotes a cross-reference to the *Operation Autism* Web site;



The computer icon denotes a reference to another online resource; and



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

Glossary

The Glossary that begins on page 65 lists and 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.

Federal, Military, and Autism Resources

Learn more about military and autism organizations and resources that may provide support to you, your child and your family by referring to the list on page 73. The list is not all-inclusive, but it represents a good starter list. Visit these Web sites to obtain information about the organizations, the resources they offer, and available support groups. Sign up for their mailing lists. In effect, you will 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 Search for Resources page on *Operation Autism* and similar listings on the Web sites and resources you consult.

Appendices

The [Appendices](#) that begin on page 77 offer supplementary information to what you will find within the Guide. Some simply amplify the discussion. Others provide templates and tip sheets that you can reproduce and use in your family’s journey through autism.

Algorithms

The [Algorithms](#) provided on page 133 are built as flowcharts to help you visualize and organize the steps involved in acquiring funding and services for your child as soon as possible once a diagnosis has been made, begin each algorithm and move through them simultaneously.

What Is Autism?

Autism is a 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.

Autism is typically diagnosed by the age of 3. In cases of later diagnosis, caregivers report developmental differences beginning in the first three years of life. The symptoms of autism involve three major areas of development: social, communications, and behavior. Specifically, a person with autism may:

- Have difficulty engaging in reciprocal social interactions with others;
- Not communicate with others in developmentally appropriate ways; and
- Exhibit self-injurious or repetitive behaviors, focus interest on a single topic or activity, or fixate on objects (such as ceiling fans or toys).

One of the hallmarks of autism is that the characteristics vary significantly among individuals with autism. No two individuals with autism are the same.

Autism is one of five Pervasive Developmental Disorders that vary in the severity of symptoms, age of onset, and association with other disorders like intellectual disability. The others are:

- **Asperger Syndrome** (or Disorder)
- Pervasive Developmental Disorder-Not Otherwise Specified (**PDD-NOS**)
- Rett Syndrome
- **Childhood Disintegrative Disorder**

Individuals with Asperger Syndrome have, by definition, average or above average intelligence, whereas individuals with autism or PDD-NOS can have a range of intellectual functioning from below to above average. Rett Syndrome and Childhood Disintegrative Disorder are very different in that they both are regressive in nature (i.e. initial development is typical prior to the onset of an extended period of cognitive and behavioral regression). They are considered pervasive developmental disorders in that they affect a child across all developmental domains (pervasive), and they occur early in and affect the course of a child's development (developmental). Children with either of these two rare disorders usually have significant cognitive and developmental differences across all domains.

What Is Asperger Syndrome?

Asperger Syndrome is a complex neurodevelopmental disorder marked by impairments in socialization, communication, cognition, and sensation. Like classic autism, Asperger Syndrome affects a person's ability to communicate and relate to others. It

is a lifelong disorder that carries with it considerable, long-term challenges. Although the characteristics of Asperger Syndrome will vary from person to person, common effects of the disorder include:

- Trouble understanding social cues and conversational language styles
- An inflexible adherence to routine or ritual
- Repetition of movements or words and phrases
- Difficulties with fine-motor skills and sensory integration (or sensory processing)
- A persistent preoccupation with objects or narrowly focused topics of interest

What Is PDD-NOS?

Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) is the term used to identify a condition that shares some of the central features of autism yet does not meet all the criteria for an actual diagnosis of autism or Asperger Syndrome. While learners with a PDD-NOS diagnosis may present as being “less affected” than the learner with autism, the course of intervention generally parallels that of an autism diagnosis.



Evolving Terminology

As you work with providers for your child, you may come across the term “sensory processing disorder”, or **SPD**, in place of “sensory integration disorder”.

Understand that neither is a medical diagnosis today. Though the meanings are essentially the same, “sensory processing” is emerging as the preferred term within the OT community as it encompasses the dysfunction symptoms that could possibly result in SPD becoming an accepted “medical diagnosis” in the future. In that event, it is possible that insurance might eventually reimburse for evaluation and treatment of SPD.

Common Characteristics of Autism Spectrum Disorders

Challenges with Social Interactions

- Challenges registering and interpreting nonverbal language
- Difficulty with pretend play
- Infrequent eye contact and/or unusual eye gaze patterns
- Facial expression may appear “flat” or may not match emotional state
- Difficulty interpreting facial expressions
- Inaccurately judges personal space; may stand too close to others
- Difficulty identifying and managing emotional states
- Challenges managing stress and anxiety
- Difficulty understanding another person’s perspective or how their own behavior affects others

continued

Communication Challenges

- Except in the case of Asperger Syndrome, often delayed in expressive and receptive language; there may be an absence of verbal language
- Very literal understanding of speech; difficulty in picking up on figures of speech and nuances
- Echolalia—may repeat words or phrases heard without regard for meaning
- Pragmatic language difficulties, in which an individual has a good or even expansive vocabulary and ability to form sentences but has difficulty using language socially.

Behavior Differences

- Unusually intense or restricted interests in things (maps, dates, coins, numbers/statistics, train schedules)
- Unusual repetitive behavior, verbal as well as nonverbal (hand flapping, rocking)
- Unusual sensitivity to sensations: may be more or less than typical individuals
- Difficulty with transitions, need for sameness
- Rigid adherence to rules, routines, and expectations
- Possible aggressive, disruptive and/or self-injurious behavior
- Possible lack of awareness of potentially dangerous consequences to behavior whether for self or others

What Causes Autism?

You'll hear a number of theories, some with very vocal adherents, but the short answer is that we don't really know. Research supports a strong genetic component, or perhaps a genetic predisposition triggered by something that happens later in development. This lack of clarity about the cause contributes to considerable speculation among parents and scientists and conflicting theories about the cause or causes of autism.

Although autism was first identified in 1943 (Kanner, 1943), the underlying neurological mechanisms that give rise to this complex disorder are still unclear and its cause remains unknown. Autism is a neurodevelopmental disorder that affects the functioning of the brain. Brain scans of people with and without autism reveal differences in the size, structure, and shape of their brains, as well as differences in how some brain regions "communicate" or connect with other brain regions. Nonetheless, much about autism remains unknown, and research to determine what may cause autism continues with investigations into a number of areas including:

- Genetics
- Immune system dysfunction
- Environmental factors

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, caused the onset of autism. Despite the strongly held beliefs of proponents of the vaccine theory, there is no scientific proof 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, a parent's questioning the role and effect of the MMR shot is quite understandable. As a result of those concerns and the advocacy of many parents and parent groups, there is ongoing research that is examining environmental factors, to include vaccines, as they may relate to autism. At present, however, there is no evidence that a link between autism and vaccines exists.

How Many Children Have Autism?

Autism Spectrum Disorders (ASDs) are found in all cultures and across all socio-economic groups with the ratio of boys to girls with ASDs being 4 to 1. In the past 30 years the prevalence rate of Autism has skyrocketed. Recent prevalence estimates indicate that autism occurs in 1 out of every 110 children born (CDC 2009), highlighting the realities that autism spectrum disorders are not rare and that effective intervention is critical. Why the increase? No one knows for sure. Some epidemiologists point to a broader definition of autism and an increasing awareness among medical professionals as key contributing factors. Others consider the potential impact of environmental factors (e.g., toxins) as a contributing cause. As more and more research is funded and completed, this question may soon be answered.



Prevalence and Statistics

You can find detailed autism prevalence data and statistics on the CDC's Web site:

<http://www.cdc.gov/ncbddd/autism/data.html>.

Until recently, the U.S. Centers for Disease Control and Prevention (CDC) estimated that 1:150 children in the U.S. have an ASD (2007). Dividing the U.S. population by 150 provides an estimate of 1.7 million people with autism in the U.S. The CDC's latest study released in December of 2009 indicates that the ratio is now 1:110; this means that the estimate of people living with autism in the U.S. has risen to 2.6 million people.

What's the Rate Among Military Families?

Just as the research conducted by the CDC in establishing its prevalence ratio reported varying ratios in the different geographic locales studied, the prevalence rate among military dependents varies and is higher. According to numbers released recently by the Department of Defense (**DoD**) in response to a request filed under the Freedom of Information Act in June 2008, there are 13,243 active duty family members and an additional 8,784 dependents of retired service members with diagnoses on the autism spectrum.

The numbers provided in response to the FOIA request compared against the total number of military dependent children, 1,177,190 according to the latest DoD study (2005), result in a 1:88 prevalence ratio among children of active duty military service members. When one considers that the numbers cited tilt heavily toward service members in the more junior ranks and the youngest parents (i.e. the families most vulnerable to the additional financial burden that accompanies having a child with autism), the implications for and potential impact on military healthcare are significant.

How Is Autism Diagnosed?

There is no genetic or medical test to diagnose autism. As a result, clinicians rely on behavioral observation, generally quantified through the use of a standardized diagnostic tool. In general, diagnosis is a two step process that involves: 1) screening, followed by 2) a comprehensive diagnostic evaluation.

If you, the parent, have any concerns about your child's development, speak to your child's primary care physician (**PCP**) and ask specifically whether your child should receive a developmental screening. 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. As a general rule of thumb, PCPs should check your child's progress against developmental milestones during every "well visit".

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



Developmental Warning Signs

If you suspect that your child might have a developmental delay or possibly autism, please see [Appendix A](#) on page 77 to learn where to start gathering information and [Appendix B](#), on page 79, to learn about milestones and red flags.

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 serve as the necessary first step toward helping your child receive the right treatment. Some examples of specialists that conduct developmental screening are neurologists, child psychologists, neuropsychologists, psychiatrists, developmental pediatricians, and speech therapists.

What Tools Are Used to Determine Autism?

Ultimately, health care professionals are looking for a constellation of social, communication, and behavioral developmental differences that are consistent with a diagnosis of autism. The variability that is observed among individuals with autism in combination with an absence of a medical/laboratory test or distinctive physical sign that can be used to identify autism can make diagnosis more difficult. In order to bring more clarity to the diagnostic process, there are specific tests given to rule out other developmental differences and several forms of assessment to 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 3, after parents begin noticing delays or differences in social interaction as well as verbal and non-verbal communication.

Several tests may be used to screen for or diagnose autism, including:

- **Modified Checklist for Autism in Toddlers (M-CHAT)** is a checklist of 23 yes/no items for early detection. Web link: http://www2.gsu.edu/~psydlr/Diana_L._Robins,_Ph.D.html.
- **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)** observes a child's behavior and uses a 15-point scale to evaluate a child's relationship to people, body use, adaptation to change, listening response, and verbal communication.



Ratings Scales

Rating scales are particularly useful to track your child's more significant changes over time.

For more information on these and other assessments commonly conducted by autism professionals in consultation with parents, see *OAR's Life Journey through Autism: A Parent's Guide to Assessment* at <http://www.researchautism.org/resources/reading/index.asp>.

If your child is diagnosed with autism, it is the beginning of a much different journey than what you had 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. Just as there are sure to be challenges, there will just as surely be moments of hope and accomplishment. The *Raising a Child with Autism* section that follows provides information that will help you adjust to this difficult diagnosis and offer tips for taking other, helpful first steps.

Intervention invariably involves more than one treatment and an intervention team of multiple providers. The American Academy of Child and Adolescent Psychiatry (AACAP) recommends that several types of professionals and services be involved in the care of an individual with autism. This team should be under the direction of one certified and experienced professional who will develop, organize, advocate for, and watch over your child's specific program. The team may include some or all of the following professionals: Developmental Pediatrician, Child Psychiatrist, Neurologist, Neuropsychologist, Board Certified Behavior Analyst, Child Psychologist, Special or General Education Teacher, Occupational Therapist, Physical Therapist, and/or Speech/Language Therapist.

Raising a Child with Autism

Diagnosis Autism: Your Child Still Has a Life to Live

Receiving a diagnosis of autism for your child will no doubt be difficult for your family and for you. Unlike the outlook for many other disabilities and disorders (including autism not long ago), there is a tremendous amount of hope with respect to autism today. Research continues to show that many children with autism improve dramatically with effective intervention and that individuals with autism can go on to live productive, meaningful lives. So, allow yourself some time to accept your child's diagnosis, but be ready to take action as quickly as possible knowing that your child is still your child, and you will always be the authority on your child—his/her personality, areas of strength and difficulty, and likes and dislikes. Your child has a life's journey ahead, and every day is an opportunity for you to positively impact his or her prognosis.

It is important for parents to understand that autism is indeed a spectrum disorder, meaning that there are many individual differences between children diagnosed with autism. We do not know which children will be most responsive to a specific intervention at first. Generally, the best outcomes for children with autism have been associated with early intervention, so it is most important for you to begin identifying resources that support your child's development and your family's quality of life from the moment of diagnosis on.

Some parents have a more difficult time than others accepting their child's diagnosis. In some cases, this may be due to a lack of understanding of what autism is, how it is caused, and what it means for their child's future. In other cases, an autism label may be something that some families prefer to avoid entirely. For parents in either case, we often suggest a shift in their focus from the label of autism to treating the symptoms that initially raised concern. Of primary importance is that the child's intervention team and the parents work to improve the child's communication and social interaction and reduce problem behaviors. Next, parents can identify other symptoms and developmental milestones (e.g. dressing, toileting) that can be targeted directly with intervention. Approaching autism in this way keeps the focus on addressing those areas that interfere with your child's learning and development, and allows you to remain solution-oriented.

Another reason that some parents struggle to accept their child's diagnosis is that autism places all of their hopes and dreams for their child in question. An autism diagnosis, though, does not mean that parents should give up on those hopes and dreams. Rather, we urge parents to use them to further inspire them in their efforts to help their child. Interestingly, when asked what it is that they want most for their child, parents of children with and without autism respond similarly: they

want their child to be healthy, have friends, secure any needed supports, and most importantly, be happy. Although raising a child with autism will be challenging at times, such aspirations for your child are achievable, particularly with strong family support. With autism you are not running a sprint, but rather a marathon with many bumps and hurdles along the way. The best thing that you can do following a diagnosis is to get started.

Your Life as Your Child's Advocate Begins

While a diagnosis with autism presents the range of emotions and complexities just described, it also brings dual jolts of clarity and purpose in terms of understanding what is going on with your child. In that light, there are three beneficial aspects. First, whereas some parents struggle to accept and cope with the label of autism, many have been able to identify areas of concern for their child—and often from a young age—without any confirmation of suspected differences in development. Receiving the diagnosis provides a name for the cluster of symptoms that initially caused your concern and for which you have been seeking answers. Once a child is diagnosed, parents can begin to better understand what they are facing and educate themselves about how best to support their child and family. Further, parents may be better equipped to discuss their child with other family members and trusted friends, as well as their child's teachers and pediatrician.

Second, the diagnosis is a prerequisite for accessing required services. Although differences across state funding agencies exist, the necessary medical, educational, and therapeutic services for children are rarely provided without a diagnosis. Children with autism require high quality, effective intervention in order to make positive progress, yet the costs of providing intervention are often high. Depending on where you live, funding is available that may assist with or even offset the costs of treatment. Your child's diagnosis, though, is the key to accessing this funding.



Accessing Services

To read more about navigating the military funding system and acquiring services for your child with autism, please see the [Algorithms](#) on page 133.

Finally, your child's diagnosis with autism signals the beginning of your expanded parental role as the principal advocate for a child with special needs. Although states and local education agencies provide funding for services (in addition to what is covered by DoD healthcare), budgets are often tight and there are almost always more families in need than there are resources available. Unfortunately, you cannot expect to be contacted by service agencies after the diagnosis and provided a menu of options for your child, nor can you expect that all the services that your child and family need will be accessible. The responsibility for taking the first action step—and likely several more—will in all likelihood rest with you. It is critical that you become

fluent in essential, trustworthy information about autism and understand your child's and family's needs, as well as the services available so that you can make informed decisions about your child's course of treatment.



Getting Started

For tips on how to effectively search for information using online search engines, please see [Appendix C](#) on page 81.

One of the greatest challenges following your child's diagnosis will be sifting through the vast array of information about autism. There are a multitude of autism resources, and it is often very difficult to distinguish between reputable and questionable sources of information. In academic parallels, autism has just placed you in a graduate level course for which your prior education has little or no bearing. What's at stake, however, is not academic. Your child's and family's lives are

truly in the balance. The information and support your child, family, and you need are available; it will be up to you to find them.

As you begin this process, you are sure to find conflicting opinions (and sometimes high emotions) about the best methods or treatment to use. You will just as quickly understand that, despite the abundance of information available, there is no central clearinghouse for autism information. Nor is there anything like a "Good Housekeeping Seal of Approval" attesting to the quality and accuracy of what you find. Some sources are excellent; others less so. Start with the organizations in the [Resource Listing](#) at the back of the Guide and use the search tools and tips contained in [Appendix C](#).

Treatment Options: What Do I Need to Know?

One of the most important considerations for parents with respect to treatment options is the complexity that arises as a result of the individual differences among children who are diagnosed with autism. Because of these differences, treatment is likely to look somewhat different across children and what might be successful for one child may not be successful for all. Although it would be convenient to have a "one treatment fits all" approach, you will not see this with autism. Rather, the selection of appropriate interventions should be individualized for each child. Any treatment that claims to be a "one size fits all" approach should be carefully scrutinized.

Accurate and regular assessment of your child and your family may be the foundation for selecting the most appropriate course of treatment. Assessments do not necessarily need to be long, nor should they be done infrequently. Think of it as the primary tool you have to benchmark your child's progress. Ongoing assessment of your child's progress and response to intervention is just as important as the initial assessment so that appropriate treatment goals and/or modifications to the treatment plan can be continually updated.

In fact, the data from ongoing assessment of your child is probably more important than the particular treatment you select. This data provides critical information about whether an intervention is working and goals are being met efficiently, or whether an intervention is ineffective, should be discontinued, and/or another approach taken. While some treatments may take longer than others to demon-



A Word of Caution

Parents should be aware that with the increase and prevalence of individuals diagnosed with autism has come an increase in the number of treatments available, many of which have not been adequately supported by scientific evidence. Beware the latest *Cure du Jour!* The more educated you become about effective treatments, the better decision-maker you can become. See www.autism-watch.org for more information.

strate improvements, do not be reticent if you have questions. 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, your family needs to be included in the assessment of your child. Treatments should be selected that are culturally sensitive and fit within your family's daily routines and the ability of your child and family to participate in all aspects of the intervention correctly.

What are the Best Treatments?

This is a trick question! There are no "best treatments" in general terms. It should be clear by now that treatment for autism is

highly individualized. So, the best treatments are those that are provided at the right level and intensity; 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 an interested and competent team leader.

Evidence-Based vs. Complementary Therapies

As you Google autism treatment, you will discover that there are more treatments available than you could have ever imagined. They run the gamut from resources well-founded in science to the other extreme, information lacking in scientific support and bordering on quackery. In between are more than a few interventions that seem to have helped some children and that some parents swear by, even if the support is anecdotal. What's a parent to do?

Most informed sources will advise you to build your child's intervention plan around treatments that have a solid basis in science (i.e. are "evidence-based"). In medicine, evidence-based is defined as "the conscientious,



Keeping Track of It All

Treating a child with autism involves a steady stream of documentation.

To learn how to organize and manage these materials, please see [Appendix D](#) on page 87.

explicit, and judicious use of current best evidence in making decisions about the care of individual patients.” In autism intervention, that same standard of care applies, wherein those responsible (the intervention team) think about the individual, the existing science that suggests what treatments might be helpful for that individual, and work with families to implement and track progress for the child.

In the end, it rests upon families to choose what treatments best fit their needs and the needs of their children. A so-called “complementary” or “alternative” therapy may offer some benefit to your child’s health, disposition, or quality of life, regardless of whether or not it addresses autism directly. With investigation and subsequent consultation with your child’s PCP or intervention team leader, you might decide to include one or more of these therapies in your child’s treatment plan.

What Are Evidence-Based Treatments?

Even though there is no universal “best” intervention, most autism and medical professionals will recommend evidence-based treatments. The six described below are some of those most frequently used in integrated intervention approaches.

Applied Behavior Analysis (ABA)

ABA is an intensive, evidence-based approach to early intervention. Children usually work up to 40 hours a week with a trained, ideally certified, professional with a Board Certified Behavior Analyst (**BCBA**) certificate. Interventions based upon the principles of ABA have been documented as highly effective in teaching a range of academic, social, communicative, motor, and adaptive skills. The central theory behind ABA is that behavior that is reinforced (rewarded) is more likely to be repeated than behavior that is not reinforced. Behavioral intervention seems to help children “learn to learn.” Research has shown that ABA-based interventions



Assessment and ABLLS

For more on assessment and ABLLS, please see OAR’s *Life Journey through Autism: A Parent’s Guide to Assessment* at <http://researchautism.org/resources/reading/index.asp>.



ABA Standards

A listing of minimum standards for ABA programs can be found at http://www.abainternational.org/special_interests/autism_guidelines.asp.

consistently teach new skills and behaviors to children with autism. Be advised that waiting lists for BCBAs can be long because the demand is so great. There is a wide variety of treatment programs that fall under the category of ABA, from highly structured intensive programs such as **Discrete Trial Training (DTT)** to parent driven naturalistic behavioral programs such as **Pivotal Response Training (PRT)**.

Developmental Approaches

Whereas ABA is derived from earlier research into the nature of learning, the Developmental Approach to intervention for children with autism is based more in developmental theory, linking development of cognition and communication with emotion, e.g., from Piaget, Vygotsky, and Bolby. So, ABA and developmental approaches come from different theoretical backgrounds. Developmental interventions look at the whole child (e.g., sensory, motor skills) and the family (e.g., deployment, moving, etc.), 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. Developmental approaches include **DIR/Floortime** (Developmental, Individual-Difference, Relationship-based approach), **ESDM** (The Early Start Denver Model), and others. For more information, please see the interdisciplinary council on Developmental and Learning Disorders' Web site (<http://www.icdl.com>).

Speech and Language Therapy

Communication challenges are at the heart of an autism spectrum diagnosis and may contribute to behavior problems. Including a speech/language pathologist (SLP) on your child's team may help improve his or her communication skills. Some speech 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. A child's progress in language acquisition can be rated with a tool used by many speech therapists called the Assessment of Basic Language and Learning Skills (ABLLS). The ABLLS is an assessment, curriculum guide, and skills tracking system used for children with autism. The ABLLS allows therapists and teachers to carefully track a child's specific task objectives.



Roles of SLPs

The American Speech-Language Association's position paper on roles of SLPs can be found at

<http://www.asha.org/docs/html/PS2006-00105.html>.



Project TEACCH

Web link: <http://www.teacch.com>

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 goal of the TEACCH approach is to provide the child with the necessary skills to understand his or

her world and other people's behavior. Because TEACCH tends to build upon skills children with autism already have, some families may see it as a more congenial approach than the more structured interventions associated with ABA.

Picture Exchange Communication Systems (PECS)

One of the main areas affected by autism is the child's ability to communicate. PECS helps get basic language underway and helps provide a way of communicating for children who do not talk.

PECS uses ABA-based methods to teach children to exchange a picture for something they want, such as an item or activity. This approach enables a child with autism to communicate more easily.



PECS

Web link: <http://www.pecs.com>



More on OT

To find out more about Occupational Therapy, please see <http://www.aota.org/Consumers.aspx>.

Occupational Therapy (OT)

Children with autism may benefit from working with an occupational therapist (OTR). An occupational therapist is a trained and licensed healthcare professional who collaborates with the family, the individual (when appropriate), and the intervention team to set intervention goals in the areas of activities of daily living (e.g. dressing, self care), instrumental activities of daily living (e.g. use of a computer, care

of personal belongings), education, work, play, leisure, and social participation. The OTR then evaluates performance to understand what interferes with desired performance of the skill and uses that information to build an individually tailored treatment plan. An OTR is trained in various intervention approaches and works closely with other members of the team. An OTR may provide direct services to an individual or serve consultatively.

Physical Therapy (PT)

Children with autism often may have challenges with physical coordination and gross motor skills. In addition, they may not always be as physically active, as typical children capability notwithstanding, partly because of their limited interest and social skills and parental considerations like supervision and safety. A physical therapist will design a regimen that will help children with autism develop muscle strength and physical fitness while at the same time addressing issues related to gross motor coordination and skills.



More on PT

To find out more about Physical Therapy, please see <http://www.moveforwardpt.com/>.

What Should I Know About Complementary Therapies?

Among the myriad treatments available to individuals with autism spectrum disorders (ASD) today, complementary or alternative therapies have gained a great deal of attention in recent years. According to a 1996 study,¹ up to 50 percent of children

¹Nickel, R.E. MD. *Controversial therapies for young children with developmental disabilities*. 1996; 8:29–40.

with autism in the United States may receive some form of complementary and/or alternative medicine.

Complementary therapy generally refers to those interventions or treatments that differ from conventional treatments like applied behavior analysis or biomedical therapies and they may be used to complement these more traditional therapies. Complementary therapies have emerged as part of a growing assortment of treatments used for individuals across the autism spectrum. In fact, many families who have chosen to use complementary therapies see them as fun, motivational, and potentially helpful treatment approaches for their son or daughter with ASD. Despite the fact that little scientific evidence exists on the efficacy of these treatments, many parents and therapists attribute improvements in their child or patient to complementary therapies, such as those briefly described below.

Treatment Types

Some complementary treatments available to children with ASD include:

Animal Therapy	Treatments include: horseback riding, also referred to as hippotherapy, which proponents claim draws on the multidimensional movement of the horse to help organize sensory input; and dolphin/dog/cat/bird-assisted therapy, a mode of treatment that purports to improve a child's cognitive skills by "relaxing" the brain.
Art Therapy	A complementary therapy that uses the artistic techniques of drawing, painting and modeling to reportedly help individuals enhance their cognitive, communication, and social/emotional skills through tactile and sensory stimulation.
Auditory Integration Training	A series of auditory treatments designed to normalize auditory processes in individuals who, it is hypothesized, experience distortions in hearing or who may be hypersensitive to sounds.
Craniosacral Therapy	A non-invasive massage technique based on a belief in a person's innate ability to heal him/herself through the use of specific massage techniques focused on the head and spine. Proponents claim this then allows for the release of tension and the dissolution of energy blocks.

Music Therapy	A therapy often used to help children with motor, speech and fluency problems The therapy uses music to increase behavioral, social, psychological, communicative, physical, sensory-motor, and/or cognitive functioning.
Play Therapy	A therapy that introduces the elements of play and develops and extends the variety of play activities intended to increase a child's cognitive abilities, language development and social skills.
Vision Therapy	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 Treatments

When considering any therapy for your child with autism, conventional or complementary, you should first gather as much information about the treatment as possible in order to make an informed decision. Given the lack of supporting scientific research in most cases involving complementary therapies, you should seek information and opinions on particular treatments and therapies from fellow mothers and fathers, health care providers and autism groups.

You should also discuss any complementary therapies you are considering with your child's current therapists and treatment professionals. The therapists may know about the therapy and 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. It's important that your inquiries go beyond the therapies to include evaluation and careful scrutiny of complementary therapy facilities before beginning any program.

Professional organizations associated with the type of therapy parents are seeking for their child are another possible source of reliable information. Their staffs may be able to help explain the treatment and offer information on the type of training required by a treatment provider, treatment guidelines, and, perhaps, a list of best practices or certified providers. At the minimum, the organization may provide a listing of therapists in the local area or state for parents to contact.

Do Your Homework in Advance and Ask Questions

After selecting a therapy, you should begin contacting therapists to gain further information about the therapy, the therapist, the facility, and the providing agency's philosophy toward and experience in treating children with autism. Begin by asking for a brief consultation in person or by phone with the therapy provider. This discussion will offer you the chance to ask a list of questions about the therapy.

First, you should inquire how much experience and success the provider has had treating children with autism at the facility and whether this experience includes having treated clients with symptoms similar to your child's. You should also ask if the provider believes the therapy can effectively address your child's condition. Be sure to ask for any research supporting the treatment's efficacy and use, especially as it relates to children with autism.

Here are a few suggested questions:

- What benefits can we expect from this therapy?
- How much time is required to see progress?
- Are there any risks associated with this therapy?
- Could the therapy interact favorably or unfavorably with conventional treatments?
- Will the therapy interfere with any of the child's daily treatments/activities?
- How long will the child need to undergo treatment? How often will his/her progress or plan of treatment be assessed?
- How is progress measured?
- What type of equipment or supplies are needed, and what will they cost?
- Are there any conditions for which this treatment should not be used?
- Are there any risks generally associated with this treatment?
- Do you have any current or previous clients who would be willing to talk with me?
- Do you make data-driven decisions about treatment?
- May I come and observe at your facility in advance of beginning treatment for my child? (Due to confidentiality concerns, this may not always be possible.)

To prepare your son or daughter for any therapy ultimately chosen, you should inquire about what will happen during your child's initial visit. Observe very closely. After each of the first few visits, you should 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, you should discuss modifications, pursue different options, or perhaps 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 provide your child.

In a Nutshell

Complementary therapies, despite many testimonials to their efficacy, are largely unproven in scientific terms. Although anecdotal reports may abound, anecdotal reports are not proof of efficacy. Taking the time to do your homework and selecting the right therapy and provider are key to ensuring children receive sound treatment. The selection process will be most effective if parents fully consider their child's strengths and needs. Unfortunately, this is one of the areas where parents are most often left on their own to do the research and draw conclusions about the effectiveness of a therapy. It may feel time consuming, but it is time well spent in ensuring your child's progress.

For all individuals with an ASD, it is important to remember that comprehensive, socially valid and research-supported educational methods lie at the center of any effective package of interventions. Beyond that, there are multiple complementary therapies that you may want to research, evaluate and ultimately consider using with your child. If you do proceed, do it wisely armed with information and with due caution.

Want to Know More About Treatments?

You will find some excellent information about evidence-based treatment in the National Research Council's (2001) report, *Educating Children with Autism*, and Richard Simpson's (2005) article, "Evidence-based practices and students with autism spectrum disorders."



"Evidence-based practices and students with autism spectrum disorders"

You can find a PDF file of the article at <https://depts.washington.edu/pdacent/Publications/Simpson/Simpson2.pdf>.

More recently, the National Autism Center published the National Standards Report, an analysis of the effectiveness of available treatment options for autism. It



National Standards Report

You can find a PDF file of the National Standards Report at

http://www.nationalautismcenter.org/pdf/NAC%20NSP%20Report_FIN.pdf.

Additionally, you can read a brief summary of the Project findings and conclusions here:

<http://www.nationalautismcenter.org/pdf/NAC%20Findings%20&%20Conclusions.pdf>.

is a good place to start when trying to understand treatment options. The Report quantifies the level of scientific evidence supporting various educational and behavioral treatments that target the core characteristics of autism spectrum disorders and rates them in four categories: established/effective, emerging, unestablished, and ineffective/harmful. The Report uses research from 775 different studies and ranks a total of 38 treatments.

Below are the 11 treatments the National Standards Project identified as effective based on scientific evidence:

Antecedent Package	The modification of situational events that typically precede the occurrence of a target behavior. <i>Examples: cueing and prompting; environmental enrichment; habit reversal; incorporating echolalia, special interests, thematic activities, or ritualistic/obsessional activities into tasks; and stimulus variation.</i>
Behavioral Package	Reduces problem behavior and teaches functional alternative behaviors or skills through the application of basic principles of behavior change. <i>Examples: behavioral toilet training/dry bed training; contingency mapping; differential reinforcement strategies; functional communication training; and progressive relaxation.</i>
Comprehensive Behavioral Treatment for Young Children	Reflects research from comprehensive treatment programs that involve a combination of applied behavior analytic procedures which are delivered to young children (generally under the age of 8.) <i>Examples: discrete trial and incidental teaching.</i>
Joint Attention Intervention	Involves building foundational skills involved in regulating the behaviors of others; often involves teaching a child to respond to the nonverbal social bids of others or to initiate joint attention interactions. <i>Examples: pointing to objects, showing items/activities to another person, and following eye gaze.</i>
Modeling	Relies on an adult or peer providing a demonstration of the target behavior that should result in an imitation of the target behavior by the individual with ASD. Modeling can include simple and complex behaviors and is often combined with other strategies such as prompting and reinforcement. <i>Examples: live modeling and video modeling.</i>
Naturalistic Teaching Strategies	Use primarily child-directed interactions to teach functional skills in the natural environment; often involve providing a stimulating environment, modeling how to play, encouraging conversation, providing choices and reinforcers, and rewarding reasonable attempts. <i>Examples: focused stimulation, incidental teaching, milieu teaching, embedded teaching, and responsive education and prelinguistic milieu teaching.</i>

Peer Training Package	Teaching children without disabilities strategies for facilitating play and social interactions with children on the autism spectrum. Peers may often include classmates or siblings. <i>Examples: peer networks, circle of friends, buddy skills package, Integrated Play Groups™, peer initiation training, and peer-mediated social interactions.</i>
Pivotal Response Treatment	Focuses on targeting “pivotal” behavioral areas, such as motivation to engage in social communication, self-initiation, self-management, and responsiveness to multiple cues, with the development of these areas having the goal of very widespread and fluently integrated collateral improvements. Key aspects also focus on parent involvement in the intervention delivery, and on intervention in the natural environment such as homes and schools with the goal of producing naturalized behavioral improvements.
Schedules	The presentation of a task list that communicates a series of activities or steps required to complete a specific activity; often supplemented by other interventions such as reinforcement. <i>Examples: written words, pictures or photographs, or work stations.</i>
Self-management	Promoting independence by teaching individuals with ASD to regulate their behavior by recording the occurrence/non-occurrence of the target behavior, and securing reinforcement for doing so. Initial skills development may involve other strategies and may include the task of setting one’s own goals. <i>Examples: use of checklists, wrist counters, visual prompts, and tokens.</i>
Story-based Intervention Package	Involves a written description of the situations under which specific behaviors are expected to occur. <i>Examples: Social Stories™ are the most well-known story-based interventions. They seek to answer the “who,” “what,” “when,” “where,” and “why” in order to improve perspective-taking.</i>

Of note, 22 treatments were rated as “emerging”, meaning that they have some evidence of efficacy but have not yet been proven to be beneficial, and five treatments were rated as “unestablished”, meaning that their effectiveness is not supported by current research.

A final consideration for parents with respect to treatment options is that some children with autism — though certainly not all — may have underlying medical conditions

that can affect their ability to respond or respond as well to evidence-based treatments. While very few medications have been FDA approved for autism, addressing co-morbid conditions such as seizures/epilepsy, anxiety, gastrointestinal issues, and attention deficits may optimize other treatments. Just keep in mind that 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 with autism can more fully benefit from behavioral, educational, and therapeutic interventions. Again, an accurate assessment should identify whether there is any need or value in beginning a medical treatment regimen. If begun, ongoing assessment is critical for determining whether such treatments should be continued or adjusted.



Finding Providers

For tips on finding other providers for your child, please see [Appendix E](#) on page 91.

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

Children who receive a diagnosis of autism demonstrate impairments in three major areas: communication, social interaction, and repetitive/restricted interests. What your child needs, then, are interventions that directly address these three areas. It is particularly important to establish a functional communication system that your

child can use to interact with other people. Many programs are very good at producing improvements in other behaviors, such as compliance, stacking blocks, or even beginning academic skills. Others may be effective at teaching children to use expressive language, but the child's vocabulary may be limited to labeling objects. It is critical that treatment programs put a communication system in place that teaches children to use it



A Starting Point

Operation Autism's Search for Resources page is a good place to start your search for additional information and resources online.

competently with their parents, siblings, other family members, peers, teachers, and other people in the child's community. Social communication deficits are perhaps the most limiting aspect of autism. Addressing them early, consistently, and well is likely to have the most meaningful impact on an individual's quality of life.

Your child's course of treatment will likely include programs that are based on applied behavior analysis (ABA). ABA-based interventions have the most scientific evidence and have been shown to be effective in improving a variety of behaviors in autism. There is, however, widespread misunderstanding about what ABA is, and what it is not. ABA is not a single, regimented treatment for autism. ABA is a science that includes a collection of principles and procedures for improving behaviors, both within and outside of the autism field. So, a number of autism treatments are based on the science of ABA. These include: discrete trail training (DTT), pivotal response

treatment (PRT), incidental teaching, precision teaching, verbal behavior, picture exchange communication system (PECS), and Learning Experiences: An Alternative Program for Preschoolers and Parents (LEAP). It is important to keep in mind, though, that not all of these treatments “fit” nicely together even though they share a common scientific foundation. Further, more research is needed to better understand which children with autism will be most responsive to which treatments. Therefore, when considering treatment options, it is helpful to work closely with someone who has extensive experience in developing programs for children with autism—preferably a Board Certified Behavior Analyst (BCBA), who can design a program that meets the individualized needs of your child and family.

In addition to treatment options discussed up to this point, your child’s treatment program should include the following components:

Early Intervention

While there may be differences of opinion on how best to treat autism, most experts agree that early intervention is critical. As mentioned earlier, the best prognostic outcomes are generally associated with early intervention, so get your child started with an intervention program as soon as possible.

Intensive Intervention

Aside from starting early, the most important component of your child’s program may be treatment of sufficient intensity and duration, that is, the number of hours of intervention. Various professional sources recommend anywhere from 25–40 hours per week of early intensive behavioral intervention, but treatment should not stop there. Children with autism should be engaged in meaningful learning opportunities throughout their day. Also, while the number of hours is important, it is the quality of the intervention during those hours that is critical. In working with the provider, take steps to ensure that interventions are implemented properly and that the therapists working with your child are well-trained and supervised.

Family Involvement

One way to increase the intensity of your child’s treatment program is to ensure that you and other family members are 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; it is to help maintain or increase the intensity of the desired treatment. Because you interact with your child regularly, teaching you how to best structure your interactions will enhance and support your child’s treatment program. Further, once you have received training, you will likely



Autism Impacts Siblings Too

For more information about caring for siblings of children with autism, please see [Appendix F](#) on page 93.

be able to train other family members, babysitters, teachers, and peers—an important consideration should new therapists be added to your team or you and your family relocate. 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 the treatment program. However, when engaging siblings, it is important to be sensitive to how your child’s sibling(s) are currently coping and what their needs are as well.

Intervention in Natural Environments

Generalizing skills to new environments and/or with new people can be challenging for many children with autism. There are two primary ways to improve **generalization**. First, if your child is taught skills in a non-natural environment (e.g. therapy room or special education classroom), ensure that a systematic plan for generalizing skills to the natural environment is in place *before* a new skill is introduced. Teaching skills or behaviors that cannot be generalized are not likely very meaningful, so either ensure that a generalization plan is in place or consider whether or not it is necessary to teach the skill.

On the other hand, intervention programs implemented directly in natural environments (e.g. home, school, and community) are more often preferable. By teaching children in natural environments where they live, learn, and play, generalization training is essentially built into the intervention. So, generalization is more likely to naturally occur.

Intervention with Typically Developing Peers

Treatment programs that are primarily implemented in natural environments likely include opportunities for children with autism to interact with their typically developing peers. Children with autism who are included in general education classrooms, for instance, may have numerous opportunities to talk with classmates. However, being physically close to peers and having opportunities to interact does not necessarily bring about social competence. The social deficits 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 Are Implemented With Fidelity

Fidelity of implementation refers to whether interventions are implemented correctly. Even the most well-researched treatments will be largely ineffective if they are not implemented with fidelity. This is similar to a medication not working properly if not taken as prescribed. Fidelity of implementation, then, is critical to ensuring your child receives a high quality treatment program. Since treatments are often implemented by interventionists who may not have extensive training in autism, it is critical to ensure that interventionists understand what to do and demonstrate

the ability to implement it in order to maintain intervention fidelity. Supervision is essential. In addition, the key to maintaining fidelity of intervention is to ensure that the necessary data are regularly collected.

Continuity of Care

Intervention invariably involves more than one treatment and multiple providers, i.e. an intervention team. Continuity of care refers to the extent to which intervention programs are coordinated across these treatment providers without lapses in treatment. Ideally, all of your child's therapists would work for one agency to ensure that everyone is on the same page. That doesn't happen much in the case of autism and is even less liable to occur in the case of a military family and autism.

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. The team may include some or all of the following professionals: Developmental Pediatrician, Child Psychiatrist, Neurologist, Board Certified Behavior Analyst, Child Psychologist, Special or General Education Teacher, Occupational Therapist, Physical Therapist, and/or Speech/Language Therapist. All of the aforementioned providers may work for different service agencies, posing challenges to maintaining continuity of care. It is critical, nonetheless, that your child's team of treatment providers works together and maintains open lines of communication to avoid conflicting therapies.

It may be helpful, then, to select a "lead" therapist/agency who is responsible for overseeing the child's overall program and for coordinating interventions across therapists and service providers. Generally, this therapist/agency should be the one who has the most expertise in autism treatment programs and spends the most time with your child.



One Excellent Resource

Autism Speaks has an online resource guide (<http://www.autismspeaks.org/community/fsdb/search.php>) of state service agencies that may be able to provide you with a list of providers in your area.

How Do I Access Services for My Child?

There are a number of ways to access the services that you need for your child. First, most states have state agencies that coordinate and provide services for individuals with developmental disabilities. It is important that you learn about your state's agency, how services are provided, and how you can secure the services that your child needs. Second, although there are differences in each state's services, the Individuals with Disabilities Education Act (**IDEA**) requires that your state's educational system also provides the appropriate services necessary for your child to

make meaningful progress (discussed in more detail in the following section). Third, insurance coverage for autism treatment is increasingly available in many states and TRICARE/TRIWEST now has funding available specifically for autism. Finally, many service providers and therapists also accept private payment for treatment.

Next, begin identifying autism treatment providers in your area. Alternatively, 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) Web site includes a certificant registry that allows you to search for a behavior analyst by name, country, zip code, city, or state. Contact providers and assess their ability to provide what your child needs (as previously discussed) and determine how you can access their services (e.g. vendored with the state, insurance coverage, or private pay).



BACB Web Link

You can access the BACB Web site at http://www.bacb.com/becom_frame.html.

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.

It Is a Life Journey

While autism primarily affects the individual diagnosed with the disorder, it also impacts the entire family, including the parents, siblings, grandparents, and extended family. For instance, some families find they can no longer go out to eat at a restaurant together because the child may be too disruptive. Siblings may be hesitant to invite friends over to the family's home or may struggle with how to play with the child with autism. It is for these reasons that treatment goals should be developed for both the child with autism and the family. For example, intervention programs can and should be designed for such things as improving restaurant behaviors or teaching siblings how to effectively interact with one another. Indeed, the family's overall quality of life likely influences outcomes for the individual with autism.

Parent training programs may be an effective way for addressing the needs of the family. In contrast to center-based programs where a therapist works one-to-one with the child without the parent(s) present, parent training programs are typically implemented in the family's home and community. Parents can be taught how to implement intervention and manage behavior during daily routines such as mealtime, toy play, bath time, or bedtime. Similarly, parent training can be provided at the park, grocery store, or shopping center. Providing parents—and even siblings and grandparents—with this type of training may help the entire family better support

the child with autism and one another. Further, parent training is often empowering for parents as they can identify the impact they are making on their child's future.

Some families struggle to cope with autism more than others, and research has suggested that many parents are under considerable stress. Parent stress may come from any number of factors, including concern over the child's future, persistent problem behaviors, marital problems, financial problems, and social support. Unfortunately, parent stress may prevent parents from actively participating in their child's treatment program, particularly if the program includes parent training as a core component.

Parents, however, are the most important part of their child's treatment team; so, it is critical that stressors be identified and parents seek help so stress can be managed. Indeed, parents must take care of themselves if they are to be effective at taking care of their child. Many communities have active parent support groups that meet weekly or monthly. For many parents, meeting with other families who are also living with autism can be helpful. Support groups can also be a useful resource for identifying treatment providers or learning about advocacy efforts.



Taking Care of Yourself

For tips on managing stress and finding support for you, please see [Appendix G](#) on page 99.

Although support groups can be helpful, some parents may benefit from counseling services provided by appropriately trained counselors or psychologists. Whether provided individually or as part of a group, counseling may help to reduce parent stress as well as provide additional family support. Counseling can also be provided for siblings and grandparents to address the broader family context.



Finding Babysitters

For tips on finding a sitter for your child with autism, please see [Appendix H](#) on page 101.

Finally, parents also need time away from the child with autism (and his/her siblings.) Many families can access respite care through state service agencies. Many service providers offer respite as a separate service for families and can help identify people to stay with the child while the parents have a night out. If not, parents can post flyers for respite workers at local colleges or share a respite worker with

another family. Occasionally, extended family members can be "hired" as respite workers. In any case, parents should commit to scheduling time away from the child with autism (and his/her siblings) at least a couple times each month.

DoD and Healthcare

The Department of Defense (DoD) has created the policies that support military families of the Army, Navy, Air Force, and Marine Corps as well as their reserve components. In order to best provide healthcare to active duty and retired uniformed service members as well as their families and survivors, DoD has established **TRICARE**—a comprehensive healthcare system serving over nine million beneficiaries worldwide. While TRICARE is equipped to manage the healthcare needs of most of its beneficiaries, DoD has recognized the unique challenges facing individuals with special needs and their families. Additionally, DoD has recently recognized the extraordinary challenges faced by individuals with autism spectrum disorder (ASD) and their families. To help families overcome these challenges, additional programs are either required or available: The Exceptional Family Member Program (EFMP), Extended Care Health Option (ECHO), and The Autism Demonstration Project. This section of the Guide describes these principal healthcare benefits to which military families with special needs are entitled, or may be entitled.



Where to Start on Base

For helpful steps regarding where to start on base during the screening and diagnosis processes, please see [Appendix I](#) on page 103.

TRICARE

TRICARE is the healthcare system the Department of Defense (DoD) provides for active duty and retired uniformed services members, their families, and survivors. In military hospitals, clinics, and healthcare facilities worldwide, active duty service members from any of the seven uniformed services—Army, Air Force, Navy, Marine Corps, Coast Guard, Public Health Service, and the National Oceanic and Atmospheric Administration—have priority for care. Through TRICARE, disabled family members of uniformed personnel have the advantage of comprehensive healthcare. Many of them who are also low-income families may qualify for both disability benefits and assistance. To provide care to all beneficiaries, TRICARE combines military healthcare resources as well as TRICARE-authorized civilian healthcare providers. Authorized civilian providers include the following categories:



- Network providers are those who have negotiated discount agreements with TRICARE.
- Participating providers are those non-network providers who have agreed to accept TRICARE's allowable charges as payment in full.

- Non-participating providers are those who do not accept TRICARE allowable charges as payment in full while requiring varying payment conditions. They may charge patients up to 15% more than the TRICARE-allowed charges, and they may also require patients to file their own claims and wait for reimbursement.

Within the United States, TRICARE is organized into three geographic healthcare service regions: North, South, and West. With support from civilian healthcare contractors (who are selected through a competitive process), a TRICARE Regional Office administers each of these geographic regions. Each TRICARE region offers the same choices for healthcare plans and coverage, although TRICARE beneficiaries living overseas have fewer options. The TRICARE Web site has links to Web sites for North, South, and West regions. It also has contact information for the TRICARE overseas regions: Pacific, Europe, Canada, Latin America, and Puerto Rico/Virgin Islands.

Northern Region (Health Net):

1-877-874-2273

CT, DC, DE, IL, IN, KY, MA, MD, ME, MI, NC, NJ, NY, OH, PA, RI, VA, VT, WI, and WV.

Southern Region (Humana Military Healthcare Services):

1-800-444-5445

AL, FL, GA, LA, MS, OK, SC, TN, and TX.

Western Region (TriWest):

1-888-874-9378

AK, AZ, CO, HI, ID, IA, KS, MN, MO, MT, NE, NV, NM, OR, ND, SD, UT, WA, and WY.

Overseas:

1-888-777-8343

TRICARE offers three healthcare options to family members of active-duty service members living in the United States and certain overseas locations. These options vary by cost, flexibility, and availability and include TRICARE Prime, TRICARE Extra, and TRICARE Standard. Family members with special needs, including autism, may receive care under one of these TRICARE options. Each service determines the eligibility status of TRICARE beneficiaries, and this status is maintained in the Defense Enrollment Eligibility Reporting System (DEERS).



DEERS

The Defense Enrollment Eligibility Reporting System (DEERS) is a military database that lists everyone who is eligible for TRICARE benefits, including autism services. It is important to keep your DEERS record up-to-date, especially with each PCS move: <https://www.dmdc.osd.mil/appj/address/index.jsp>. DEERS enrollment is a prerequisite to eligibility for autism services under TRICARE.

TRICARE Prime

TRICARE Prime is a managed care option similar to a civilian health maintenance organization. Beneficiaries receive their care from a Military Treatment Facility (MTF) or through the Regional Contractor's provider network. Active-duty family members enrolled in TRICARE Prime pay no fees, deductibles, or co-payments for authorized medical services, emergency care, and other care authorized by their Managed Care Support Contractor. Family members living with their active-duty service members in locations at least 50 miles or one hour from the nearest MTF may enroll in TRICARE Prime Remote for Active Duty Family Members.



TRICARE Prime

TRICARE Prime is the only option for active-duty service members. This restriction does not apply to families and dependents.

TRICARE Extra

TRICARE Extra is a preferred-provider option that allows active-duty family members to receive care from the network of providers with whom TRICARE has negotiated discounted costs. Beneficiaries must pay cost-shares for services after they have met the annual deductibles. Although there are no claims to file, the choice of providers is limited to those in the network. TRICARE Extra is not available overseas and is not available to active-duty service members.

TRICARE Standard

Formerly known as CHAMPUS, TRICARE Standard is a fee-for-service option that allows active-duty family members to receive care from any TRICARE-authorized provider. Beneficiaries must pay cost-shares after they have met the annual deductibles. Cost-shares are 5 percent higher than with TRICARE Extra. However, TRICARE Standard can be used simultaneously with Extra, and beneficiaries who use a network provider will have their claims adjudicated under Extra. Furthermore, by visiting a non-network provider, they will incur greater out-of-pocket expenses, and they may have to file their own claims. TRICARE Standard provides the broadest choice of providers, and in some locations, it may be the only option available to family members. TRICARE Standard is not available to active-duty service members, but it is available to their families and dependents.

Exceptional Family Member Program (EFMP)

DoD has also established the Exceptional Family Member Program (EFMP) for service members and civilian personnel within DoD who have children with special needs, including autism (i.e. an Exceptional Family Member, or EFM). However, members of the Coast Guard who are part of the Department of Homeland Security are covered under a special program called The Work-Life Program (<http://www.uscg.mil/worklife>). EFMP is mandatory for all active-duty service members, and enrollment is required



A Note about the Coast Guard

Members of the Coast Guard who are part of the Department of Homeland Security are covered under a special program called The Work-Life Program. See <http://www.uscg.mil/worklife> for more information.

immediately upon identification of a family member's qualifying special need. Enrollment in EFMP does not adversely affect selection for promotion, schools, or assignment. There are two functions of EFMP: a personnel function for administrative and management purposes and one that provides a range of family support. Although the personnel function of EFMP is standardized across all services, the family support function is not. Both functions are discussed in greater detail below.

Informing Your Command

As described in Chapter 2, having a child with autism immediately 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. Simply put, there will be times when the military parent's presence is necessary for the best interest of the child. It is important then 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 for any reason, be sure to make your request as early as possible to allow the best opportunity for your command to react and adjust schedules as needed.



Tell Your C.O.

Please see [Appendix J](#) on page 107 for tips on effectively communicating your family's unique needs to your Commanding Officer and other leaders within your command.

Personnel Function

Through the personnel function, EFMP handles administrative and management duties uniformly across all services. 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. The program also includes case management, supplying information regarding a family member's specific needs to agencies that provide managed care support. However, EFMP does not contact care providers or agencies directly; this remains each family's responsibility. The DoD's Web site defines the EFMP personnel function as follows:

- A mandatory program for all active-duty service members.
- Service is standard across all services, and the services these families require are documented.
- Family members with special medical and/or educational needs are identified, and the services these families require are documented.

- The family's needs are also considered during the process of personnel assignments (especially while family members are being approved for accompanied travel to overseas locations.)
- The personnel and medical commands and members of the DoD educational system overseas are also included.

Family Support Function

The purpose of the family support function is to provide a range of direct support for families with special needs, including autism. Procedures for this support function are not standardized, so the services it offers may vary widely, depending on the type of service needed and on location. The EFMP family support function is not mandatory. DoD policy on family centers allows, but doesn't require, the military services to offer family support services to exceptional family members within the military services' family support systems. Furthermore, as mentioned above, the support function itself differs from service to service and from location to location. Military Homefront (www.militaryhomefront.dod.mil/) offers detailed information for each service on its web site.

For the purpose of the Guide, a summary of how EFMP works in each service is provided here.

EFMP: Understanding How It Works in Each Service

Air Force

The Air Force uses EFMP as part of their approach to supporting military families with an EFM, as well as an additional program called the Air Force Special Needs Identification and Assignment Coordination (SNIAC). The SNIAC participates in the personnel function of EFMP and provides management support of medical information for the EFMP enrollment functions. The EFMP enrollment information is critical in the relocation process, as this information is used to ensure that a family is located somewhere that can accommodate the EFM's medical



and educational needs. It is essential that families keep enrollment information as current as possible. For families of an EFM, SNIAC coordinates relocations and works collaboratively with EFMP family support to provide comprehensive support. This includes finding community resources and support as well as coordinating educational and medical services, PCS assignments, and housing accommodations to families enrolled in EFMP. A new



Air Force EFMP/SNIAC

Interim policy letters and the AFI (when published) may be found on the Air Force Special Needs Web site: <https://www.afspecialneeds.af.mil/skins/afsn/home.aspx>.

Air Force Instruction (AFI) on special needs and **Educational and Developmental Intervention Services (EDIS)** is being developed now that the Family Advocacy Program no longer handles the relocation process for the special needs/family member.

The Air Force Special Needs Coordinator (SNC) and Family Member Relocation Clearance Coordinator (FMRCC) are typically located in the Life Skills Support Center and/or Family Advocacy office at the Medical Treatment Facility (MTF). The EFMP Re-Assignments Branch is a personnel function. Staff members for the Family Support Center provide services for members, but they don't have a designated Coordinator.

Army

EFMP performs both personnel and family support functions for the Army. EFMP Enrollment information allows assignment managers to consider an EFM's needs during the reassignment process. Sponsors are responsible for keeping all enrollment information current, providing updates whenever there are changes or at least every 3 years. In order to provide adequate family support, EFMP works in conjunction with other military and civilian agencies to provide a comprehensive approach for medical, educational, community, support, housing, and personnel services to families with special needs.



The Army staffs family centers with EFMP managers, who are professionals responsible for administrative duties, coordinating care for each individual, as well as establishing and serving as a member of the special needs resource team. The special needs resource team includes several other professional members as well as the parents of the EFM. Together, the team determines what local resources and services are a match for the EFM.

In order to initiate enrollment, Special Needs Advisors serve as the point of contact and are located at an Army MTF.

Marine Corps

Similar to the Army, the Marine Corps uses both the personnel and family support functions of EFMP. With personnel functions, EFMP enrollment information allows Marine Corps Occupational Field Monitors to consider an EFM's needs during the relocation process. For this reason, it is essential that families keep enrollment information as current as possible; at a minimum, sponsors must update enrollment information every two years, at least nine months prior to receiving orders and/or with the change of status of an exceptional family member. The Marine Corps uses four enrollment



categories as guidelines when making assignment decisions. The Military Homefront Website provides more information about these categories.



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/efmp/ on the family support page.

Marine Corps Community Service centers are staffed with EFMP Coordinators who help families navigate the enrollment process and local resources. In addition to administrative duties, EFMP Coordinators are available to help families with a variety of tasks, including obtaining medical and educational evaluations, educating local commands and communities of EFMP issues, identifying useful local resources, and providing advocacy support.

These EFMP Coordinator services are a significant part of how the Marine Corps uses EFMP to improve the quality of life for Marine Corps families with special needs. The Marine Corps also recognizes the complexities involved in coordinating care for an EFM, so Marine Corps EFMP helps support families in their efforts to coordinate military and civilian medical communities and educational systems.

Enrollment in Marine Corps EFMP begins with enrollment in DEERS, which is a prerequisite for obtaining services under TRICARE. Following enrollment in DEERS, family members should contact their EFMP Coordinator, who will provide assistance with the enrollment process. Once family members have completed the enrollment paperwork, the EFMP Coordinator forwards enrollment paperwork to the Central Screening Committee and to Headquarters Marine Corps for processing and category assignment.

Navy

The Navy also uses both the personnel and family support functions of EFMP; however, the focus is on the personnel function. Like EFMP personnel in the Marine Corps, EFMP enrollment information allows Navy Detailers to consider an EFM's needs during the reassignment process. For this reason, families must keep enrollment information as current as possible. When making assignment decisions, the Navy uses six enrollment categories as guidelines. The Military Homefront Web site (www.militaryhomefront.dod.mil/) provides more information about these categories.



EFMP Coordinators are professionals located at the MTF instead of family centers. Although Navy EFMP Coordinators serve both the personnel and family support functions, the emphasis of their work lies with the personnel function. EFMP Coordinators assist families through the enrollment process, and once families have

completed all of the paperwork, EFMP Coordinators maintain copies and forward enrollment applications to the Navy EFM Central Screening Committee. In addition, EFMP Coordinators have other administrative responsibilities. They also work with the Health Benefits Advisor and TRICARE Area Case Manager to coordinate medically related services. Beyond the EFMP Coordinator's critical role in personnel, the EFMP Coordinator provides EFMP family support services by referring enrollees to the Fleet and Family Support Center EFMP Liaison for community assistance. The Fleet and Family Support Center (FFSC) can assist families with relocation information, including medical and educational information as well as information on other community resources. In addition, FFSC staff can provide referrals to community agencies.

Enrollment in Navy EFMP begins with the EFMP Coordinator at the MTF. The EFMP Coordinator assists with completion of the application; when it is complete, the EFMP Coordinator sends it to the appropriate Central Screening Committee for review.

EFMP Enrollment

Enrollment in EFMP is mandatory for active-duty service members, and it is required immediately as soon as a special medical and/or educational need is identified. The required forms are as follows:

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

It is important for families to understand that enrollment primarily supports the personnel function. For therapeutic intervention and EFMP family support, the service member and/or spouse must contact the appropriate staff, and 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. This way, services can resume as quickly as possible rather than remaining on hold while documentation travels with household goods.



Find an EFMP Office

For contact information on EFMP offices in special locations, families can visit **Operation Autism's** Resource Directory or follow the Military Installations link on the DoD Military Homefront Web site at <http://www.militaryhomefront.dod.mil>.

ECHO

In 2005, TRICARE replaced the Program for Persons with Disabilities with the Extended Care Health Option (ECHO). ECHO provides financial assistance to eli-

gible beneficiaries who qualify based on their specific mental or physical disabilities. It also offers services and supplies that are not available through the basic TRICARE program. In other words, ECHO supplements the benefits of the basic TRICARE program option that eligible family members use.

To be eligible for ECHO benefits, families are required to be enrolled in their Service's Exceptional Family Member Program. Those who qualify for special needs benefits should speak to an EFMP representative, who will ensure that they are properly enrolled in EFMP and provide appropriate ECHO contact information. To qualify for ECHO benefits, dependents of an active-duty service member must have a qualifying condition. In this case, the regional managed — care support contractor will determine program eligibility.

Once a family member qualifies and is registered with ECHO, ECHO provides financial assistance through a cost-share program, which is monthly and based on the sponsor's pay grade. This financial assistance can be used for a variety of services and equipment, including assistive services (e.g. qualified interpreter), in-home respite care services (please see following paragraphs), Home Health Care (please see following paragraphs), medical and rehabilitative services, training for assistive devices, special education (including Applied Behavior Analysis Therapy), transportation (in limited circumstances), institutional care when a residential environment is required, equipment, durable equipment (including adaptation and maintenance), and assistive technology devices.

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." To provide caregivers this time, ECHO's additional benefits include respite care and ECHO's Home Health Care. Respite care provides relief for caregivers of EFM, including family members with an ASD. 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. However, respite care is authorized only when the beneficiary is receiving some other ECHO benefit during the same month.



Respite Care

Unrelated to TRICARE, some respite care may be available through EFMP. Availability varies by branch of service and location. At the time of this Guide's publication, the Army and Marine Corps have EFMP respite care programs and the Navy is beginning a pilot program in various locations.

ECHO also includes extended home health care and respite care for caregivers of an EFM whose condition keeps him/her homebound. Under ECHO's Home Health Care (EHHC), licensed or registered nurses provide skilled home health care for more than 28 hours a week. Members should speak to their regional contractor or TRICARE Area Office to determine the maximum monthly limit (cap) for EHHC home-care benefits.

Under EHHC, respite care may allow for a maximum of eight hours, five days per week, which may be used as a sleep benefit. However, respite care under EHHC cannot be used in conjunction with ECHO's respite care. Furthermore, the monthly maximum benefit has increased from \$1,000 to \$2,500, and with no adjustment for the cost-share liability. Monthly cost-shares range from \$25 to \$250, depending on the sponsor's pay grade.

ECHO benefits do not automatically transfer when a family's active duty sponsor is reassigned. Families must obtain new ECHO benefit authorizations before receiving services at a new location. To ensure a smooth transition, families should contact their regional contractor, local MTF, TRICARE Area Office, or case manager before moving.

Autism Demonstration Project

The TRICARE Autism Demonstration Project helps provide Educational Interventions for ASDs (EIA). EIA are defined as those intervention services that are evidence-based, based on intervention rooted in applied behavior analysis, and (upon meeting the former) can be covered by TRICARE. These interventions have been shown to reduce or eliminate specific problem behaviors and to teach skills to individuals with autism. These EIA services are not covered under basic TRICARE benefits (TRICARE Prime,

TRICARE Standard and Extra), and they are only partially covered through ECHO. Through an expanded network of educational intervention providers (including both EIA supervisors and tutors), the Enhanced Access to Autism Services Demonstration allows eligible beneficiaries to have access to a greater range of existing EIA services.



Autism Services Demonstration Online

You can read more about the Autism Demonstration Project at
<http://www.tricare.mil/mybenefit/home/overview/SpecialPrograms/ECHO/AutismServicesDemonstration>.

The Enhanced Access to Autism Services Demonstration began on March 15, 2008, and it is available only in the 50 United

States and the District of Columbia. The TRICARE Autism Services Demonstration Web site has additional information. Additional Autism Services Demonstration Resources include the following:

- Department of Defense Report and Plan on Services to Military Dependent Children with Autism.
- TRICARE's Autism Services Demonstration Power Point Presentation.
- Autism Eligibility Checklist.
- Frequently Asked Questions about the DoD's Enhanced Access to Autism Services Demonstration.

Families who would like to enroll in the Autism Demonstration Project should enroll their EFM in EFMP. Following enrollment in EFMP, families should register their EFM in ECHO. Services may begin during the ECHO registration process. Families will need to submit their EFM's Individualized Education Program (IEP) or Individualized Family Service Plan (IFSP) documentation to the Managed Care Support

Contractor (there are special requirements for EFMs who are home-schooled and who are not required to have an IFSP or IEP). The EFM's behavioral plan, developed by the EIA supervisor, must be sent to the medical provider who oversees care for the EFM. The EFM's Primary Care Physician will need to submit verification of the ASD diagnosis.



IEPs and IFSPs

To read more about IEPs and IFSPs, please see the *Autism and Education* chapter that follows.

In order for an EFM to participate in the Autism Demonstration Project, at least one parent/caregiver must participate in some training activities, including classroom training and practical training from the EIA supervisor. The DoD and TRICARE offer more information on parent training as well as other aspects of the Autism Demonstration Project in a PowerPoint linked through the Military Homefront Web site (<http://www.militaryhomefront.dod.mil/>).

Command Support

The TRICARE policy requires service members who have overseas orders to verify that the command sponsors accompanying family members to enroll in the TRICARE Overseas Program Prime, including TRICARE Global Remote Overseas.

When TRICARE Standard beneficiaries need care overseas, they may be required to pay the entire bill at the time of service and then file a claim for reimbursement. Under TRICARE Standard, family members must pay an annual deductible and cost shares each time they get care outside the Military Treatment Facility (MTF). TRICARE Standard and Plus beneficiaries are eligible only for space-available care in an MTF overseas.

Autism and Education

Securing your child's education will naturally become one of your highest priorities, if it is not already. When a child begins school, it is a significant milestone for the child and the parents, often causing tears for them all. For parents of a child with autism, it is even more complex and stressful. It is a transition that raises even greater anxiety and uncertainty for both you and your child. Each school year, a new teacher and a new school or classroom can bring those same anxious feelings and new challenges. Nonetheless, establishing an educational program that is the best match for your child while also ensuring that your child has a positive experience in school is essential to your child's meaningful progress in school and future quality of life.

The complexities of military life do tend to exacerbate the challenges associated with establishing and maintaining a child's educational program. The transitory nature of military service results in family separation and frequent moves, which results in new schools. These circumstances are difficult enough for individuals who do not have a disability. For a person with special needs like autism, transitioning from a familiar school, teacher, and classroom setting to another presents an even greater challenge. It can be incredibly difficult to maintain the integrity of your child's educational program and secure his/her continued progress, but there are steps you can take to smooth the transition and support your child's development. There is one important factor in your favor. 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**).

This chapter is designed to give you the tools you need to support your child's education in the context of life with the military by providing a background on your child's educational rights as well as information regarding the process and documents that outline your child's unique educational needs. It also offers some guidance on how you can work with your child's teacher and school to create a positive and supportive learning environment for your child.

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 legislation is 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 that children with disabilities should be educated with children who are not disabled to the maximum extent possible. IDEA also sets forth the requirements for an educational team, of which you are a critical member among

school staff who are required or requested to participate. No IEP decision should ever be made without your participation. Finally, this law requires that students with disabilities must have an IEP, which describes the student's current level of functioning, his or her 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 profound. Therefore, children with autism (and very frequently **Asperger Syndrome**) are considered disabled under the IDEA guidelines and are legally entitled to an IEP from the school 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 his/her educational team, and the process of determining eligibility can take up to 60 days.

IDEA: Understanding Your Child's Educational Rights

Understanding your child's educational rights is both essential and at times overwhelming. This section of the Guide presents a simple overview of your child's rights and what you can expect as you work with the school to establish your child's educational program.

In summary, IDEA governs the way that school districts must find, evaluate, develop, and implement special education programs. IDEA requires a specific procedure from the identification of a student who may require special education through the implementation and ongoing evaluation of that student's educational program. That process can be time consuming and 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 specific eligibility of the student.
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. Every 3 years, an educational team is required to determine if a new evaluation must be conducted.

Evaluation and Eligibility

Obtaining initial eligibility can be the most time consuming step in the process, but it is vital to clearly establishing your child's specific areas of strength and need. This evaluation becomes a source of common understanding for the team and the primary information source for educational program decisions. Initial evaluation data will be updated annually with data from your child's performance at that time. It may 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, of which autism is one. Some states will assign multiple diagnostic categories where appropriate. Remember, you are a part of the educational team and must be included in all of these decisions.

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

There should be a meeting (before evaluations are conducted) at which the educational team determines which specific assessment tools will be helpful in understanding how and why your child demonstrates the difficulties he/she does at school. The educational team may use assessments that measure cognition, academics, social emotional domains, and those relevant to related services (OT, PT, and SLP). The school psychologist, social worker, classroom teacher, and/or speech pathologist

are some of the educational professionals who conduct educational assessments. An audiologist may complete hearing tests, and the classroom teacher will give input about your child's academic progress and classroom behavior.



A Parent's Guide to Assessment

For more information about assessment, refer to *A Parent's Guide to Assessment*, part of OAR's *Life Journey through Autism* series:
<http://www.researchautism.org/resources/reading/index.asp>.

You will 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 will 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). Parents should always feel comfortable asking the team questions about different assessment tools, how they will be conducted and what the results will mean for their child. If you have heard of an assessment that you think would be helpful to your child and the team, you should ask the team about that assessment.

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

You should bring copies of any evaluation tools you would like to provide to the educational team. You may also want to bring copies of other reports that have been generated by service providers (e.g. your child's PCP documenting a medical diagnosis of autism or your child's private SLP's progress reports). You should also bring materials you can use to record the events in the meeting (e.g. notebook paper, pen, laptop, and/or specific notebook that you would like to use to keep track of school-related documentation). You may want to bring a friend or family member who can be present to support you. It might be helpful to ask your friend or family member to

take notes so that you can focus more on the meeting itself. You may also want to bring a photo of your child.

In summary, hang in there. The eligibility process requires time and patience, but it is worth all the thoughtfulness and dedication of every team member. Always remember that you are a valuable member of the educational team, and you have a wealth of information to share with the team about your child.



A Parent's Tip

"There is no assessment that can measure your child's spirit, will, or how much he is loved or valued. It is up to me, as his Mom, to keep my WHOLE son in mind. It helps sometimes if I bring a picture of him with me to meetings where he is being discussed."

—Parent of an adolescent with autism

The Individualized Education Program (IEP)

Once your child is determined eligible for special education, he/she has specific rights governed by the Individuals with Disabilities Education Act (IDEA), which is 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).

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, speech and language therapists, occupational therapists, school psychologists, and parents.



Effective IEP Goals and Meeting Planning

For tips on writing clear, measurable IEP goals for a student with ASD, and preparing for a successful IEP meeting, please see [Appendix K](#) on page 111.

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. The IEP also specifies the educational placement for your child, which is discussed further in the next section. The team will meet intermittently to discuss your child's progress on IEP goals.

More specifically, an IEP always includes the present levels of academic achievement and functional performance, annual goals, short-

term objectives, special education services the student requires, and a determination regarding placement. In addition, IDEA requires yearly review and revision of the IEP to see if the goals were met and to generally review student performance. Annual goals must be written objectively and measurably while capturing the performance

changes expected in the following year. The short-term objectives should contain incremental and sequential steps toward meeting each annual goal. Annual goals and short-term objectives can be about developing academic, social/emotional, communication, and/or motor skills, as well as specifying any targets for the reduction of problem behavior.

In addition to annual goals, the IEP will specify what accommodations and modifications are required for your child. For example, most students with autism profit from some form of a visual schedule. If this applies to your child, this should be specified in accommodations and modifications. For more information on this section of the IEP, please see Wrightslaw.com.

Finally, the IEP will outline what services are required for your child (e.g. special education, adaptive physical education, SLP, OT, and/or PT). The IEP will also specify the educational placement for your child. This is discussed in greater detail in the next section.



A Great Educational Resource

Wrightslaw provides parents, educators, advocates and attorneys with accurate, reliable information about special education law, education law, and advocacy for children with disabilities.

For more information, see www.wrightslaw.com.

Once the IEP is final, your child's teacher will be 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. This underscores the importance of collaboration and continuous communication between the teacher and you on IEP goals and more. One good practice that enhances communication is the use of a student calendar; this may be customized for an individual student and used to document your child's progress toward each specific, measurable goal.

Determining the Right Educational Placement for Your Child

This is the last step of the IEP process, and it is an IEP team decision. There should never be a placement decision made without you. Conversely, the educational placement of your child can not be made solely by you. Therefore, it is important that you come to the IEP meeting prepared to discuss educational placement. In order to do this it is essential that you are knowledgeable about:

- The educational placements available within your school district
- The educational placements typically made available to students with autism (you can do this by reaching out to local support groups)
- Any private, special education schools ("out of district schools") available in your area

The following is intended to help you understand the types of placements that exist so that you can better participate in your team's discussion of your child's educational placement. There are a many strong opinions out there about proper placement for students with special needs. Some parents and professionals believe that every student with a disability belongs in the regular education mainstream while others believe that students with disabilities are best served in settings that are specifically tailored to special needs. The intent of IDEA and its accompanying LRE requirements is that a student should participate in the general education environment as much as is possible without interfering with that student's ability to access a FAPE. Each of the following four types of special education placements has its supporters and critics, but all that matters is the best match for your child, and that may change over time. While it is important to be familiar with the following terms, it is essential to remember that discussion regarding educational placement is the final step in the IEP development process, and educational placement is a team decision.

General Education Setting

In the general education setting, (also known as "inclusion class" or "mainstream placement") a student is in a regular ("general") education class with his/her grade-level peers. In addition to the general education teacher, there may be a special education teacher whose job it is to adjust the curriculum to the abilities of the student with an IEP. The incorporation of a special education teacher depends on your child's IEP. When a general education placement is the best match for a student's needs, it allows a student to participate in his/her education program in a more complex, natural setting that affords almost continuous opportunities for generalization. However, this setting is only truly helpful if it does not interfere with your child's ability to make meaningful progress in his/her educational program. When appropriate, related services such as OT, PT, and SLP can be provided in the general education setting. There are some students whose educational requirements are too complex and intense to be effectively addressed in the general education setting.

Special Education Placement

Students whose educational needs cannot be adequately met in the general education setting may require specialized attention in a more controlled setting. In such a case,



Finding the Right School

The following Web sites have helpful search engines that allow you to find schools based on a variety of criteria:

School Data Direct:

www.schooldatadirect.org

School Matters:

www.schoolmatters.com/schools.aspx

Military Child Education Coalition (MCEE):

www.militarychild.org

Military INSTALLATIONS:

http://benefits.military.com/misc/installations/Landing_Page.jsp

Operation Autism:

www.operationautismonline.org/search-for-resources

School Quest:

<https://schoolquest.org/Login/Login.aspx>

students complete grade-level work in targeted subject areas in a setting frequently called the Resource Room. In the Resource Room, a special education teacher works with a small group of students and utilizes instructional methods that will foster meaningful progress for those students. Related services may be provided in the Resource Room setting or a different room outside of the general education environment. Different students require different amounts of time in the Resource Room, and the IEP will designate what percentage of a student's school day should be in the Resource Room and what percentage in General Education. When the Resource Room is the best match for a student, it offers a combination of the features of the general education setting and the controlled setting of the Resource Room.

Self-Contained Educational Placement

Placement in a self-contained classroom means that the student is removed from the general education population for all academic subjects to work in a small, controlled setting with a special education teacher. Some students who are in a "self-contained" educational placement continue to access some general education settings (e.g. lunchroom, recess, and/or special classes like art, music, and library), while some students are "100% self contained", meaning that those students are never included in the general education setting. For a student who has autism and whose team has determined partial inclusion in settings that include special classes and recess, there is a particular caution. As with all inclusion, this type of inclusion must be carefully planned. For many students with autism, the lunchroom, for example, can be one of the most problematic settings in the school. The following is important: students with autism have a primary impairment in social skills. Therefore, occasions when they may be included for social participation will need as much planning and support as might be required for inclusion in an academic period of the school day.

In addition, students in a self-contained class may be working at various academic levels with different textbooks and curricula. When a self-contained educational placement is the best fit for a student, it can often meet the more intensive special education requirements of some students; however, as students are placed in these more "restrictive" educational placements, planning for generalization must be a consideration.

Out-of-District Placement

While a self-contained educational placement may require a student to go to a school outside your neighborhood, an out-of-district educational placement places a student in a specialized 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. However, similar to a self-contained educational placement, generalization must be carefully considered and access to the "general" population by the school can be limited or nonexistent.

So Which Educational Placement Is Right for My Child?

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

- In which educational placements can my child access the educational supports, modifications, and services required for him/her to meet the annual goals/objectives set forth in the IEP?
- Of these educational placements, in which placements will my child have the most access to the general education setting?
- In which of these 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 his/her development is either stunted or, worse yet, set back?

It is typically the third question that presents the educational team with the greatest challenge. For example, a child may have the academic skills to participate in the general education setting, but that child becomes so overwhelmed by the social and physical context that he/she is unable to learn. Some students have been the victims of severe bullying and can no longer participate in the general education setting. This varies significantly from student to student.

Additional considerations include:

- In what setting does my child learn best, and in what setting is my child the least productive?
- Does my child have friends and/or a meaningful social support network in the general education setting?
- Has the general education setting been dangerous or unfriendly for my child?
- Where will my child be most comfortable?
- How much will my child be integrated into the general education setting?
- How is a child who is having a “meltdown” or significant behavioral difficulty supported?
- How does the classroom setting comport with any sensory issues my child may have?
- 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?

There should be an open dialogue at the IEP meeting about possible placements. If you are concerned with the proposed educational placement, you can ask to have the meeting rescheduled to give you time to evaluate the proposed educational placement. In the meantime, you can speak to your child’s teachers, other parents, special education personnel, advocates in your area, and most importantly to your child, and try to gauge what setting would be the most productive, most beneficial, most stimulating and least threatening place for your child to learn.



One Mother's Advice

"Open communication is essential between a child's teacher and parents. The child's IEP happens only once a year for most children, but needs to be implemented daily."

—Mother of a 12-year-old diagnosed with Asperger Syndrome

Although IDEA sets forth a process by which the general education setting must be ruled out before considering other educational placements, ultimately, your child needs to be in an educational placement that will allow him/her to access a FAPE. In addition, your child may require a "more restrictive" setting now, but there may come a time in the future when a less restrictive setting is a better match. The IEP team will discuss educational placement every year when conducting the annual IEP review. Once your child has an educational

placement, monitor it closely. Your child's placement is not set in stone, 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.

Regardless of your child's educational placement, IDEA mandates that students receive qualified instruction from a well trained professional. However, there are still many teachers and therapists who do not have specialized training in autism.

Ideally, your child's educational placement understands autism and has methods in place for teaching children with autism. They carry a positive attitude about autism and place expectations on your child for progress, in whatever way it occurs, in the school setting.

Once the IEP team has made a determination for educational placement, it is only really the beginning, as you then need to work closely with the teachers to ensure that they know all about your child. They may well know about autism and Asperger Syndrome, 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.

What Should I Do to Prepare for the IEP Meeting?

Be familiar with your child's current evaluation data and performance at school. It is valuable to review work samples from school and recent documentation about his/her performance. If possible, you may want to observe your child at school. You should also become familiar with the types



IEP's Practical Value

"The IEP contains information about the student's strengths and needs, as well as goals and objectives based on these areas of need. Regular monitoring of student progress not only helps to evaluate whether the student is making progress toward these identified goals, but also helps the teacher to examine the effectiveness of the curriculum and the strategies used to teach the student."

—Autism program specialist

of educational placements that may be discussed at the IEP meeting. You can do this by talking with other families, talking with local advocates and possibly your EFMP representative, and doing some research on the Internet. If there is a program in which you are particularly interested, it may be valuable to conduct an observation at that program to better understand it.

What Should I Bring to the IEP Meeting?

Bring any documentation that may help inform the IEP team's decisions. In particular, if you have a concern, you should bring documentation verifying your concern. Similar to the evaluation meeting discussed on pages 46–48, you should bring materials with which to record the meetings, a photo of your child, and someone to provide support to you. Some families also bring other service providers who work with your child outside of school (e.g. behavior therapist, SLP, OT).

What If I Disagree with the School's Recommendations?

There are different ways to proceed in such a case, and depending on the nature of your disagreement, you will need to take a different course. Here again, Wrightslaw.com is an excellent source of information about how to proceed when in disagreement with the school.

In summary, the development of your child's IEP will require time and patience and should represent the highest priorities for your child's education in the coming year. The IEP meeting should provide an opportunity for open dialogue and the development of a mutual understanding about your child.

Creating a Partnership with the School

Once you've chosen a school, it is important to start building relationships, beginning with your child's teacher. Teachers today are busier than ever before. Each teacher may have up to 30 students in one classroom. Two or three of these students, in addition to your child, may have special needs. An additional one or two may be at risk for learning and behavioral challenges like attention deficit disorder and ADHD. Teachers are increasingly required to teach to strict state standards of learning that emphasize core subjects like reading and math. Accountability to state testing requirements, even at the elementary school level, is the norm rather than the exception.



Communicating with Teachers

The questionnaire in [Appendix L](#) is a good tool to open the dialogue between you and your child's teacher. [Appendix M](#) directly following provides a reproducible daily or weekly worksheet template you can use to communicate with teachers about your child's performance and progress throughout the year.

You can help your child succeed by helping his or her teacher understand autism, your child, and the impact of having a child with autism in the classroom. Through your years of experience, you have become informed about autism and are an expert on your child. The teacher surely will appreciate your establishing a pattern of efficient and respectful communication. This exchange of information can take place in the form of in-person meetings, telephone calls, e-mails, audio tapes, or journal exchanges. You can provide teachers with essential information about your child's sensitivities and behavioral challenges. You can communicate about the areas where your child struggles and which adaptations have been successful in the past.

The Parent's Role in the Six-Step Plan for Inclusion

Parents are the teacher's most valuable resource and source of information on your child. Although resources like OAR's *Life Journey through Autism: an Educator's Guide* and *Life Journey through Autism: An Educator's Guide to Asperger Syndrome* may be useful to your child's teacher, the first and best source of information he or she will have about your child will be *you*. You will have taken a vital first step in creating a strong relationship with the teacher by reaching out to discuss your child and autism. It simply starts there. The only way to maintain and build that bond is through communication, teamwork and trust.

In both *Educator's Guides*, we recommend that the teacher follow a six-step plan in preparing an inclusive classroom environment that supports your child's strengths and challenges as well as the education needs of all the students. While the steps are nominally the same and similar to some degree, some aspects of the steps prescribed vary much in the same way children with autism and Asperger Syndrome do. The teacher's challenge, then, is to learn about autism and your child while at the same time teaching all the students in the class. You can be of great assistance in this learning process.

The Six-Step Plan for Inclusion: How You Can Help	
Teacher	Parent
Educate yourself	Help the teacher understand your child and autism
Reach out to the parent	Be receptive and reach back
Prepare the classroom	Visit classroom in advance and look at its set up
Educate peers and promote social objectives	Assist/support peer education when invited
Collaborate on the implementation of an educational plan	Collaborate on the implementation of an educational plan
Manage behavioral challenges	Inform teacher of any challenging behaviors and ways to address or prevent them

The Importance of Peer Education

Educating the typically developing peers about the child's disorder is perhaps the most powerful tool in creating a positive environment and increasing positive social interactions between the child with autism and his or her peers. Research has shown that typically developing peers have more positive attitudes, increased understanding, and greater acceptance of children with autism when provided with clear, accurate, and straightforward information about the disorder. You can help teachers understand the importance of this step and advocate for the ongoing education of the peers who share your child's class. In fact, you might be an important resource for the teacher who might want to draw upon your experience and knowledge to help educate your child's classmates.

One of the themes that runs throughout *The Educator's Guides* and is a constant in dealing with your child's teacher and the school is the importance of clear, frequent communication with you, the parent. Do not assume they understand autism. We recommend that you provide one of OAR's *Educator's Guides* to your child's teacher as early in the school year as possible, or even before school starts. It is meant to be a springboard for conversation about the challenges and strengths of your child in particular; it will be most effective when it serves as a bridge to a more comprehensive conversation between you and the teacher or the whole team. Reading the *Educator's Guide* in its entirety will help you draw connections between its content, your child's experiences and performance in school, and the conversations you will have with the teacher throughout the school year.

Teachers today are very busy with large classes and new requirements for student testing in place. In the midst of these plentiful responsibilities, teachers are also challenged daily to create an inclusive, supportive school community. Your participation in your child's education is essential to his or her success in learning and growing and the goals you set for your child cannot be achieved unless you first develop a working partnership with the teachers your child sees every day. By providing teachers with information on your child's abilities, limitations and challenges with autism and working with them to make best use of resources like OAR's *Educator's Guides*, you can make their job just a little easier, and they will love you for it. Consistent and frequent communication between you, your child's teacher and the school will help ensure that the classroom and the schoolhouse become comfortable and productive places where your child will learn, make friends, and grow.

Note for Military Families, from Wrightslaw

When children with disabilities move to a new different school district—in the same state or a different state—the new school district must provide services that are comparable to the services in the previous IEP.

Transfer in Same State

“In the case of a child with a disability who transfers school districts within the same academic year, enrolls in a new school, and who had an IEP that was in effect in the same state, the LEA (school district) shall provide such child with a free appropriate public education, including services comparable to those described in the previously held IEP, in consultation with the parents, until such time as the school district adopts the previous IEP or develops, adopts, and implements a new IEP that is consistent with Federal and State law.”

Transfer Outside State

“In the case of a child with a disability who transfers school districts within the same academic year, who enrolls in a new school, and who had an IEP that was in effect in another state, the school district shall provide such child with a free appropriate public education, including services comparable to those described in the previous IEP, in consultation with the child’s parents until such time as the district conducts an evaluation, if determined to be necessary, and develops a new IEP, if appropriate, that is consistent with Federal and State law.”

Wrightslaw: Special Education Law, 2nd Edition, pages 102–103.

Transitions

For children and adults with autism, unforeseen changes to their schedule or daily ritual, or *transitions* as they are called, can be especially difficult and can sometimes lead to an array of potentially disruptive behaviors and often at the most inopportune, or stressful, moment. Military service is rife with transitions of all sorts for service members and, by extension, their families. Anticipation of transitions, prior planning, and even rehearsals in varying forms can help children with autism successfully cope with transitions.

Defining Transitions

For children with autism, any changes or shifts to their schedule or, at times, physical environment can be difficult transitions. Regardless of whether the changes are large or small, they can prove difficult and produce challenges for both the children and their families.

The term *transition* encompasses a multitude of changes ranging from minor variations in school schedules and daily life to more significant changes, such as the move from elementary to middle to high school or the phases of development from childhood to adolescence to adulthood. Events that might be routine for most children, such as haircuts, visits to the doctor, or taking a different route home from school, can produce stress and anxiety in some children with autism. More significant events, like moving to a new school or community, can also prove challenging for persons with autism and their families. It should be noted, however, that the “size” of the transition is generally not correlated with the intensity (or even presence) of challenging behavior. For example, moving all the furniture in the living room might result in calm acceptance whereas moving one pillow on the couch may result in a tantrum or meltdown.

Tips for Successfully Managing Change

Besides major transitions like a PCS move and a change of school, lesser transitions, such as: home to school, classroom to cafeteria, school to home, and more—are part of everyone’s daily routine. Most people adapt to these changes throughout the day. Unfortunately, many individuals with autism do not adapt as readily and these seemingly simple changes can result in a variety of challenges. Here are some things you can do to help your child better handle both expected and unexpected change:

- Establish and maintain a daily routine.
- For consistently difficult transitions, consider verbally or pictorially walking your child through the upcoming transition including what reward he or she will earn. (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 is one that can be implemented consistently by all involved.
- Engage peers and teachers as supports and sources of reinforcement for successful transitions.

There are many books, journal articles, and Web sites (e.g., <http://www.paulakluth.com/articles/transitions.html>) that address transitions, the challenges some persons with autism have with them, and strategies for managing change. Most resources you will find on this subject build on the points just discussed in one way or another.

Military Transitions

Military families that have children with autism face all the emotions and challenges that accompany the diagnosis compounded by the realities of military service: war, extended family separation, frequent moves, varying access to specialized healthcare, and other stressors that complicate and often work against obtaining effective treatment for children with autism. There are, however, strategies and techniques that are helpful in managing transitions on any scale. This section provides information on dealing with some of the more common transition challenges for children with autism, regardless of setting, and other challenges that are more unique to military families as a result of one or both parents' service in uniform.

Changing Duty Stations

Orders and transfers to new duty stations are part of everyday life in the military. Rarely do military families establish roots anywhere before the next set of orders has them planning, packing, and executing a move to another duty station. While moving can be a difficult transition for anyone, it can be especially challenging for children with autism as it entails significant and sudden environmental changes. When a child with autism is part of the family, any move presents at least three major transitions in addition to the challenges associated with the disruptions caused by packing and the physical move:

- Moving to a new home;
- Finding a new school and ensuring continuity in your child's required services and supports; and
- Maintaining continuity of care and services beyond the educational setting.



Tips for PCS Moves

The Tip Sheet for PCS Moves, [Appendix N](#), provides some helpful hints to make any move and its associated transitions as smooth as possible for the entire family.

Finding a New School and Ensuring Continuity

The previous section, *Autism and Education*, discussed much of what is entailed in finding and choosing a new school. If you do your homework right, including researching potential schools, visiting possible schools, and asking the right questions, the chances are that you will have found a possible educational placement for your child. As emphasized before, that is the end of one important process and the beginning of the next, particularly as acceptance into any program other than a public school program can be very difficult to obtain. In addition, do not assume that the required services and supports for your child as established in the IEP will naturally and smoothly follow, despite the provisions of law (IDEA).

Although following the steps outlined in the preceding paragraph should help shift the odds of a good placement in your favor, it is no guarantee. It is one of the most significant areas of challenge for military families with a child with autism. It is not uncommon for military families to seek command and legal support as they battle to protect and ensure their child's educational rights. OAR reprinted an excellent article from *Exceptional Parent* magazine on the topic, "A Military Family's Experience with Autism" in the October-November issue of *The OARacle*, OAR's e-newsletter. Kyla Doyle, a Marine wife and mother of two including a daughter with autism, describes many of the challenges military families touched by autism face to include the hurdles and obstacles she encountered as she sought to ensure that her daughter received the educational services to which she was entitled. She closes with some very practical tips for other parents in similar circumstances. You can access the article on OAR's Web site in *The OARacle* archives (<http://www.researchautism.org/resources/newsletters/archives/index.asp>).

Other Transitions

Besides the potential upheaval a move can bring to your child with autism's routine, military duty often requires the service member to be away from home for periods ranging from 24-hour duty assignments to temporary assignments of weeks to months for training or duty, and to extended deployments for training or combat operations. Although the immediate impact of such absences on your child with autism may vary from almost calamitous to barely noticeable, you can do some things to help mitigate the effect, including:

- Create a "Countdown Calendar" with your son or daughter to mark the days until one parent or the other is to be deployed. Although not always possible, include subsequent dates on the calendar for emails, 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.
- Create a series of short videos of the soon-to-be deployed parent and show them to your child on a regular basis.
- To the extent possible work with your son or daughter with autism to take advantage of electronic media (such as e-mail or Skype®) to stay in touch with his or her deployed parent.

- 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. If it is true that it takes a village to raise a child then, by extension, it takes two or three villages to raise a child with autism and a mainstay of that second village is now absent. 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, specifically, you are going to need and prioritize your needs. For example, even though it may be quite helpful to have someone assist in getting everyone ready for the school in the morning, it might be more important to have someone to help out after school when you are making dinner. Don't be afraid to ask for help if you need it. See if your child's school has an after-school program he or she 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 simple fact that despite all your best efforts there will be days that are, to be generous, less than perfect. If it is the result of a problem that can be fixed, do so and move on. If you find yourself having to modify your personal standards of success (e.g. accepting that getting into a battle on the use of a specific "sippy cup" may not be the best use of your time) then do so and move on. All that can be expected of you is your best effort and on days when that simply does not seem to be enough, do what you can and move on. Tomorrow is always another day.
- 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.
- Although it is a cliché, you will need to find some time for yourself 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.

Leaving the Service

Regardless of whether you are leaving the service because your term of enlistment has been met or you are retiring after serving 20 or more years, it is a major transition for you, your family, and your child with autism. It will include your final PCS move and all that goes with that as discussed above. It is most important for you to find out which healthcare services that your child receives now will continue or may be transferable in any manner after your change of status. Even if you are no longer eligible under **TRICARE**, you will want to ensure continuity of care from your providers whether within the TRICARE system or not. So be sure to include liaison with TRICARE as one of the items on your personal *Separating from Service*

checklist. To read more, please see the *Autism and Military Healthcare* section of this Guide.

OAR's Transition Resources

Several OAR resources may be useful in planning for or managing transitions. This Guide and its online counterpart, *Operation Autism*, specifically address transitions for military families. OAR's publications in its *Life Journey through Autism* series, notably *A Guide for Transition to Adulthood* and the two *Educator's Guides* (*Educator's Guide* and *Educator's to Asperger Syndrome*), are useful in planning for life and educational transitions. The *Transition Guide* focuses on major life planning considerations for persons with autism and their families as that person progresses through adolescence to adulthood. The *Educator's Guides* identify many of the challenges specific to autism or **Asperger Syndrome** that teachers in the inclusive classroom face. Understanding how autism looks from the teacher's perspective will help guide you as you work with your child's teachers. As discussed in the *Autism and Education* chapter, the strategy for ensuring the most positive learning environment for your child will be the product of collaboration between your child's teacher and you.

In addition to the resources just mentioned, OAR has featured a number of articles related to various transitions in *The OARacle*, its monthly newsletter, since the first issue in September 2002. These are easy-to-read articles, complete with references in many cases, so they are an excellent place to start to research a topic.



Transition Articles

You can access a listing of articles at <http://www.operationautismonline.org/tips-for-pcs-moves-other-transitions/suggested-readings>.

Glossary

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

504 Plan—refers to **Section 504 of the Rehabilitation Act** and the **Americans with Disabilities Act**, which specifies that no one with a disability can be excluded from participating in federally funded programs or activities, including elementary, secondary or post-secondary schooling. A 504 Plan spells out the modifications and accommodations that will be needed for these students 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

AD - Autistic Disorder—complex developmental disability characterized by deficits in verbal/nonverbal communication and social interaction in addition to the presence of repetitive behaviors or interests. See <http://www.operationautismonline.org/autism-101/what-is-autism-2/> for more information.

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 <http://www.ada.gov> for more information.

AS - Asperger Syndrome—a neurodevelopmental disorder that is part of the autism spectrum. People with AS can be high functioning and are well suited for complex, multistep tasks involving attention to detail. AS is sometimes characterized by poor social interactions, obsessions, and speech patterns. Children with AS often have difficulty interpreting the body language and facial expressions of others, engage in obsessive routines, and/or display an unusual sensitivity to sensory stimuli.

ASD - Autism Spectrum Disorders—the neurobiological range of developmental disabilities that includes autism (**Autistic Disorder**), **Asperger Syndrome**, and Pervasive Developmental Disorder-Not Otherwise Specified (**PDD-NOS**). Each has symptoms that can appear in different combinations and in different degrees of severity. See <http://www.operationautismonline.org/autism-101/what-is-autism-2/the-autism-spectrum/> for more information.

BCABA - Board Certified Assistant Behavior Analyst—an autism professional certified by the Behavior Analyst Certification Board. A BCABA may conduct descriptive behavioral assessments, interpret the results, and design ethical and effective behavior analytic interventions for clients. BCABAs can 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 Behavior Analyst Certification Board. This is a higher certification than **BCABA**. The BCBA conducts descriptive and systematic behavioral assessments and provides behavior analytic interpretations of the results. BCBA's 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. See <http://www.operationautismonline.org/autism-101/intervention-and-quality-of-life/> for more information.

BIP - Behavior Intervention Plan—a set of strategies to support children with inappropriate classroom behaviors by helping suggest 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 <http://www.cdc.gov> for more information.

CDD - Childhood Disintegrative Disorder—is one of the five pervasive developmental disorders under the diagnostic category of autism, displaying itself at 3 and 4 years of age in children appearing to have typical development until age 2. Over several months, a child with CDD will begin to regress academically, socially, and linguistically.

DHHS - Department of Health and Human Services. See <http://www.hhs.gov> for more information.

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. See <http://www.defenselink.mil> for more information.

DIR/Floortime - Developmental, Individual Differences, Relationship Approach, also referred to as **Floortime**—a developmental-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 with one another, they 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 the accessibility to educational interventions for children with an **ASD**. It provides eligible active duty family members with an additional financial resource for 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. See <http://www.military.com/benefits/tricare-extended-care-health-option> for more information.

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 that identifies family members with special medical and/or educational needs. See <http://www.operationautismonline.org/autism-and-military-healthcare/dod/exceptional-family-member-program/> for more information.

EIA - Educational Interventions for Autism Spectrum Disorders under the **TRICARE** Autism Demonstration Project. EIA consists of individualized behavioral interventions employed to systematically increase adaptive behaviors and to modify maladaptive or inappropriate behaviors. These interventions are usually one-on-one and are intended to help children with **ASD** achieve independent, full inclusion in

a general education setting and increase their ability to participate in social environments and other therapies. See <http://www.tricare.mil/mybenefit/Glossary.do?F=E> for more information.

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. See <http://www.ed.gov/about/offices/list/ocr/docs/edlite-FAPE504.html> for more information.

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 will help in eliminating or changing 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. (For example, recognizing that the same skills used to wash a plate may also be used to wash a glass.)

IDEA - Individuals with Disabilities Education Act—Federal program which provides funds to states and local school districts to support education for children with disabilities, age 3 to 21. IDEA provides guidelines and protections for children with disabilities to ensure that they have access to a free and appropriate public education (FAPE). See <http://www.operationautismonline.org/educating-children-with-autism/individuals-with-disabilities-education-act/> for more information.

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**. See <http://www.ed.gov/parents/needs/speced/iepguide/index>.

<http://www.operationautismonline.org/educating-children-with-autism/ieps-and-other-program/> for more information.

IFSP - Individualized Family Service Plan—a written statement for an infant or toddler 0–2 years of age with developmental needs and their family. See <http://www.nichcy.org/babies/IFSP/Pages/default.aspx> for more information.

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.—The IDEA’s guiding policy on inclusion. It requires school districts to educate students with disabilities in regular classrooms with their nondisabled peers in the school they would attend if not disabled, as much as possible. See <http://www.wrightslaw.com/info/lre.index.htm> for more information.

MDT - Multidisciplinary Team—team of professionals meeting the needs of a specific child. The MDT for a child with ASD 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 center 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. See <http://www.cdc.gov/ncbddd/autism> for more information.

NECTAC - National Early Childhood Technical Assistance Center—supported by the U.S. Department of Education’s Office of Special Education Programs, NECTAC 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. See <http://www.nectac.org> for more information.

NICHCY - National Dissemination Center for Children with Disabilities—serves as a centralized information resource by collecting, organizing, and disseminating current, research-based information about disability and special education for children, ages birth through 21 years. See <http://www.nichcy.org> for more information.

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 or movement; and fine motor and self-help skills, such as dressing, tying shoes, and eating with a fork and spoon.

PCP - Primary Care Provider—the provider 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 him or her, to a different duty location such as a military base. See <http://www.operationautismonline.org/tips-for-pcs-moves-other-transitions/> for more information.

PDD-NOS - Pervasive Developmental Disorder-Not Otherwise Specified—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 or Asperger Syndrome.

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, although speech is encouraged indirectly and some children begin to spontaneously use speech while enrolled. See <http://www.pecs.com> for more information.

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 person with a disability who is in the school district’s jurisdiction, regardless of the nature or severity of the person’s disability. Please see entries for **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 to teach or maintain social skills, daily living skills, or behavior management skills. They address specific situations by teaching the student appropriate behaviors and responses (i.e., 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 <http://www.polyxo.com/socialstories/> for more information.

SPD - Sensory Processing Disorder—a neurological disorder causing information received through the senses (vision, touch, sound, smell, taste, movement, and proprioception or positional sense) 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 **ASDs**.

Specialized ASD Provider—a **TRICARE** authorized provider who is board-certified or board eligible in behavioral developmental pediatrics, neurodevelopment pediatrics, pediatric neurology or child psychiatry. Or, a physician or PhD educated psychologist working primarily with children through a specialized fellowship or on-the-job training.

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 <http://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 <http://www.tricare.mil> or <http://www.operationautismonline.org/autism-and-military-healthcare/tricare-health-plan-coverage/> for more information.

Resource Listing

Federal

Centers for Disease Control and Prevention—Autism Information Center

<http://www.cdc.gov/ncbddd/autism/index.html>

A comprehensive resources with autism facts; definitions; data and statistics; information about screening and diagnosis, treatment, and research; downloadable materials; and links to a number of useful Web sites.

Learn the Signs. Act Early.

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

A section of the CDC's Web site campaign that aims to educate parents, healthcare providers, and early childhood educators about childhood development, including early warning signs of autism and other developmental disorders, and encourages developmental screening and early intervention. It also has excellent resources, downloadable materials, and links to a number of useful Web sites.

National Dissemination Center for Children and Youth with Disabilities (NICHCY)

<http://www.nichcy.org/>

A central source of information on disabilities in infants, toddlers, children, and youth; special education legislation; No Child Left Behind as it relates to children with disabilities; and research-based information on effective educational practices.

The National Institute of Child Health and Human Development

<http://www.nichd.nih.gov/autism/>

One of several Institutes doing research into various aspects of autism, including causes, prevalence, and treatments. The site provides easy access to the most current information about NICHD research projects, publications, news releases, and activities related to autism.

National Institutes of Health—Autism Spectrum Disorders (Pervasive Developmental Disorders)

<http://www.nimh.nih.gov/health/publications/autism/complete-index.shtml>

This site contains general information on autism spectrum disorders as well as information on current research into the causes and treatments.

Military

Military Homefront

<http://www.militaryhomefront.dod.mil/>

The DoD Web site for official Military Community and Family Policy (MC&FP) program information, policy, and guidance designed to help troops and their families, leaders, and service providers.

Military OneSource

<http://www.militaryonesource.com/>

A 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.

MilitaryINSTALLATIONS

<http://apps.mhf.dod.mil/pls/psgprod/f?p=MI:ENTRY:173949407528960>

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

Military Health System

<http://www.health.mil/>

The official DoD Web site for the Military Health System.

TRICARE

<http://www.tricare.mil/>

The official Web site for TRICARE, a healthcare program that provides civilian benefits for military personnel, military retirees, and their dependents, including some members of the Reserve Component.

Military Child Education Coalition (MCEC)

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

Worldwide non-profit organization whose goal is to “level the educational playing field for military children wherever they are located around the world, and to serve as a model for all highly mobile children.”

STOMP: Specialized Training of Military Parents

<http://www.stompproject.org/default.asp>

Federally funded organization whose goal is to provide support and advice for military families who have children with special education or health needs. STOMP’s downloadable fact sheets cover a wide variety of healthcare topics for military parents and professionals.

Autism

American Academy of Pediatrics (AAP): Autism

<http://www.aap.org/healthtopics/Autism.cfm>

A national organization of 60,000 pediatricians committed to the attainment of optimal physical, mental, and social health and well-being for all infants, children, adolescents, and young adults. The AAP Web site provides a wide range of support, from general information related to child health to specific guidelines and resources for autism.

Association for Behavior Analysis International

http://www.abainternational.org/special_interests/autism_guidelines.asp

Primary professional organization for members interested in the philosophy, science, application, and teaching of behavior analysis. The ABAI Web site includes a useful set of guidelines for determining qualified ABA providers for individuals with autism.

Autism NJ's Sibling Pen Pal Program

<http://www.autismnj.org/SupportGroups.aspx#sibling>

Autism NJ operates a pen pal list for sisters and brothers of individuals with autism or related disorders around the country as well as internationally. To join the program, go to the Web address above and complete the sign-up form.

Autism Society of America

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

The Autism Society promotes community involvement of individuals with autism spectrum disorders through education, advocacy, and public awareness campaigns. The ASA Web site lists state and local chapters, provides resources for parents and teachers, includes information about autism legislation, and answers frequently asked questions from parents about autism spectrum disorders.

Autism Speaks

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

Autism Speaks funds global biomedical research into the causes, prevention, treatments and cure for autism. This Web site provides general information about autism, research and resources for support and offers some excellent resources for parents and teachers.

Cambridge Center for Behavioral Studies

<http://www.behavior.org/autism/>

The internationally-recognized resource for quality information about behavior, including scientifically validated information about the causes of autism and the Applied Behavior Analysis (ABA) approach to treating it.

First Signs

<http://www.firstsigns.org/>

First Signs is dedicated to educating parents and professionals about early identification and intervention for children at risk for developmental delays and disorders, including autism. Its Web site is another excellent resource for parents of children with autism or those interested in learning more about early childhood development.

The National Autism Center

<http://www.nationalautismcenter.org/>

The National Autism Center (NAC) is a non-profit organization that provides reliable information and offers resources for people affected by autism spectrum disorders.

The NAC supports evidence-based treatment approaches and shares the results with families. In 2009, NAC completed and published the National Standards Project, which evaluated and categorized autism interventions and therapies.

Organization for Autism Research (OAR)

<http://www.researchautism.org/>

OAR funds research and provides information that focuses on the challenges for those living with autism. The Web site offers information for parents of children with autism, family members, educators, and service providers. It also has information about research studies OAR funds and a directory of research centers across the U.S. OAR's resources include publications in the *Life Journey through Autism* series; *The OARacle*, a free monthly e-newsletter; and *Operation Autism*, a Web site specifically for military families impacted by autism.

Sibling Support Project

<http://www.siblingsupport.org/>

A national effort dedicated to the interests of over six million brothers and sisters of people with special health, mental health, and developmental needs. The Sibling Support Project offers reading lists, children's books, information on local workshops and sibling group meetings, online resources and listservs for young and adult siblings to share experiences and issues.

The Southwest Autism Research and Resource Center (SAARC)

<http://www.autismcenter.org>

A non-profit, community-based organization dedicated to autism research, education and resources for children and young adults with autism spectrum disorders (ASDs) and their families. SAARC undertakes self-directed and collaborative research projects, serves as a satellite site for national and international projects, and provides up-to-date information, training and assistance to families and professionals about ASDs. 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

If You Suspect Your Child Has Autism

If you suspect your child has a delay in development, autism or an autism spectrum disorder (ASD), the first step is to gather information and become more educated about what to expect. There are several good Internet resources for information on child development to include:

- **The National Dissemination Center for Children with Disabilities.** Web link: <http://nichcy.org/Pages/Home.aspx>.

For general information about child development: click the “Families and Communities” tab; then click “Developmental Milestones”

For information about a specific disability (including autism): click the “Families and Communities” tab; then click “Specific Disabilities” under the “Differences and Disabilities” heading. Choose the difference or disability you are interested in from the list.

- **The Department of Health and Human Resources (DHHR), Center for Disease Control and Preventions (CDC), National Center on Birth Defects and Developmental Disabilities (NCBDDD).** Web link: <http://www.cdc.gov/ncbddd/index.html>.

For general information about child development: click “Child Development” under the “Child Development and Parenting” heading.

For information specifically about autism: click on “Autism Spectrum Disorder” under the “Child Development and Parenting” heading to go to the CDC’s Autism Information Center.

For signs and symptoms of autism: click on “Child Development and Parenting”; then click on “Learn the Signs. Act Early.” to learn about developmental milestones.

- **The Organization for Autism Research (OAR).** Web link: <http://www.researchautism.org>.

Click on the “Family and Friends” tab.

- **The Autism Society of America (ASA).** Web link: <http://www.autism-society.org/>.

If, after reading, you continue to have concerns that your child may have autism or any developmental delay, make an appointment to see your child’s Primary Care Provider (PCP). The PCP may also be known as the Primary Care Manager (PCM).

You can help your PCP by providing a copy of this appendix and talking about it at the appointment. Also call the local Early Intervention Services (EIS) agency. To find out how to contact the EIS Agency in your area, go to:

- **The National Dissemination Center for Children with Disabilities (NICHCY).** Web link: <http://nichcy.org/Pages/Home.aspx>.

Click on “State Specific Info” and select the state where you are living now.

If your child is not yet 3 years old, contact the people listed under “Programs for Infants and Toddlers with Disabilities: Ages Birth through 2.”

If your child is 3 years old or older but not yet in school, contact the people listed under “Programs for Children with Disabilities: Ages 3 through 5.”

If your child is in school, contact the people listed under “State Department of Education: Special Education.”

NOTE: Military families living on base where there is a Department of Defense (DoD) school will receive services from the Educational and Developmental Intervention Services (EDIS) team from the local military treatment facility (MTF). Call the EDIS Office or the MTF Information Office or Customer Service Center for assistance. Military families that live off base and military families living in an area where there are no DoD schools must call the local Early Intervention Services Agency.

You can read about the EDIS program at:

- **Military HOMEFRONT.** Web link: http://www.militaryhomefront.dod.mil/portal/page/mhf/MHF/MHF_HOMEPAGE. Type “EDIS” in the search field.
- **Military One Source.** Web link: <https://www.militaryonesource.com/skins/mos/home.aspx>. Type “EDIS” in the search field.

Appendix B

New to Autism?

Our friends at the Autism-Asperger's Digest publish a nice, concise "New to Autism?" page in every issue. The information may come in handy when explaining autism and its effects to family members, neighbors, teachers, and others for the first time. It is included in this Guide with the generous permission of the Autism-Asperger's Digest.

Autism is a developmental disorder, typically diagnosed during the first three years of life. It is neurological in nature, affecting the brain in four major areas of functioning: behavior, language/communication, social skills, and sensory systems. The cause of autism remains a mystery. Current research suggests there may be different subsets of individuals on the spectrum, arising from genetics, environmental insults, or a combination of both.

Every person with autism is unique, with a different profile of strengths and challenges. No two individuals manifest the same characteristics in the same degree of severity. It is a "spectrum" disorder, and the various individual diagnoses are collectively referred to as autism spectrum disorders (ASD). Individuals on the spectrum range from those who are nonverbal with severe challenges that can include self-injurious behaviors and accompanying mental retardation, to individuals on the higher-functioning end of the spectrum (known as Asperger's Syndrome) who are extremely intelligent, with good expressive verbal language, yet markedly impaired social skills and weak perspective-taking abilities.

The rate of autism is now 1 in every 110 births (Centers for Disease Control, 2009) and continues to escalate at alarming rates. Every 21 minutes a child is diagnosed on the spectrum. It is four times more common in boys than girls, and is consistently prevalent around the globe, and within different racial, social and ethnic communities. On a family level, 1 in every 68 families will be affected by autism.

Autism is a different way of thinking and learning. People with autism are people first; autism is only one part of who they are. ASD is no longer viewed as strictly a behavioral disorder, but one that affects the whole person on various fronts: biomedical, cognitive, social, and sensory. With individualized and appropriate intervention, children with ASD can become more functional and learn to adapt to the world around them.

Great strides are being made in our understanding of autism and Asperger's and how best to help these individuals. Children are now being diagnosed as early as 12–15 months old, and many who receive intensive early intervention are able to enter elementary school in class with their typical peers, needing minor supports and

services. However, no matter the age of diagnosis, children and adults with ASD are constant learners and significant improvements in their functioning can be made at any age with the appropriate types and intensity of services.

Early Warning Signs of Autism

The following list of symptoms represents the broad range of the disorder and is not meant to be a checklist to determine whether or not a child has ASD. Trust your gut instincts. If your child manifests several of these symptoms and your intuition suggests “something is just not right,” discuss your concerns with your pediatrician and ask for an evaluation. Get a second opinion if warranted. The earlier services are started with a child, the better is the opportunity for optimal positive learning and change to occur. Be proactive.

<p>At 6 months</p> <ul style="list-style-type: none"> • Not making eye contact with parents during interaction. • Not cooing or babbling. • Not smiling when parents smile. • Not participating in vocal turn-taking (baby makes a sound, adult makes a sound, and so forth.) • Not responding to peek-a-boo game. <p>At 12 months</p> <ul style="list-style-type: none"> • No attempts to speak. • Not pointing, waving or grasping. • No response when name is called. 	<ul style="list-style-type: none"> • Indifferent to others. • Repetitive body motions such as rocking or hand flapping. • Fixation on a single object. • Oversensitivity to textures, smells, sounds. • Strong resistance to change in routine. • Any loss of language. <p>At 24 months</p> <ul style="list-style-type: none"> • Does not initiate two-word phrases (that is, doesn't just echo words.) • Any loss of words or developmental skill.
--	--

Source for Early Warning Signs: Dr. Rebecca Landa, Center for Autism and Related Disorders at the Kennedy Krieger Institute, Baltimore.

Autism Asperger's Digest © 2009. All Rights Reserved. Real life information for meeting the real life challenges of autism spectrum disorders. <http://www.AutismDigest.com>.

Appendix C

Become an Informed Consumer of Information

As you begin to learn about autism and evaluate treatment options and claims, you will have to put a great deal of time and effort into becoming a knowledgeable consumer of information. General information on autism can be full of false hope and anecdotal information. From this point on, you will be the primary advocate for your child, so it will be important for you to be able to evaluate your child's needs with research that supports various interventions for autism. Although much information about autism is available, there is no central resource for it. Furthermore, there can be conflicting opinions about the best methods of treatment to use. You will have to gather information from a variety of sources, including the Internet, mass media, professional journals, reports from conferences and workshops and educational providers. Networking with other parents and educational or medical professionals will also help you identify sources of information that have been useful to others. What you choose for your child may well end up coming from a number of different sources and a variety of approaches.

A word of caution is in order: *Beware of those who claim to have a cure.* Your hopes for your child may leave you vulnerable to those marketing a variety of educational, medical, and other alternative treatments for autism. An emotional appeal from these promoters can be difficult to resist. Although many promoters of various treatments truly believe in their products or services, few of these fads or miracle cures hold up when scientifically tested.

One of the purposes of this Appendix is to provide you with some basic tools for evaluating the validity of these sorts of claims. The same process can be used to evaluate research from more academic sources. This Appendix will give you a basic understanding of the purpose of research, how it is conducted, and the criteria upon which to judge its value. When you are faced with new treatment decisions for your child, you will then be better prepared to ask the right questions of your child's doctors, therapists, and teachers about specific interventions when you are faced with new treatment decisions for your child.

One of the greatest challenges for parents of children just diagnosed with autism is will be sifting through the vast array of information about the disorder. There are a multitude of autism resources, and it can be very difficult to distinguish between reputable and questionable sources of information. This section will provide you with guidance on where and how to search for resources on autism and autism research.

Finding the Research

Autism is in the news these days. You will undoubtedly hear reports on television when major research findings are released, or you will read articles in newspapers and magazines about autism, prevailing theories and debates, and ongoing autism research studies. Television, newspapers, and magazines report scientific research “second hand” in a brief manner suited to the medium and designed for immediate consumption by the general public. In these reports, journalists may cite the author and name of the professional journal where the research is published, but many of the details of the research may be left out. For the most part, journalists do a good job reporting the research, but it is important to remember that there is no scientific review process to make sure that what journalists report is accurate. Therefore, to be sure that the research cited or discussed is interpreted and reported accurately, it is best to get the report “first hand” from the source, the person or persons who conducted the research.

Professional journals are the best source for reports on current research by the scientists who conduct the studies. Prior to publication, the research reported in journals is usually submitted to a process called a “peer review.” During a peer review, other researchers read and comment on the quality of the research based on whether it adheres to the ethical and quality standards of the profession. There is a great deal of competition to publish, so the articles that appear in journals are the best of the research being done. This section will help you find these “first-hand” reports and determine their applicability to your child’s situation.

Web Sites

Many Web sites cover the topic of autism. Unfortunately, not all are good sources of information. Without some experience or training in searching the Internet, it can be very difficult to discriminate among these many Web sites and sources of information. The Web sites for the autism organizations provided in the Resource Listing on page 73 are reputable and provide good information on a range of autism-related topics. Many provide links to other good sites and scientific articles on autism. When trying to gauge the reliability of any site, look for ones that do the following:

- Provide links to other major autism organizations, academic research institutions, and professional research articles;
- Are hosted by government agencies or other non-profit organizations; and
- Clearly cite sources of information.

Searchable Online Databases

Searchable online databases are very good sources of information about autism and autism research. Some databases (such as PsychInfo compiled by the American

Psychological Association) are for members only and only accessible to the general public through university libraries.

Increasingly, very good online databases are becoming available that can be searched from home-based computers. Three searchable databases available to the general public are: PubMed (Medical Publications), SCIRUS (for Scientific Information Only) and ERIC (Education Resources Information Center).

PubMed is maintained by the National Library of Medicine at the National Institutes of Health and contains an extensive collection of medical and psychological literature.

PubMed is located at <http://www.pubmed.gov> on the Internet.

SCIRUS is maintained by Elsevier Science, the leading international publisher of scientific information, and is available to the general public on the Internet. This Web site provides a searchable database of the professional literature and other sources of scientific information on the Internet in a user-friendly format.

Scirus is located at <http://www.scirus.com> on the Internet

ERIC is supported by the U.S. Department of Education, Office of Educational Research and Improvement, and the National Library of Medicine. It contains an extensive collection of literature in the field of education and is an excellent source of school-based research. OAR's *Life Journey through Autism* series of publications have just been added to ERIC's database.

ERIC is located at <http://www.eric.ed.gov> on the Internet.

Online databases are designed to retrieve research articles by using the "keyword" system. This means that when a word is entered, the online database retrieves all articles that contain that word. The advantage of this system is that it is very easy to use. The disadvantage is that this system retrieves more information than the average person needs or can possibly review. For example, by entering the keyword "autism" into PubMed, the system retrieves more than 6,000 articles!

Therefore, the challenge to new users of online databases is learning to narrow a search so that only articles of interest are retrieved. This will usually require some "trial-and-error" before you master the use of these databases. Below are some tips for narrowing an online search using PubMed, SCIRUS, and ERIC.

Tips for Searching PubMed

- Enter keywords such as “autism” and “children” with the word “and” between the words to narrow a search; if too many references are retrieved, another keyword can be added to the search; if too few references are retrieved, a word can be deleted.
- Another way to narrow a search is to choose the “limits” option on the home page, which allows a search to be narrowed through publication date, author, population, field, and so forth.
- If an article is related to a topic of interest, click on the “similar articles” option, or try entering the author’s name in the author field of the “limits” option to retrieve similar articles. Authors typically publish more than one article on a topic.

Tips for Searching SCIRUS

- Using SCIRUS, you can enter keywords such as “autism” and “children” with the word “and” between words to narrow a search by using the same method as PubMed described above.
- Another way to narrow a search using SCIRUS is to enter a phrase in quotation marks, such as “children with autism.” This will retrieve all articles containing the entire phrase.
- SCIRUS also has a “similar articles” option and provides a box of similar search term options on your results page to help you narrow your search.
- When you retrieve an article, you may have to click on the “abstract” link to retrieve the abstract. At the end of the abstract, SCIRUS provides a telephone number and email address for contacting the author of the study.

Tips for Searching ERIC

- Choose the “selected fields” option on the Search ERIC Database page to enter keywords; if too many references are retrieved, add another keyword; if too few references are retrieved, delete a word.
- Choose the “ERIC Thesaurus” option on the Search ERIC Database page, and then enter search terms in the “ERIC Wizard.” The “ERIC Wizard” converts search terms into similar indexed terms in the thesaurus.
- When an article of interest is located, choose “author” in the “selected fields” option, and enter the author’s name to find other articles written by that author.

Medical and University Libraries

Medical and university libraries contain a wealth of autism research. Those who are fortunate enough to live within commuting distance of one of these libraries can conduct online searches using databases that these libraries have purchased. These databases are usually more comprehensive than those accessible from home computers.

Medical and university libraries also own large collections of professional journals. The general public is usually welcome to browse these journals and make photocopies of articles to take home; be sure to check the rules at your local library.

The most recent issues of professional journals are usually kept in the reference section of the library. Past issues are generally housed together with book collections. The reference librarian is your best source of help for locating these journals.

Article Location Services

For those who do not live within commuting distance of medical or university libraries, there are several good article location services that will either email, fax, or mail copies of articles to subscribers. It is important to note that there is a fee for these services. Prices of articles typically begin at around \$12.00, and users must subscribe to these services to access articles.

Contacting Individual Researchers

Once you begin reading research reports, you may discover that a particular researcher has published articles in an area of interest to you. Most autism researchers are approachable and often are more than happy to provide reprints of their articles to interested parents. The best way to contact researchers is through e-mail.

Some tips for finding contact information for researchers:

- Articles published in recent years provide contact information, including an email address, on the bottom of the first page of an article or at the end of the article, near the reference section.
- The abstract of an article is another source of author contact information. The abstract usually provides the author's institution of affiliation, which will usually be a government agency, private company, or university. Authors from government agencies and private companies can often be contacted by e-mail from the agency or company Web site. The SCIRUS database described above provides authors' e-mail addresses with the abstract.
- Researchers at universities can often be located by conducting a "person" search on a university Web site. Typing the name of the university using any search engine (such as yahoo.com, google.com, or msn.com) will take you to its Web site.

Appendix D

Keeping It All Organized

Throughout a family's journey with a child who has an ASD, there is a constant stream of documentation: evaluations, progress reports, Individualized Education Programs, Procedures and Safeguards, general paperwork, and more. The volume of material is often overwhelming and difficult to manage. The key to effectively managing the unrelenting flow of paper and information is to create a system that helps you:

- Quickly assess what needs to be kept and what can be tossed.
- Quickly store the documentation/information in a location that can be easily referenced if needed.
- Archive documents/information that is no longer necessary for immediate referencing but must be kept on file.

There are two basic steps to keeping it all organized. The first step is to *establish a system that works* for you and your family. The second step is to *set up an easy way to maintain that system*. The more routine you can make your maintenance system, the easier it will be to keep it up as time passes.

Different families have different preferences about organization. You may wish to modify the following recommendations to create a better fit for your family.

Which Documents Should I Keep?

Generally, the following documents should be kept in your system.

- 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 IEP
 - Your notes as well as a copy of notes taken by school personnel
 - Evaluation reports
 - Other paperwork (e.g. notice of action refused, written requests you've made)
 - Report cards and progress reports
 - Notes from important conversations with school personnel
 - Other paperwork (e.g. notice of action refused, written requests you've made, 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

How Long Should I Keep Paperwork?

- Keep a record of these documents for as long as you can. Though it may be rare when you need old documentation, most families are relieved they still have it when such a time arises.
- As a general rule, evaluations are valid for about three years (some assessments differ from this). However, if you believe the information in an evaluation report is no longer accurate for your child, it is important to obtain a current evaluation.

Organization System Basics

There are two basic components of the system:

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

How Do I Set Up My Organization System?

Keep it as simple as possible. Your organization system will mirror the bullet points in the “What Documents Should I Keep?” section. Your archival system will most

likely stay in your home somewhere whereas your reference system will be portable. (Imagine walking into your next IEP meeting with all of your child's current documentation right at your finger tips, accessible within seconds).

The Reference System:

You will need:	Steps:
<ul style="list-style-type: none"> • 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 (you may chose to print the labels instead of handwriting them) • 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 year based on the 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). <ul style="list-style-type: none"> a. Current IEP b. Most recent school and private therapy evaluations (see above) c. Progress reports and report cards for school and private therapies d. Any current notes or other paper work (see "What Documents Should I Keep?" section above) e. Any current funding source documentation 	<ol style="list-style-type: none"> 1. The following list is of section headings. Write/print one per tab. You will see a one letter prefix for each section: S = School, T = Therapy, M = Medical, paralleling the above section. Use a different color for each section. <ul style="list-style-type: none"> a. S - IEP b. S - Evaluation c. S - Progress d. S - Other e. T - Evaluations f. T - Progress g. T - Home Program (when applicable) h. T - Other i. M - Evaluations j. M - Other 2. Insert tabs into the dividers (or if using files, place file labels on the folders). 3. If using a 3-ring notebook, 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 folder is used to keep TRICARE and funding source documentation.

The Archival System:

You will need:	Steps:
<ul style="list-style-type: none">• One hanging “box bottom” file pocket (at least 3 inches wide) for each year since your child has been diagnosed• Pen (or use your printer)• Clear tabs and inserts (should 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, etc.)	<ol style="list-style-type: none">1. Label each file pocket with one academic year (e.g. 2009–10)2. Begin sorting through the paperwork you’ve accumulated since your child’s diagnosis. Place each document in the corresponding year’s file pocket. In future years, your system will be even more organized.3. In future years, you will be able to 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 more crude than the reference system, but you won’t be accessing it nearly as often.4. When your child receives an updated evaluation, place the old evaluation in the file pocket year that corresponds with the evaluation date (i.e. an evaluation completed in April 2008 will go in the archive file labeled 2008–09.)

How Do I Maintain the System?

- Once you have the system established, maintenance will be easier.
- As you receive new evaluations, place the previous evaluation in the corresponding archive file pocket. Place the new evaluation in the reference notebook behind the corresponding divider.
- When you receive the final IEP, place the previous IEP in the corresponding archive file pocket. Place the new IEP in the reference notebook behind the corresponding divider.
- Otherwise, at the beginning of each school year, remove the contents of the notebook from the notebook (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.

There are many possible variations on this system that might make it more useful to you. This system requires a few hours to set up but minutes to maintain and at minimal financial cost. Parents usually find that there is a net gain in time, as they spend less time looking for critical documents when it is all organized. Hopefully, this system provides you with the same benefits.

Appendix E

Finding Other (Non-Military) Providers

Often you will be stationed in a location that has a lot of private therapists and other services available to your family that cannot be found through the military. Below are some tips on how to find these other providers.

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

- Speech and language pathologists (<http://www.asha.org>)
- Occupational therapists (<http://www.aota.org>)
- Physical therapists (<http://www.apta.org>)
- Behavioral specialists (http://www.bacb.com/ecom_frame.html)
- Psychologists (<http://www.apa.org>)
- Respite care providers (<http://archrespice.org>)

Where Should I Look?

- A local phone book or online yellow pages
- Internet search
- Pediatricians' offices usually have a list of community resources
- Call the local school district and ask to speak with one of their speech therapists (or occupational therapists, physical therapists, psychologists, etc.) and ask if they know of any private providers in the same field
- The local Chamber of Commerce
- The county's or state's Early Intervention program (usually on the state's Department of Health & Human Services Web site)
- The state's Developmental Disabilities Council
- Local Child Development Centers
- Local or state autism support groups

Appendix F

Caring for Siblings of Children with Autism

In families with multiple children, a frequent parental concern is developing a healthy relationship between their children in order to promote positive individual and cooperative growth. That concern is increased when a family is faced with an autism diagnosis. You must react not only to the diagnosis, but also to the effect that the diagnosis might have on the other children in the family.

Raising a child with autism while simultaneously raising a typically developing child presents challenges for the entire family. Despite these difficulties, however, there are many positive characteristics and emotions that can be fostered by the relationship between a child with autism and his or her typically developing sibling. As a parent, you have the opportunity to instill relationship-building skills, promote positive coping strategies, and constructively influence behavior.

The first section of this Appendix offers some tips on how to care for siblings of children with autism and foster a healthy home environment in the midst of your family's journey with autism. The second section contains an article from the September 2004 edition of *The OARacle* that addresses some common questions siblings may have and how to answer them effectively.

Tips for Parents

Find a Balance

A child with autism often requires extra support in his day-to-day activities, and siblings frequently want to lend support. You must find a balance between asking your typically developing child (or children) to help and a reasonable expectation of what and how much that child can do. It is important to make it clear to your other children that although their roles are important and their help appreciated, they still have their own lives and are allowed to be kids. Finding this balance helps teach responsibility without overloading the child.

Share Your Time

You will likely have to dedicate a great amount of time to your child with autism in order to give him the specific supports he needs. From the moment of diagnosis, a child with autism will need more specialized services and attention than his typically developing sibling. This means more providers, more time in doctors' offices, and more interactions with his teachers. In casual settings, he may interrupt others, draw attention to himself through noise or behavior, or pay no attention to proximal people or conversations. It is important that you do not become so focused on his needs that

you neglect hers. All children, regardless of age or ability, require parental guidance and attention. Although it may not be as apparent, your typically developing child has a unique set of needs that must not go unaddressed. You might try setting aside special times during the day just for her. Make a point to share special moments as well as responsibilities.

Keep Uniform Rules

It might seem impossible to provide equally for your children because of their differing needs; however, all children, regardless of ability, should be held to the same standards in the family. If your typically developing child must make her bed in the morning, so must your child with autism. If your typically developing child must wait her turn to speak when someone else is talking, so must your child with autism. This may be frustrating initially; however, behavioral therapists can help you create a routine that will benefit both children. By maintaining consistent rules, your child with autism will develop better behavior and social skills and your typically developing child will be less likely to feel resentment or jealousy, thereby promoting a positive relationship between the two.

Foster Peer Support

Autism can be a confusing topic for anyone, especially for siblings of children with autism. Your child may have feelings, worries, or questions that other children without her experiences may not understand. It is important to find a setting where she can interact with peers who understand what it is like to have a family member with autism. The autism organizations listed on pages 74–76 of this Guide may be able to direct you to local support groups designed just for kids, where she will have the opportunity to interact with children in similar situations. Providing her with this kind of support can help her feel less alone and empower her with coping mechanisms and information she can share to promote understanding among typically developing peers.

Identify Learning Opportunities

Though raising a child with autism in a family of multiple children inevitably presents some challenges, the unique circumstances and experiences you will face provide many opportunities for learning and growth. A typically developing child growing up with a sibling with autism will come to understand the meaning of patience and tolerance early and develop the capacity for sharing, empathy, leadership, and teamwork—all life skills that will serve her well in the future. The more you cultivate these skills in your home, the stronger and more supportive your family unit will be.

Encourage Communication

It is vital to create an outlet to ensure that your typically developing child's needs, concerns, and questions are being addressed. You can initiate a variety of activities to achieve this communication in a creative way, such as scrap booking, puppet plays, or journaling. You might also try creating a “feelings box”—family members write

down unspoken anger, sadness, frustration, or happy moments on scrap paper, drop them in the box, and discuss the contents of the box in a structure that works for your family (i.e. family meeting once a week.)

Recommended Reading

Autistic Kids: The Sibling Problem by Amy Lennard Goehner

12/24/2007 | Time Magazine

<http://www.time.com/time/health/article/0,8599,1698128,00.html?cnn=yes>

“Special Ed” for Siblings: What Do Brothers and Sisters of Individuals with Autism Need to Know?

By Beth Glasberg, Ph.D.

September 2004 | *The OARacle*

When a child is diagnosed with autism and begins intervention, parents are often given various protocols and guidelines to follow. The child with autism is identified as “the patient” or “the learner” and treatment begins. Unfortunately, this narrow focus on the individual omits a critical part of the picture. Children typically live in families, and family members impact upon one another. If one member of a family is socially aloof or aggressive, for example, this impacts upon every family member. Perhaps a mother needs to leave her job to manage a home-based educational program. Maybe a brother has to lock up his belongings to protect them. Because autism impacts the whole family system, rather than just an individual, it is helpful to think of each family member as a “patient” or “learner,” rather than just the one with the diagnosis.

Certainly, many therapeutic approaches acknowledge the pivotal role that parents play in helping their child with autism. Schools and community agencies often offer parent education and support opportunities. These strategies acknowledge the special needs of parents. In contrast, only a minority of intervention programs provide siblings with skills training or support. Nevertheless, siblings face tough challenges each day, like eliciting social responses from their brother or sister with autism, or answering questions from neighborhood kids. To support them in their challenges, siblings need their own “special ed”. Below is a proposed list of the top five curricular areas that “sibling special ed” might cover. These topics are primarily geared toward the home, as the most available option, but may also be targeted in sibling discussion groups or individual counseling sessions outside the home.

1. What is autism?

Defining autism, explaining related behaviors and discussing family adjustments are best presented as part of an ongoing, open-ended conversation. Some parents withhold information to shelter their child, but this may backfire as children create explanations for what they observe that may be worse than the truth (Brewster,

1982, Lobato, 1993). Other parents may offer one or two “big talks” about autism and then leave the subject off-limits. This may also promote misconceptions and confusion.

For example, as part of a study designed to clarify how siblings think about autism, I met with 63 siblings aged 5 to 17 and asked some general questions about autism. I also met with their parents and had them predict their child’s responses. The first question was, “Have you ever heard the word, autism?” While only 8% of parents predicted that their child would say no to this question, in fact 21% of siblings reported that they had never heard this term (Glasberg, 2000). Similarly, siblings who participated in this study expressed a number of surprising false beliefs. For example, 26% of siblings interviewed either thought that autism was contagious or weren’t sure. This contrasts with only 9% of parents who predicted these responses. Other myths created by siblings ranged from doctors giving a child autism at birth because he cried too loudly, to a concern that autism might evolve from witnessing an evil act as in the musical “Tommy” (Glasberg, 1998). Increased access to age-appropriate autism-related information may have prevented the formation of these erroneous beliefs.

Some parents wonder how to effectively share information. Guidelines include capturing naturally occurring opportunities, keeping explanations as simple as possible, and anticipating what might be comforting to the sibling. An illustration might involve a girl who is trying to play a game with her brother while he continually picks up the game pieces and “flies” them in circles. A father might approach the girl and say, “Thanks for trying to play this with your brother, but it looks like he prefers a different way to play right now. Autism makes it hard for him to use toys the way we expect, but there are other ways to play with him. Would you like me to teach you how you can help him play next time?” For a more detailed discussion of strategies for sharing information with siblings, see *Siblings of Children with Autism: A Guide for Families*, by Sandra Harris and myself.

2. How do I share my feelings?

Siblings are placed in difficult positions every day. The nature of autism requires some differential treatment by parents, and a great deal of family time, money and attention. Siblings may be embarrassed by public behaviors, or may be the victims of aggression. On the flip side, siblings often experience an intense pride in their brother or sisters’ accomplishments or in their own ability to help their brother or sister. Siblings need a way to let parents know how they are feeling. Parents can help siblings share their feelings by modeling sharing their own feelings and asking to hear about the sibling’s feelings. Strategies for siblings to share feelings at difficult moments may include writing notes to be read after a crisis has passed or using a code word to cue parents of a certain feeling in a public or heated setting. Once the value of communication is stated directly, parents and siblings can together define any potential obstacles and strategies to overcome them.

3. How do I answer questions or taunts from peers?

Most parents of children with autism have at least one story of when they were in the grocery store, mall, etc. and someone commented rudely about their child's behavior. Even questions from well-meaning onlookers can sometimes be difficult to answer. Finding the right words to respond is a struggle. For siblings, whose understanding of the disorder, self-confidence, and ability to explain abstract topics is likely more limited than their parents, these situations prove even more challenging. The first way to help your child with this situation is to make sure that he/she understands autism. Your responses to questions that your child asks serve as a model for him/her to answer other people's questions. Next, offer to practice these situations with your child. Consider role-playing, creating scripts, or making stick figure cartoon scenarios as vehicles for practice. Be sure to discuss how each of the characters in the practice situation is feeling as well.

4. How can I get my brother or sister to respond to me?

Siblings of individuals with autism need special skills to successfully "play" with their brother or sister. These skills also enable them to help their siblings accomplish daily tasks and to protect themselves from challenging behaviors. While some parents express fears of pressuring the sibling to be "a little teacher," or altering the equality of the sibling relationship, research suggests that skills-training leads to positive outcomes. Celiberti and Harris (1993) taught siblings behavioral skills to facilitate play such as giving clear directions, using praise to reward behavior, and prompting to engage in play behaviors. They found that not only did the siblings learn these skills, but they were seen by independent raters as more confident, more interested in the child with autism, and more pleased by their interactions after acquiring these skills. Similarly, within the context of sibling discussion groups, a common feeling described is helplessness to elicit engagement from their brother or sister. In contrast, siblings in these groups who had either formal or informal behavioral training reported developing closer relationships with their affected siblings and expressed pride in their ability to help them. Such skills training might also help the sibling identify and avoid triggers to aggressive or other challenging behaviors. However, even trained siblings need to rely on parents to keep them safe. Together, a decision can be made as to the degree of supervision needed and a system can be devised as to what the sibling should do if he/she feels threatened.

5. How can I meet other siblings of children with autism?

Many siblings have never met another sibling of an individual with autism. This can lead to isolation and difficulty in finding an understanding ear. The most appealing option to remedy this is joining a sibling discussion group. Lobato and Kao (2002) studied the impact of participation in these groups and found that siblings benefited from increased knowledge about their sibling's condition, high satisfaction, increased connectedness, and decreased behavioral problems; they maintained these gains at a three-month follow-up. Siblings that don't have access to a local group can find

other siblings online. Two sites to check include: www.thearc.org/siblingsupport and www.siblingsofautism.com. Finally, even reading about other siblings' experiences may decrease isolation. Try Donald Meyer's *Views from Our Shoes* for brief stories written by brothers and sisters of children with varied disabilities, including autism, at different ages.

Beth Glasberg, Ph.D. has both her doctorate and masters in clinical psychology. She has served as Director of Clinical Services at both the New Jersey Center for Outreach and Services for the Autism Community (COSAC) and the Rutgers Autism Program. Currently, Dr. Glasberg is a consultant with the Douglass Outreach program at the Douglass Developmental Disabilities Center in Piscataway, New Jersey. Co-author of a book on siblings, Siblings of Children with Autism: A Guide for Families, Dr. Glasberg has written many articles and book chapters on the subject of siblings, as well as other autism related topics.

References

- Brewster, A. B. (1982). Chronically ill hospitalized children's concepts of their illness. *Pediatrics*, 69, 355–362.
- Celiberti, D. A., & Harris, S. L. (1993). Behavioral intervention for siblings of children with autism: A focus on skills to enhance play. *Behavior Therapy*, 24, 573–599.
- Glasberg, B. A. (1998). The development of a child's appraisal of a sibling's autism. Unpublished doctoral dissertation. Rutgers, The State University of New Jersey.
- Glasberg, B. A. (2000). The development of siblings' understanding of autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 30 (2), 143–156.
- Harris, S. L. & Glasberg, B. A. (2003). *Siblings of Children with Autism: A Guide for Families* (2nd ed.). Bethesda, MD: Woodbine House.
- Lobato, D. (1993). Issues and interventions for young siblings with medical and developmental problems. In Z. Stoneman & P. Berman (Eds.), *The effects of mental retardation, disability, and illness on sibling relationships: Research issues and challenges* (pp. 85–98). Baltimore, MD: Paul H. Brookes Publishing Co.
- Lobato, D. J., & Kao, B. T. (2002). Integrated sibling-parent group intervention to improve sibling knowledge and adjustment to chronic illness and disability. *Journal of Pediatric Psychology*, 27, 711–716.
- Meyer, D. (1997). *Views from our Shoes*. Bethesda, MD: Woodbine House.

Appendix G

Establishing Support for Yourself

Many parents tend to put themselves last when it comes to the list of “Things to Do”. This arises from necessity, too few hours, and a deep instinct to put their children first. These drives are natural and encountered by most families. However, it is important to consider that by making time for yourself (your relaxation, stress elimination, enjoyment), you generate more internal resources that you can draw upon to support your child and family.

There are a number of ways that you can do this. Join a support group to help you find ways to cope with the different stressors you face, or set aside a couple of hours each week to do things for yourself that you enjoy, such as reading, gardening, or exercising.

Seek out support networks for you and your immediate family, including the grandparents. You will find groups on- and off-base for parents, siblings, grandparents, and other extended family members. To find a support group, consult the Resource Listing in this Guide and the Resources Directory on *Operation Autism*. In addition consider the following resources:

1. The Autism Society has local chapters across America (www.autism-society.org).
2. Autism Speaks (www.autismspeaks.org) has an excellent online resource database.
3. Contact your MTF and EFMP office to find out if there are local groups.
4. Contact other local hospitals to find out about any other groups.
5. Contact your local school.
6. Do an Internet search. Use key words such as “autism support group” plus the city you live in. Also search Yahoo Groups for any autism support groups in your area.
7. Can’t find a support group in your area? Then start one yourself! This may sound daunting, but you can be assured that you are not the only parent in your area who is looking for support. Start with finding just one other parent who has a child with autism and suggest you meet one day. (You can no doubt find another parent in your area via local schools.) If this is successful, continue to meet regularly and spread the word about your new support group. Word of mouth is your biggest advertiser, and in no time you will have a support network in your area. Plus, you will have the personal accomplishment of initiating this support group!

When looking for a support group, it is wise to visit different ones to find a group that is the best fit. You may want a group that focuses both on support as well as education (e.g. bringing in guest speakers). You may not always have too many options, but many groups are open to suggestions in order to better meet the needs of their members.

Setting aside personal time can be very difficult, as already mentioned. Where does one find “extra” time? What should you do with that time? There may be respite care available to you, and remember that ECHO allows for provisional coverage, which should include respite care. If you have a group of people you trust (e.g. friends, fellow support group members), consider starting a babysitting co-op through which families exchange hours of babysitting. There are Web sites available that help organize such groups. If you can’t find childcare, you may be able to reserve a couple of hours when your child(ren) is/are sleeping. Once you find that time, use it to choose an activity from a menu of favorite activities that you enjoy and help you decompress. To develop this list, think about those activities that make you happiest and bring you satisfaction. Keep any needed materials as well as your list in one location. This can help maximize the limited time that you may have. You may want to “try on” different activities to see how they work for you (e.g. yoga, Wii, watching a new sitcom).

Please remember that by renewing your internal resources, you may not only feel less stress, but you may find yourself better able to meet your family’s needs.

Appendix H

Finding a Sitter for Your Child with Autism

It comes as no surprise that parenting, especially for a child with autism, can become exhausting and stressful. Without a break every now and then, you could actually put your own health at risk. Therefore, it is important to be able to find a qualified babysitter to care for your child while you take some time off!

Although many families are able to turn to close friends and relatives to look after their children, military families are often unable to take advantage of this option. Other options are available, however.

Whom Should I Contact?

- Local church, synagogue, or other religious organization.
- Local Autism Center/ARC Organization.
- If a college campus is nearby, check its Departments of Education (or Special Education), Psychology, Social Work, and Behavioral Studies.
- Your child's school (a familiar teacher or aide).
- Your child's pediatrician or specialist (explain that you need respite care for your child—either may be able to put you in touch with the right people).
- Other parents who have children with special needs.
- Any trusted adult who has formed a bond with your child.

Once You Find a Sitter

- Have the babysitter visit before the actual babysitting date and when you are at home so that your child can meet him or her in a comfortable setting.
- Train the sitter specifically for your child by watching the sitter interact with your child and giving advice where appropriate.
- Prepare your child ahead of time by going over the "rules": how to behave with the sitter, what to expect, and the reassurance that you will come back home.
- Leave notes and lists to help aid the sitter through the first few visits and always have your cell phone available.
- Provide the sitter with a "cheat sheet" that includes your child's schedule/routine, favorite toys and hobbies, favorite foods, any allergies, and any unique behaviors and how to deal with them.
- Get into a routine so that you, your child, and the sitter become comfortable with each other.

Appendix I

Where to Start on Base

The following step-by-step information may prove helpful in determining how to take action before and after your child's diagnosis of autism.

Before the Diagnosis: Screening

Before the age of 3, there are many warning signs of autism that parents can recognize. The CDC's program, *Learn the Signs. Act Early.*, describes the early childhood developmental milestones (such as smiling, first words and walking) that correspond to specific ages. Delays in reaching certain milestones may suggest a developmental disorder, such as autism. If you suspect that your child has developmental delay or autism, there are a few steps to take next.

Learn or review the (warning) signs here: <http://www.cdc.gov/ncbddd/actearly/index.html>

Step 1:

Make an appointment with the child's Primary Care Provider (PCP), or their Primary Care Manager (PCM). If he or she detects a developmental delay, this person can provide a referral to your local Early Intervention Services (EIS) agency.

Step 2:

In order to find your local EIS agency, you can call The National Dissemination Center for Children with Disabilities (NICHCY) at 1-800-695-0285, or go to their Web site: <http://nichcy.org/>. On the Web site, click on "State Specific Info" and select your state of residence. Depending on the age and education level of your child, there are different departments in charge.

- If your child is under 3 years of age, contact the people listed under "Programs for Infants and Toddlers with Disabilities: Ages Birth through 2."
- If your child is 3 years or older, but has not yet entered school, contact the people listed under "Programs for Children with Disabilities: Ages 3 through 5."
- If your child is 3 years or older and enrolled in school, contact the people listed under "State Department of Education: Special Education."

From birth to age 3

Under Part C of the Individual with Disabilities Education Act (IDEA), local authorities are required to provide a free evaluation when parents of children

in this age range call and express concern about their child's development. The free evaluation will not provide a diagnosis, but it will determine what services and therapies may help the child.

Once referred to an EIS agency, 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).

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 for EIS, 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.

Ages 3 to 21

Part B of the IDEA establishes guidelines for educating children with disabilities. A referral to evaluate your child can be made by a parent, teacher, doctor, or a child development program. If your child is deemed eligible for special education, an Individualized Education Program (IEP) will be created. Your child's IEP will be evaluated and modified on a yearly basis, with an extensive review performed every 3 years.

After the Diagnosis: Getting Healthcare for Your Child

If your child has been officially diagnosed with autism, it is important to get him or her the help that is needed. Services can be provided to children diagnosed with autism through the TRICARE Autism Demonstration Project, also known as the Autism Services Enhanced Access Demonstration Project. To initiate services under this program:

Step 1:

Enroll your child in the Exceptional Family Member Program (EFMP) by contacting the EFMP Office at your base, your child's PCP, or your case manager. You will need to complete DoD form 2792, which is a medical summary. If your child is in school, you will also need to complete DoD form 2792-1, which is a summary of EIS or special education services.

Step 2:

Once enrolled in the EFMP, you will then want to register your child in the TRICARE Extended Care Health Option (ECHO) program. Your child must be 18 months or

older in order to participate in ECHO. To register your child, contact the ECHO case manager of your regional contractor. Also, you will need to show the Managed Care Support Contractor (MCSC) proof that your child has been enrolled in the EFMP. Make sure you submit your child's IEP or IFSP documentation to the MCSC.

Step 3:

In order to be eligible for the TRICARE Autism Demonstration Project, make sure that your PCP submits verification and date of a diagnosis of autism or ASD to the MCSC.

Family Resources

Specialized Training for Military Parents (STOMP)

www.stompproject.org

STOMP helps families who have special education or healthcare needs. It is a great resource for support, information, and advice.

Parent Training Centers

www.taalliance.org

Every state has at least one Parent Training Center that is designed to help families who have children with disabilities from birth to age 22.

Parent ToolKit

<http://www.militaryhomefront.dod.mil/> (Search for "Special Needs Parent Toolkit")

The Parent Toolkit is created by the DoD and provides information and guidance for military families with special needs children.

Appendix J

Communicating with Commanders

Having a child with special needs can pose challenges within your command and cause stress within the family. Autism is not widely understood, so it should come as no surprise that the demands associated with raising a child with autism would not be common knowledge to the members of your unit or leaders in your chain of command. It is incumbent upon you to inform and educate them in order to balance two competing priorities, which become even more challenging to reconcile the more operational the mission of your unit. As a member of the military, you want to perform your duties to a high standard without interruption or special qualification. At the same time, as a parent and head of household, you know that your family and you will need command support to meet the varying and many demands that the availability of the professionals and teachers working with your child will impose.

Since command structures and terminology differs among the branches of service, we will use the terms “chain of command” or “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. When it comes to autism, it will rest largely on you and your spouse’s shoulders to inform the command about having a child with autism and explain the disorder and the type of support and consideration you may be requesting. This section offers a 4-step approach to promote better communication and understanding of your situation vis-à-vis autism and your child among the leaders and fellow service members within your command.

Step 1. Inform Your Immediate Leader/Supervisor

This is where you always start, of course, but it is not simply a perfunctory step. When you need to request leave or time to go to a medical appointment with your child or an IEP meeting, you are going to want the full and willing support of your immediate leader/supervisor and the members of your unit. So, you will want to be sure to explain what’s going on and why it’s important. You should also be prepared to go the extra mile when possible to compensate in part for times you may need to be absent.

Step 2. Speak to the Commander 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 may be requesting. Therefore, once you have taken care of Step 1, go up the chain of command to 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. Request to meet with that person in your chain of command.

For this meeting, do not assume anything. Approach it 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 anticipate needing from the command. Think of this as an information briefing more than a decision briefing. Remember that you are making him or her aware of your circumstances for the first time, so be professional and mindful of the leader's time, and don't expect final resolution of anything from this meeting. Your purpose is to make the command aware of your situation.

Things to Consider:

Come prepared. You might want to have your own meeting outline or topic list and a folder with information about autism with a 1–2 page autism information sheet. You might photocopy *Appendix A: New to Autism?* for this purpose and perhaps include some information downloaded from OAR's *Operation Autism* Web site. 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 family's situation. Be sure to discuss the level of confidentiality regarding the situation that you desire. Finally, it is wise to keep a personal 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. Few people other than parents of children with autism and their child's various therapists have any idea what an autism treatment regimen entails. 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 where your presence and participation will be important to your child's treatment plan and development. In this vein, be sure to point out that your child's progress is also dependent on your spouse's and your ability to follow through with supporting programs in the home. Thus, it will be important for you to be present for selected therapy sessions.

In addition, you need to 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 you feel comfortable sharing your child's IEP and/or goals, include a copy in the information folder. This will give him/her a better idea of the extent of your child's delays 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 group activities. For example, if your child is over-stimulated in loud and crowded environments, explain this and describe what you or your spouse may do to help your child adjust. Explain that in certain circumstances, you may need to leave a function early. (In addition, it may be helpful to share this kind of information with others in your unit prior to command or social functions so they too can be educated and in turn tell their family members. In this way, everyone present can be better prepared to assist you and your child at these functions. This will also help to ease your spouse's and your anxiety levels.)

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 he/she 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 beforehand in order to have them in place before you deploy. This may require you to request extra leave time before a deployment. 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.

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. Get as many people from your unit as possible to sign up with you as a group and run a local race. This is 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 its support invaluable should you need to consider other options, such as requesting PCS reassignment to a duty station with more appropriate resources. Keep an open mind, however, as there are limits to what your immediate command may be willing or able to do. Also keep in mind that mission requirements, imperatives, and operational priorities will certainly demand your commander's time and interest. Even though

it may not be an easy task to approach your command about your personal, family situation, it is important 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 best of your ability.

In summary, by following these four steps, you will be serving the immediate interests of your child with autism and enhancing your family's capability to contend with the daily challenges of autism. You will also be supporting the readiness objectives of your unit and command. 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 K

Developing Objective and Measurable IEP Goals for Learners with ASD and Preparing for IEP Meetings

As mentioned previously in this Guide, the Individualized Education Program (IEP) is a very important tool to help your child with autism achieve his or her full potential in the classroom. Federal rules and regulations indicate that every IEP must have six components, including:

- Statement of the student's current level of performance,
- Statement of annual goals, including short-term instructional objectives,
- Appropriate objective criteria and evaluation procedures and schedules for determining (at least annually) whether short-term objectives are being met,
- Statement of the specific educational and related services (e.g., speech, OT/PT, transportation) to be provided to the student,
- Projected dates for the start of the services, along with how long they will be provided; and
- Statement identifying the extent to which the student will be able to participate in general education classes, and any modifications or accommodations necessary to enable that participation.

As a parent of a child with an ASD, you should (1) participate in the development of individualized, specific educational goals and objectives and (2) communicate frequently with your child's teacher to determine your child's progress toward meeting these milestones.

Essential to your child's success are goals and objectives that are clearly stated based on your child's needs and accurately measured. Although goals are often more broadly stated (*"In math, Jim will learn addition and subtraction using carrying and borrowing."*), for best results the objectives associated with the goal must present the clear steps for attaining it. (*"When presented with 10 double-digit addition problems involving carrying, Jim will complete all problems with 90% accuracy within 10 minutes. Jim will be able to complete this task at this level for 2 consecutive days."*) Such clearly defined objectives are generally referred to as **behavioral objectives**.

In general, a good behavioral objective must:

- Identify the learner,
- Identify the specific skill or behavior targeted for increase,
- Identify the conditions under which the skill or behavior is to be displayed; and
- Identify the criteria for competent performance.

Each of these components will be discussed in turn below.

Identify the Learner

In most cases, it will be a simple matter to identify the learner (e.g. “*Jim will...*” or “*Susan will...*”) However, more than one learner may be identified in a behavioral objective (e.g. “*Jim and Susan will...*”), and this needs to be clearly stated.

Identify the Specific Skill or Behavior Targeted for Increase

In identifying the specific skill or behavior targeted for increase, you are, in effect, clearly stating exactly what the learner is expected to be doing when the objective is met. This requires a precise description of the skill in terms that are both observable and measurable. In the previous example, the overall goal was stated as here: *In math, Jim will learn addition and subtraction using carrying and borrowing.* This is a general statement with little specificity or measurability.

On the other hand, in the second example given, the behavioral objective is stated as this: *When presented with 10 double-digit addition problems involving carrying, Jim will complete all problems with 90% accuracy within 10 minutes.* In this case, we know:

- **Where** the task is to be presented (in the classroom)
- **How many** problems are presented (10)
- **What types of problems** are presented (double-digit addition with carrying)

In writing clear and measurable behavioral/educational objectives, it is important to use those verbs and related descriptors that are observable and measurable. Examples are given below:

Observable Verbs	Non-observable Verbs
to write to point to to name to jump to count orally	to conclude to appreciate to be aware of to discover to learn to develop

Identify the Conditions Under Which the Behavior is to be Displayed

A good behavioral/educational objective should include, when appropriate, conditions for performance, such as these:

- **What prompts the behavior:** *When presented with the verbal direction, Jim will...*
- **A list of required materials:** *Using the math workbook, Jim will...*
- **Characteristics of the environment:** *During school assemblies, Jim will...*

In this way, myriad aspects of the individual instructional interaction can be presented in as consistent and productive a manner as possible.

Identify Criteria for Competent Performance

In this case, the definition of “success” is clearly stated: *90% accuracy in a 10-minute time frame, for at least two consecutive days*. Once this objective is achieved as stated, Jim is to be considered competent at the task and ready to move on to the next objective. A solid IEP goal should always have similarly clear criteria, allowing team members to determine the success of the objective.

Summary

Creating an IEP for a child with autism is both an art and a science. Using clear language to write achievable objectives is the first step to success.

Preparing for Your IEP Meeting

You do not need to be a special education lawyer to be an effective advocate for your child in the IEP process. What you must do is prepare and plan ahead. Every parent—whether it’s your first or your tenth IEP—will benefit from taking the following steps in advance of every IEP meeting.

Do Ahead of Time

Educate Yourself

- Know your rights as a parent and a team member and understand what you can expect for your son or daughter from the IEP process.
- Request that you be provided a copy of the proposed IEP at least 10 days before the meeting and review all aspects of this document carefully.

Prepare documentation:

- Prepare questions for the team; list in order of priority
- Make a list of the goals, both long and short term, that you want addressed
- Prepare a preliminary list of services (transportation, speech, etc.) you think may be appropriate

Review background information:

- Review your child's previous IEPs and progress reports. Don't be afraid to ask questions if goals are not being met or not being met quickly enough.
- Make copies of relevant research articles, supporting your positions, to distribute to other members of the team. The more in advance you can do this, the more well informed the rest of the team will be for the meeting.

Logistics—attendees and location:

- Find out who will be attending the meeting. Know their names and their roles at the meeting.
- Consider who else you would want to invite to the meeting. Another parent? A home consultant? Remember, as your children gets older he or she can participate in the IEP meeting to whatever extent possible.
- Confirm meeting time and location

Set goals and have a strategy:

- List what you want to have accomplished by the end of the meeting

Bring to the Meeting

- A photo of your child if he or she is not with you. IEP meetings tend to be somewhat impersonal, and your child's photo will serve to remind everyone whom they are there to help.
- Notebook and pen
- Tape recorder (inquire if you need permission from the school to record the meeting)
- Any recent assessments or reports on your child that may be useful
- Any articles or other research that may help the team better understand your child's needs
- Copy of the last IEP document
- A positive attitude. A good approach is to "expect the best but prepare for the worst."

Follow up to the Meeting

- Go over all your notes from the meeting and put them in usable form (e.g. Word document) noting, in particular, who is responsible for what items and on what timeline. If you taped the meeting, you might want to consider having the tape transcribed and distributing the transcription (if appropriate)
- To the extent the meeting went well, let those in attendance know with a short note or follow up phone call.

- Work cooperatively with your child's teacher to ensure that the IEP is implemented effectively, and as written.
- File the IEP and all related documentation (notes, articles, emails, etc.) with your child's other records (See Appendix D, "Keeping It All Organized", for a recommended system).
- Start preparing for your next IEP.

Appendix L

Communicating with Teachers

This worksheet should be used as a template to share important information with your child's teachers. It should not be viewed as an endpoint in itself. It is meant to begin the discussion of classroom issues and challenges between educators and families.

1. What are your child's areas of strength?

2. What types of things work best for your child in terms of rewards and motivation?

3. Does your child have any balance, coordination, or physical challenges that impede his or her ability to participate in gym class? If yes, describe:

4. How does your child best communicate with others?

☐ Spoken language

☐ Communication device

☐ Written language

☐ Sign language

☐ Combination of the above: _____

5. Does your child demonstrate echolalia (repeating last words used without regard for meaning)?

☐ Never

☐ Sometimes

☐ Frequently

6. Do changes in routine or transitions to new activities affect your child's behavior?

☐ Never

☐ Sometimes

☐ Frequently

If yes, what types of classroom accommodations can I make to help your child adapt to change and transitions?

7. Does your child have any sensory issues that could be an issue in class or at schools?

☐ Yes

☐ No

If yes, what type of sensitivity does the student have?

☐ Visual

☐ Auditory

☐ Smells

☐ Touch

☐ Taste

☐ Other: _____

Describe in more detail: _____

What kinds of adaptations have helped with these sensitivities in the past?

8. What behaviors related to autism am I most likely to see at school?

Are there triggers for these behaviors?

☐ Sensory sensitivity

☐ Change in schedule or routine

☐ Social attention

☐ Escape a boring task

☐ Other: _____

In your experience, what are the best ways to cope with these challenges and get your child back on task?

9. Is there anything else you think I should know about your child?

10. What is the best approach for us to use in communication with one another about your child's progress and challenges?

☐ Telephone calls – Phone number: _____

☐ E-mails – Address: _____

☐ Audiotape exchange

☐ Other: _____

Appendix M

Daily/Weekly Journal for Teacher Communication

Date: _____

Student's Name: _____

Overall rating of the day/week (please circle): 1 2 3 4 5
Poor → Excellent

Things that went well in class this day/week:

1. _____
2. _____
3. _____
4. _____

Things that could have gone better:

1. _____
 2. _____
 3. _____
 4. _____
- _____
- _____

Teacher's Signature

Parent's suggestions and advice about things that could have gone better:

Parent's Signature

Appendix N

Tips for Permanent Change of Station (PCS) Moves

You get your orders for a permanent change of station (PCS), you have a child with autism, and you don't know where to start! Use this tip sheet to help you navigate before, during, and after your move to ensure a smooth transition with your child.

Preparing for the Move

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. You can work together 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.

If your child thrives on a daily routine, it may help to have a **picture schedule and calendar** in place. Have your child cross off each day on the calendar with a big "X" at the same time each evening. This will help him or her understand the concept of days and to "see" the big 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 have a long car ride, etc.

With all of the stress of traveling during a PCS, you may also encounter some 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 and are not able to explain autism to onlookers! You can view and print a sample card at <http://www.bridges4kids.org/AutismCards.pdf>.

In addition to the bundle of paperwork needed for a PCS, you will need to 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. Request this letter from your physician at least 3 months prior to your PCS in case it takes some time to generate. You don't want the added stress of trying to obtain this letter at the last minute before your move.

If your child has a preference for a certain color of cup or type of plate or eating utensil, don't forget to pack these items too. A little extra planning for these details will go a

long way. 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!

If your PCS involves staying in a hotel or temporary lodging facility, you may want to start 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.

Tools for Planning Your Timeline

Among *MilitaryHOMEFRONT's* many resources is the DoD Special Needs Parent Toolkit

(http://www.militaryhomefront.dod.mil/portal/page/mhf/MHF/MHF_DETAIL_1?section_id=20.40.500.570.0.0.0.0.0&content_id=218947), which has comprehensive information and tools geared towards helping military families with special needs children navigate the maze of medical and special education services, community support and benefits and entitlements. The Families in Transition module will guide you to some additional, excellent supports: *Plan My Move* and *MilitaryINSTALLATIONS*.

Plan My Move

(<http://apps.mhf.dod.mil/pls/psgprod/f?p=MHF:RELO:8939169077817578>) is an on-line moving tool that generates a personalized calendar based on the parameters of your move, complete with general and installation-specific information. The calendar's length can be customized to meet your family situation. (*Note:* OAR recommends at least a six-month calendar for families that have children with autism.) In addition to the helpful tips and articles, there are checklists, phone lists, additional resources for each subject and key contact information for offices on both the old and new installation. Topics addressed for each installation include:

- Child care and youth services
- Shipping household goods
- Housing (permanent and temporary)
- Education and employment
- Special needs
- Healthcare
- Sponsorship
- And many other areas of interest

Military INSTALLATIONS

(<http://apps.mhf.dod.mil/pls/psgprod/f?p=MI:ENTRY:2377883460025801>) works hand in hand with *Plan My Move*. It provides contact information for programs and services, maps and directions, links to comprehensive location overviews, and community points of interest for military installations worldwide. With this resource, service members and family members can quickly find relevant information about their new

installation. They can also print a booklet of all the installation information in hard copy from the Installation Overview pages of *MilitaryHOMEFRONT*.

For those looking for more information about the surrounding community, *Military OneSource* (<http://www.militaryonesource.com/>) can provide detailed information about the programs and services available in the civilian communities near the new installation. (Note: You must be an active duty or Reserve service member or a member of a service member's immediate family to access this resource. The registration process is very simple and straightforward.)

While you are focusing on your next duty station and getting your family smoothly and safely from one place to the other, remember that moves pose challenges for everyone in the family, including pets. DoD has created *Military Youth on the Move* (<http://apps.mhf.dod.mil/pls/psgprod/f?p=MYOM:HOME:991793526777725>), a Web site designed for children ages 6–18 to help them deal with some of the anxiety and challenges caused by a PCS move and change of schools. It uses humor, empathy, testimonials, and upbeat visuals to address the challenges of moving with the military. It addresses things from elementary, middle, and high school perspectives and extends to topics like healthy eating, physical activity, handling money, and coping with difficult issues like loneliness, bullying, or perhaps their parents' divorce.

Occupying Your Child While Traveling

Are you dreading that 10-hour car ride or 8-hour plane ride? Not to worry. Here a few tips to keep your child(ren) busy!

Make customized activity bags for each child. If the trip will be really long, give your child only one item at a time so the novelty of the items does not wear off shortly after the trip begins. Have some old toys as well as new toys and activities in each bag. Examples include: a new coloring book, hand-held games like ball mazes or Rubix cubes, interactive books (with flaps, hidden pictures, or stickers), Legos, or a soft squeeze ball.

Bring along headphones with a variety of music to include calm instrumental songs for relaxation, kid-friendly tunes, and any other favorites.

Bring along a DVD player with headphones and some old favorite movies, shows, and cartoons, along with one or two new videos your child has never seen.

Sensory toys may be helpful at certain times during your trip. The following items are helpful for calm and relaxation:

- Vibrating massagers
- Weighted lap pad

- Weighted vest or pressure vest
- Hard candy (if this does not pose as a safety hazard for your child)
- Vibrating bean bags or teething rings if your child needs additional oral input
- *Consult with your child's Occupational Therapist for more specific sensory strategies to use*

Other items to have handy just in case:

- Flushable wipes
- An extra set of batteries for a DVD or music player
- Two changes of clothing in the case of an accident (this is likely due to heightened anxiety and multiple transitions associated with moving)
- A few plastic bags
- Medicine for nausea or other illness

Special Considerations for Airplane Moves

It is a good idea to have **earplugs or noise canceling headphones** for your child. If this will be your child's first time in an airplane, be sure to discuss the sights and sounds of the airplane ride in your Social Story™.

Try to **book a direct flight** if you can, or at least minimize the number of connecting flights. Children with autism often have difficulty coping with the "popping" of their ears as the airplane ascends and descends. Many children do not understand this phenomenon. 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.

Contact the airport where you will be departing, explain your child's diagnosis, and request a time to come to the airport and **do a "dry run"** of what your child should expect. The airport may allow you to come during a time of day where it is less crowded and let you walk through exactly what will happen on the day you leave, even allowing you to walk your child through the security gate. 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**. More and more airports are offering these. Take advantage of the play area, if available, and 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** that serves as a quiet haven for military personnel and their families. These lounges provide free amenities, including snacks, internet access, and TVs. Be sure to have your Military and/or Dependent ID cards handy.

If your child is a picky eater or has allergies and if your airline will serve one or more meals during the coming flight, contact the airline in advance to ask if they offer

special meals or have an alternate meal option. For example, you may find that the vegetarian meal provides more food that your child will eat than the regular meal. Do not forget to plan for favorite snacks ahead of time as well.

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.) This will give you a little extra leg room and will likely put you close to a restroom. If you think looking out the window will be interesting for your child, request a window seat. On the other hand, if you think your child may become anxious at the thought of being in the air, request an aisle seat 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 his or her understanding of why your child may not follow the instructions.

Board the airplane at the **first call for special boarding**. Having 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.

If you have a child who is a frequent wanderer, it may greatly benefit you to invest in a type of **personal locator product** in the form of a watch or attachable belt unit. With all of the other things you need to keep track of, such as luggage, carry-on bags, other children, and plane tickets, this may ease your worries should your child wander out of sight when you turn away for a moment to dig in your bag. A personal locator product can cost \$200 and up, but it may prove to be a great investment for your move this time and in the future.

Note: A less expensive way to track your child is to get a military-style dog tag 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). You can also get a bracelet made with the same information. Or, get creative and pin the same information on a small laminated index card attached to your child's shirt or shoelace. For an older, verbal child, teach the child his or her 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" at airports and how your child can find one. Write key words down for your child on an index card, such as "Information" and "Lost". Carry a recent photo to alert security personnel in case your child wanders.

Special Considerations for Long Car Rides

Use a **behind-the-seat organizer** to store your child's items. Be sure this is within his or her reach. This will enable you to focus on your driving and maintain an organized car.

Take frequent rest stops at designated rest areas off interstate highways or at gas stations. 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, bring along a timer and set it for 60 minutes. This way, your child knows that when the timer goes off, he or she will be able to get out of the car. Alternately, you can ask an older child to time the interval on the clock in the car and then pull the car over for a break at the intended time.

If you know your child enjoys playgrounds, do some research in advance and **find some playgrounds along your route**. You can use the Internet to find this information. Tell your child that the next stop will be at a playground so he or she 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**. You may choose to start your trip at night when your child normally goes to sleep. This will (hopefully) ensure your child be asleep for a good portion of the ride.

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 where you need to drive before you get to your final destination.

Initiate creative games using the things you see along the road:

- *Bingo game:* before your trip, prepare a Bingo sheet using pictures or words of things frequently seen on the road.
- *Alphabet game:* take turns finding things that start with a designated letter until you get through the entire alphabet.
- *License plate game:* write down all the license plates you see from different states and see how many you can find by the end of your trip.
- See <http://www.MomsMinivan.com> for more car game ideas that you can modify for your child’s age and developmental level.

If your child has an oversensitivity to sound, take a look at this transcript from the National Public Radio Weekly Show, *Car Talk* (<http://www.cartalk.com/content/columns/Archive/2004/April/04.html>.) Hosts Ray and Tom Magliozzi (otherwise known as Click & Clack) discuss cost-effective options for minimizing road noises that can be painful to children with autism.

Most important: be realistic. Do not expect your child to sit placidly in a car seat for a 15-hour drive. Consider your child’s needs and set realistic goals for how far you’ll travel each day. Take a little more time and break the trip up if possible. Plan to spend the night in a hotel, or take the scenic route and turn it into a mini-vacation where your family can enjoy a few sights along the way. Trying to rush travel produces more stress and anxiety and increases the chances that you will forget something or that something else may go wrong. Take some deep breaths and relax. Bring some soft music for the drive to help you relax, especially if you get caught in a traffic jam!

Contact Log Sheet

Reproduce this form to keep track of communications with your child's service providers, school staff, and other organizations.

Agency/Organization	Contact Information*
*Individual you spoke with, address, phone number, and e-mail	

Date	Notes	Follow-up Information

NOTES



ORGANIZATION FOR AUTISM RESEARCH

Research and Resources that Help Families Today

About OAR: The Organization for Autism Research (OAR) is a national charity led by parents of children and adults with autism and Asperger Syndrome. OAR supports research that focuses on the challenges of living with autism, striving to help families, educators, and caregivers find the answers to their most urgent questions.

More Resources: Autism is a life journey. In addition to this *Guide for Military Families*, OAR has published five other community-friendly guides in its *Life Journey through Autism Series* (* available in Spanish):

- *A Parent's Guide to Research**
- *An Educator's Guide to Autism**
- *An Educator's Guide to Asperger Syndrome**
- *A Guide for Transition into Adulthood**
- *A Parent's Guide to Assessment*

Some of these resources may prove useful in your family's journey through autism. You can download any of the Guides for free or order a hard copy for a \$5 donation at www.researchautism.org/resources/reading/index.asp.

Current Programs: OAR's programs focus on funding new research and disseminating evidence-based information that translates the technical into layman's terms for the non-scientific consumer. OAR funds new research through an *Annual Applied Research Competition*, hosts an annual "State of the Science" conference, and offers college and vocational school scholarships to individuals with autism through the *Schwally Family Scholarship Program*. Most recently, OAR created *Operation Autism* (www.operationautismonline.org), a Web site for military families impacted by autism, which serves as a companion to this Guide.

RUN FOR AUTISM: More than half of OAR's research dollars come through the success of the *RUN FOR AUTISM*, OAR's signature fundraising program. The *RUN FOR AUTISM* features runners in prestigious races like the Bank of America Chicago Marathon, Marine Corps Marathon, New York City Half Marathon, races in the Rock 'n' Roll series, and more. In addition, OAR's *iRUN* program gives you the opportunity to dedicate your efforts to autism research at any run, walk, bike, hike, swim, or triathlon anywhere in the world.



For more about OAR or to join the *RUN FOR AUTISM*, please visit

www.researchautism.org.

I want to support OAR's ☐ Scholarship Fund ☐ Research ☐ Autism Information Programs. I have enclosed a contribution in the amount of (Please make your check payable to OAR):

☐ \$1,000 ☐ \$500 ☐ \$250 ☐ \$100 ☐ \$50 ☐ \$35 ☐ Other _____

Name: _____

Please charge my (circle one) VISA/MC/AMEX

Company/Organization: _____

Credit Card #: _____ Exp: ____/____

Address: _____

Signature: _____

Phone: (____) _____ - _____

City: _____

State: _____ Zip Code: _____

E-mail: _____

To request information, please see the reverse side.





FAST FACTS

Autism ...

... is a neurodevelopmental disorder that affects a person's ability to communicate and interact socially.

... is the fastest growing developmental disability in the U.S., according to the Centers for Disease Control and Prevention.

... occurs in as many as 1 in 110 births, directly affecting up to 2.6 million persons in the U.S. alone.

... is more prevalent than Down's Syndrome, childhood diabetes, and childhood cancer combined.

... has an estimated annual cost of \$90 billion.

Did You Know?

There is no genetic marker or medical test for autism.

Autism affects boys more than girls by a ratio of 4:1.

Autism is found in all cultures and across all socio-economic backgrounds.

The cause of autism is unknown, and there is still no known cure.

There is Room for Hope and Answers.

Autism can be reliably diagnosed by age 3 and sometimes as early as 18 months.

Early diagnosis allows earlier intervention and greater opportunity for children with autism to enjoy fuller, more complete lives.

There are evidence-based treatments that help.

www.operationautismonline.org

Please send me OAR's newsletter by ☐ E-mail ☐ Mail

I would like more information about: ☐ Volunteer opportunities

☐ Research programs

☐ Honor/memorial gifts

☐ Other: _____

☐ RUN FOR AUTISM

☐ OAR's next conference

☐ Scholarships

The Organization for Autism Research (OAR) is a national charity dedicated to funding practical research into the many challenges of autism. OAR is established in accordance with section 501(c)(3) of the IRS Code and is incorporated in the Commonwealth of Virginia (EIN#54-2062167). As provided for under the laws of Virginia, copies of OAR's financial statements are available upon request from the State Division of Consumer Affairs in the Department of Agriculture and Consumer Services in Richmond, VA. Donations to OAR are tax deductible.

www.researchautism.org

Toll free: (866) 366-9710

Algorithms for Navigating Intervention and Funding Systems

The Military Family and Autism

Introduction

These algorithms are built as flowcharts that help you organize the steps involved in acquiring funding and services as soon as possible. Both algorithms assume that a diagnosis has been made. For more information about obtaining a diagnosis, please contact your Primary Care Physician and follow the steps outlined in Appendix A. In addition, the final page provides some ideas for establishing a social network for you and your family.

You will move through both algorithms at the same time. By doing this, you stay continuously engaged in activity though you may be waiting for one step to be completed (e.g. waiting for someone to phone back or to hear back from TRICARE). This continuous engagement helps in two very important ways. It reduces anxiety (it's said that doing something about a problem helps allay the anxiety associated with that problem) and helps minimize as much as possible the time between diagnosis and the beginning of services. It's a little like building a railroad. One builds the railroad and lays the tracks because they are necessary for the rail service. If one waited for the engine and passenger cars first before putting in the tracks, all the more time would be required.

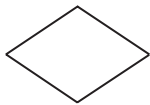
Algorithm Key:



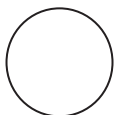
Start



Action / Process



Decision



Stop

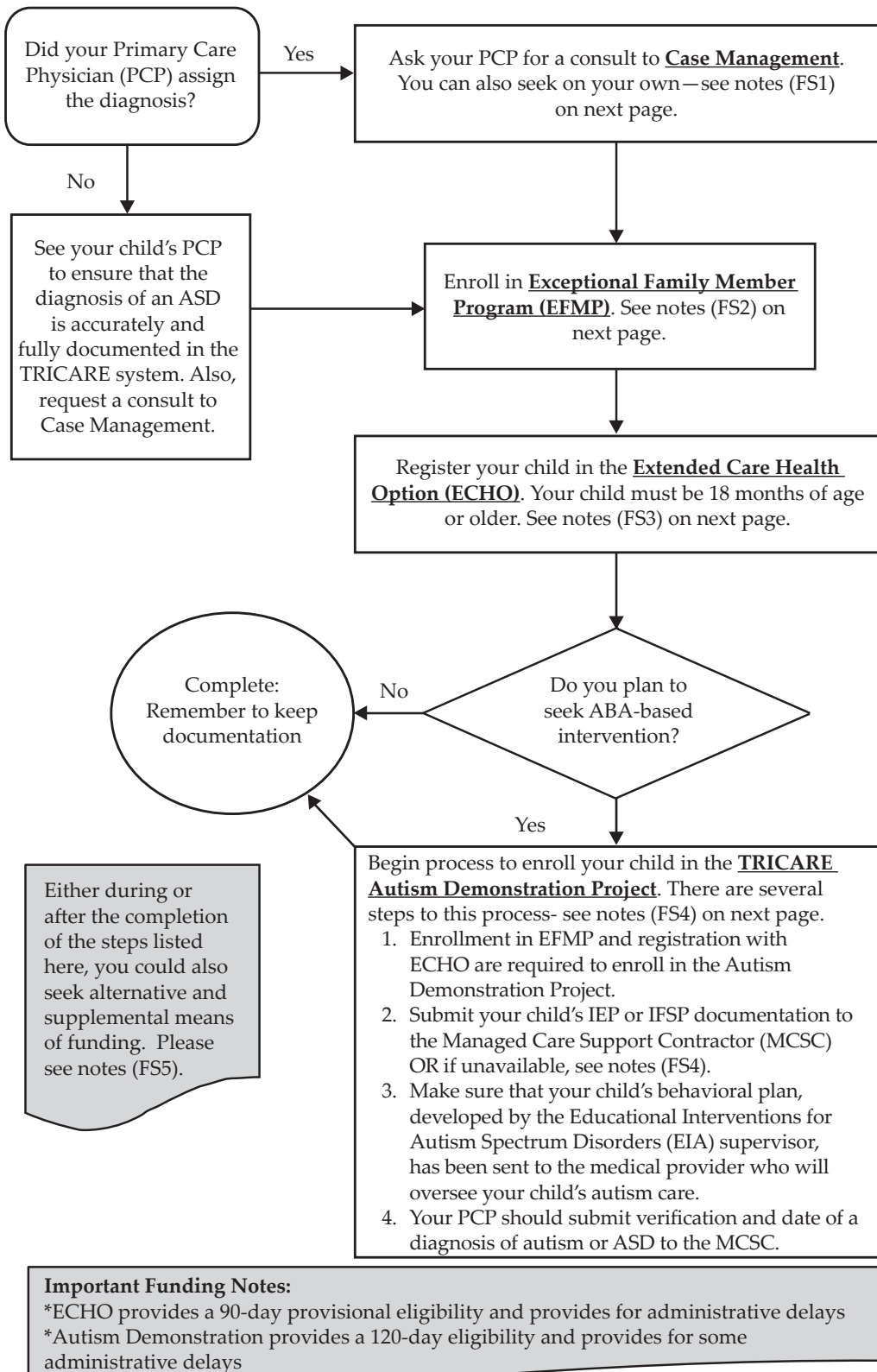


Alternatives

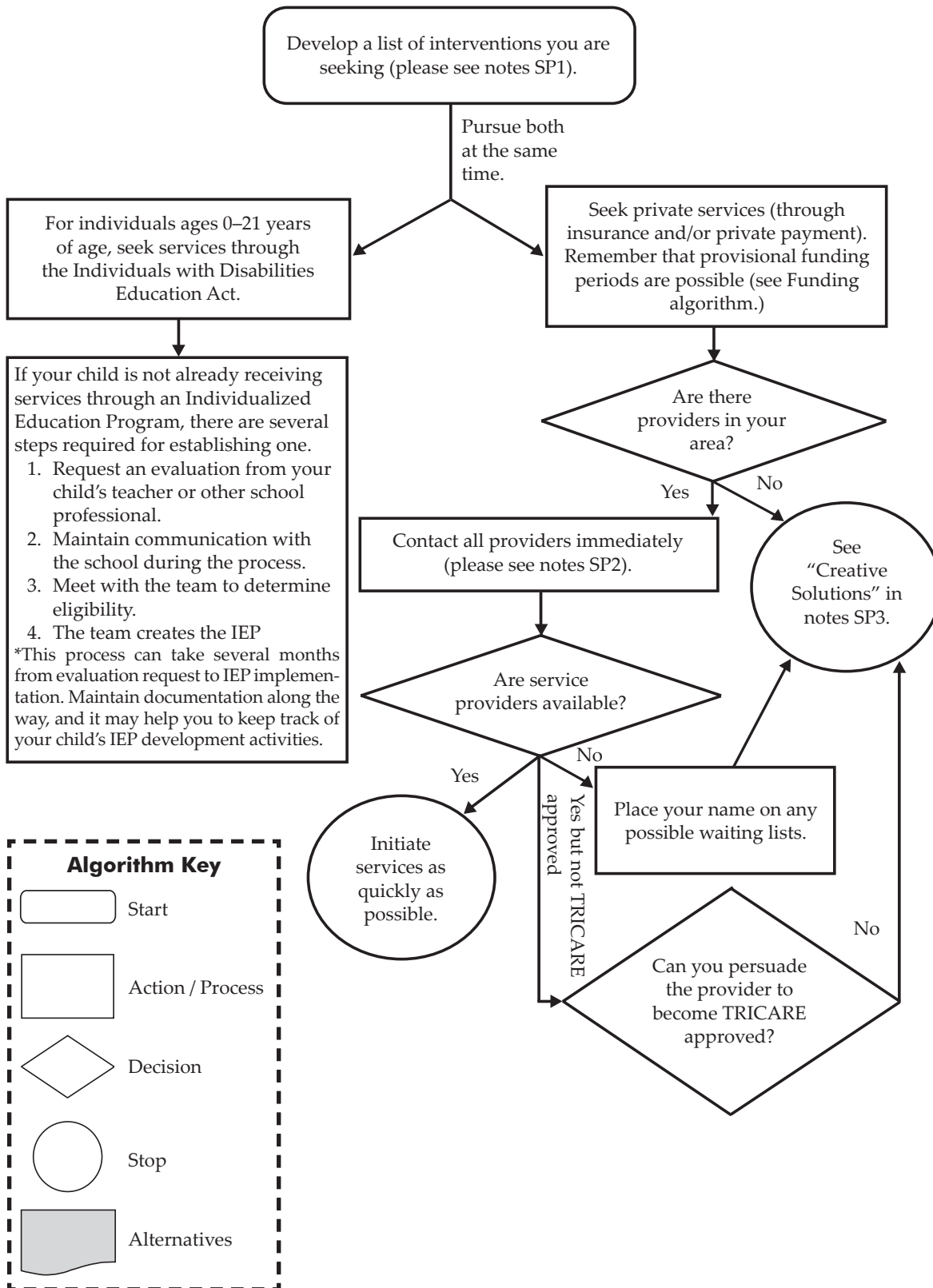
Notes for Navigating the Military Funding System

FS1	<p><u>Case Management:</u> A Case Manager can be very helpful in guiding and/or assisting you in obtaining services for your child. The Case Manager should have a list of local support services for all families and for families with autism.</p> <ol style="list-style-type: none"> 1. Obtaining Case Management: You may ask your child's PCP or ask your MTF Information Center/Customer Service Center how to contact the Case Management office. Case Managers may work for the MTF and be directly available or work for the Managed Care Support Contractor and be available by phone. 2. A Case Manager can also provide you with information about enrollment in various military funding programs.
FS2	<p><u>Exceptional Family Members Program (EFMP):</u> Contact the EFMP Office at your base, your child's PCP, or your Case Manager for information. EFMP is designed to help active-duty service members who have a family member with a medical condition that requires special medical, dental, mental health, developmental, or educational services.</p> <ol style="list-style-type: none"> 1. EFMP is mandatory for active-duty personnel in all services. 2. EFMP aids assignment of the active-duty member to locations where services needed by the family are available.
FS3	<p><u>Extended Care Health Option (ECHO):</u> ECHO is a program specifically for active-duty family members who have specific mental and/or physical disabilities. ECHO provides financial assistance for services not available through the basic TRICARE program. It is a supplemental program.</p> <ol style="list-style-type: none"> 1. ECHO is a cost-share program in which the cost share is based on rank. 2. You may be required to complete a Public Facility Use Certification to provide verification that you are seeking services that are not offered publicly, as ECHO does not cover services that can be obtained publicly. 3. There are several requirements that must be met in order to qualify for ECHO. 4. Please find more information at: http://www.triwest.com/beneficiary/echo/default.aspx
FS4	<p><u>The TRICARE Autism Demonstration Project:</u> The Autism Demonstration Project helps provide evidence-based, ABA-based services to children with autism, above what is already covered by TRICARE. It is a program exclusively for active-duty families who live in the United States. If you are interested in more information, please see the military healthcare section of this Guide.</p> <p>Note: If your child is home-schooled and your state does not require an IFSP or IEP, you must provide a letter from your child's PCP or specialized ASD provider verifying that the child's disability related to autism results in dysfunction severe enough to require special education and other support services.</p>
FS5	<p><u>Alternative Funding:</u> There are several grant programs that exist for families with children who have autism. It may be worth searching the Internet for possible funding sources. Some families have collected money within the extended family to help fund services. This can be particularly helpful while you are waiting to get TRICARE funding in place. Some families have even held small fund-raising events (such as a golf event or walk) to obtain money for services. This should only be done as a supplement to TRICARE-based funding.</p>

Navigating the Military Funding System




Establishing Services



Notes for Establishing Services

SP1	<p><u>Developing a List of Desired Services:</u></p> <ol style="list-style-type: none"> 1. It is helpful to have an evaluation that details your child's areas of strength and difficulty, recommending services based on those findings. If you do not have such an evaluation, begin by asking for service/intervention recommendations from your diagnostic source (e.g. PCP). Once you have those recommendations, you can begin looking for services. You may still want to consider obtaining a comprehensive evaluation so as to ensure you are attending to every possible area of need. Such an evaluation should consider aspects like: cognitive abilities (e.g. IQ, executive function), social skills, adaptive skills (e.g. daily life skills like dressing), speech/language abilities, motor skills, and sensory processing. The evaluation conducted by your school may sufficiently address these areas, but many families also seek independent evaluations. 2. Once you have recommendations for services, it is helpful to understand as much as possible about the services recommended. <ol style="list-style-type: none"> a. Applied Behavior Analysis: The Center for Autism and Related Disorders provides helpful information on its Web site, http://www.centerforautism.com/getting_started/aba.asp b. Speech/Language Therapy: The American Speech-Language-Hearing Association (ASHA) provides detailed information on the role of Speech/Language Therapy for individuals with ASD, http://www.asha.org/docs/html/PS2006-00105.html c. Occupational Therapy: The American Occupational Therapy Association also provides information regarding occupational therapy for individuals with ASD, http://www.aota.org/Practitioners/Resources/Docs/FactSheets/Children/38517.aspx d. Generally, most professions are governed in part by a national organization, which can be a terrific way to find more information about a given therapeutic or educational service.
SP2	<p><u>Contacting Providers:</u> You may be in the fortunate position to select from a variety of service providers in a given type of intervention. If so, consider interviewing several providers to better ensure that the therapist(s) you select is/are a good match for your child's needs and personality, as well as your family's. Asking questions that help you understand the following can be helpful: attitude toward working with parents, philosophy regarding intervention, use of evidence-informed interventions, and any other topics or concerns whose answers will help you choose your child's therapist(s) more confidently.</p>
SP3	<p><u>Creative Solutions:</u> If there are no providers available to begin working with your child and you, there still may be other options that help you begin to integrate supports and interventions into your child's life.</p> <ol style="list-style-type: none"> 1. Consider consultative services. You may encounter a provider who cannot take on an additional full-time client, but may be available to provide some needed services as a consultant. Families sometimes underestimate how effective this level of support can be. Through these means, a provider can help you establish a visual schedule or make modifications to the physical environment or help you make modifications to your routine that help make your life a little easier and help your child acquire important skills. 2. There may be providers who can offer support and recommendations from a distance. A good place to start is in major metropolitan areas (e.g. Washington DC), where there are multiple service providers. Start by contacting a private, special education school that specializes in serving students with ASD. This school's staff should be able to recommend the best providers in the area, and these providers may be able to provide some level of interim support from a distance. 3. There may be a special educator in the area who would be willing to come into your home for a few hours and offer the kind of support proposed in #1. It is important that this person not come from your child's school, as this could pose a conflict of interest. However, a teacher from a different school could provide some level of needed support. Consider a teacher from a local private, special education school, if available. 4. There are some families who seek more intensive training so that they can run programs out of the home. This is a last resort for most families, as it has its difficulties.



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 is designed for those families. Its purpose is to give each family the information and tools it needs on its unique life journey through autism. More specifically, it offers:

- An understanding of autism and related intervention and treatment
- Strategies for dealing with autism from the moment of diagnosis to adulthood
- An overview of DoD and service policies related to having a child with autism
- Information on autism treatment options under the military healthcare system
- Practical information and tools to guide your child's education
- Tips and advice on major transitions including moves, new schools, and more
- Links to additional resources relative to autism and military families

The Organization for Autism Research (OAR) is a national nonprofit organization dedicated to promoting valid research that can be applied to help families, educators, related professionals, and individuals with autism spectrum disorders find the much-needed answers to their urgent questions. Committed to excellence in service to the autism community, OAR seeks to fund applied research that will make a difference in individual lives; 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.

The Southwest Autism Research & Resource Center, founded in 1997, is a leader and collaborator pioneering a fully integrated approach to autism research, resources and community engagement. The nonprofit, community-based organization is dedicated to autism research, education and outreach for children and young adults with autism and their families. SARRC undertakes self-directed and collaborative research, serves as a satellite site for national and international projects, and provides up-to-date information, training and assistance to families and professionals about autism spectrum disorders. For more information about SARRC, visit www.autismcenter.org.



For additional information and resources, please visit Operation Autism, www.operationautismonline.org, a web-based resource specifically designed for military families that have children with autism.



This publication and its companion resource, Operation Autism, were made possible through a grant from the American Legion Child Welfare Foundation.