ontent

Birth to Age Three.....1 Early Intervention..... 4 What is Early Intervention?..... 4 Why Start so Young? 4 The Eligibility Meeting......7 Preparing for Your IFSP Meeting......9 Making the Most of Available Services......11 Your Rights......11

Books
Special Education
Introduction
IDEA 15
The Special Education Cycle 16
Referral
Evaluation17
Evaluation from the Child's Perspective
The Evaluation Conference
What if there is a Disagreement?20
Eligibility20
Eligibility Meeting22
Preparing for the Eligibility Meeting22
What if there is a Disagreement?22
Managing Emotions
Section 504 of the Rehabilitation Act
Individual Education Program (IEP)
Who Attends IEP Meetings?25
Preparing for the IEP Meeting
Potential Problems
Focus on Your Child's Needs26
Are You Satisfied With the IEP?26
Placement
Placement Options
Instruction and Related Services
Instruction
Related Services
Finally, You Have a Plan
Annual Review
Triennial Review
Records
Transition to Adulthood
Guardianship and Declaration of Incapacitation36
For More Information

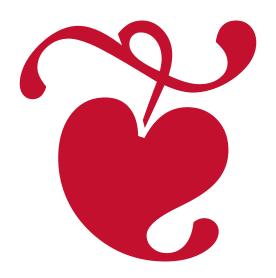
Parenting Advice
Writing A Successful IEP
Advocacy Information
Your Rights
IDEA
Health Benefits
Introduction
TRICARE 39
TRICARE Options for Active Duty Family Members 40
TRICARE Prime
TRICARE Prime Remote40
TRICARE Standard41
TRICARE Extra41
Pharmacy Benefit
TRICARE's Benefits for Families with Special Needs 42
Extended Care Health Option (ECHO)
Who Qualifies?
How Do I Register?43
What Benefits are Available?43
TRICARE Regional Offices:
Respite Care
ECHO Cost Shares
ECHO Home Healthcare (EHHC)44
How Do I Qualify For EHHC?
EHHC Respite Benefit
Home Healthcare
Skilled Nursing Facility Care47
Hospice Care47
Mental Healthcare
Case Management
Help and Information49
TRICARE Service Center (TSC) Directory
Beneficiary Counseling and Assistance Coordinators (BCACs)/
Health Benefits Advisors (HBAs)49

Debt Collection Assistance Office Program50
Catastrophic Cap51
IDEA and TRICARE51
Federal and State Programs with Benefits for Special Needs
Families 52
Supplemental Security Income (SSI)
Medicaid52
Medicare
Food Stamps and Women, Infants and Children (WIC)52
Acronyms
For More Information 54
Families in Transition
Families in Transition
Introduction
Relocating
The Exceptional Family Member Program
Family Support Centers
SITES
Schools
Medical Concerns
Tell the Kids
Packing
Overseas Suitability Screening
Traveling with Kids
Air Travel
Traveling by Train
Traveling by Car
Temporary Lodging
Housing
Schools
Childcare
Moving In
Safety in a New Home
Spouse Employment
Military Spouse Career Center67

Installation Support67
Deployment
Help is Available
Coming Home
Disaster Preparedness
Service Animals
Power Loss
Transition to Adulthood
Independent Living71
Caring for Your Adult Child
Supplemental Security Income (SSI) and Medicaid
The Special Needs Trust
Letter of Intent
Guardianship and Declaration of Incapacitation
ID Cards for Adult Children
Hospice Care
For More Information
Advocating for Your Child
Advocating for Your Child
Introduction
Introduction 77 Effective Communication 77
Introduction77Effective Communication77Stay Cool, Communicate Clearly77
Introduction77Effective Communication77Stay Cool, Communicate Clearly77Letter Writing78
Introduction77Effective Communication77Stay Cool, Communicate Clearly77Letter Writing78Getting Organized79
Introduction. 77 Effective Communication 77 Stay Cool, Communicate Clearly 77 Letter Writing 78 Getting Organized 79 The Medical File 80
Introduction 77 Effective Communication 77 Stay Cool, Communicate Clearly 77 Letter Writing 78 Getting Organized 79 The Medical File 80 Educational File 80
Introduction 77 Effective Communication 77 Stay Cool, Communicate Clearly 77 Letter Writing 78 Getting Organized 79 The Medical File 80 Educational File 80 Medical Advocacy 81
Introduction 77 Effective Communication 77 Stay Cool, Communicate Clearly 77 Letter Writing 78 Getting Organized 79 The Medical File 80 Educational File 80 Medical Advocacy 81 Getting the Referral You Need 82
Introduction. 77 Effective Communication 77 Stay Cool, Communicate Clearly 77 Letter Writing 78 Getting Organized 79 The Medical File 80 Educational File 80 Medical Advocacy 81 Getting the Referral You Need 82 Appealing TRICARE Decisions 82
Introduction 77 Effective Communication 77 Stay Cool, Communicate Clearly 77 Letter Writing 78 Getting Organized 79 The Medical File 80 Educational File 80 Medical Advocacy 81 Getting the Referral You Need 82 Appealing TRICARE Decisions 82 Educational Advocacy 82
Introduction 77 Effective Communication 77 Stay Cool, Communicate Clearly 77 Letter Writing 78 Getting Organized 79 The Medical File 80 Educational File 80 Medical Advocacy 81 Getting the Referral You Need 82 Appealing TRICARE Decisions 82 Educational Advocacy 82 Legislation 82
Introduction. 77 Effective Communication 77 Stay Cool, Communicate Clearly 77 Letter Writing 78 Getting Organized 79 The Medical File 80 Educational File 80 Medical Advocacy 81 Getting the Referral You Need 82 Appealing TRICARE Decisions 82 Educational Advocacy 82 Legislation 82 The School System 84
Introduction 77 Effective Communication 77 Stay Cool, Communicate Clearly 77 Letter Writing 78 Getting Organized 79 The Medical File 80 Educational File 80 Medical Advocacy 81 Getting the Referral You Need 82 Appealing TRICARE Decisions 82 Educational Advocacy 82 Legislation 82 The School System 84 Assessments 84

The Bell Curve and Standard Deviations
Independent Educational Evaluations86
IEP and Eligibility Meetings
Writing an Effective IEP88
Disagreements
Benefits Advocacy90
Supplemental Security Income (SSI)90
Medicaid91
Teaching Your Child to Self Advocate
Influencing Public Law 92
For More Information 93
Seek Other Parents of Children with Disabilities
Contact STOMP
Find Your State Parent Training and Information Center 93
Books94
D
Resources and Support
Introduction
Military Community Resources
Family Support Centers (FSC)
New Parent Support Program
Family Advocacy Program (FAP)96
Child, Youth and Teen Development Programs
School Liaison Officers
Relief Societies
Service Sponsored Websites
Additional Military Resources
MilitaryHOMEFRONT's Special Needs/EFMP Module98
Military OneSource99
Military Teens on the Move (MTOM)100
SITES100
TRICARE
Federal, State and Community Resources
American Red Cross101
Computer/Electronics Accommodations Program (CAP) 101

	Disabilityinfo.gov
	Cadre (National Center on Dispute Resolution)101
	Food Stamps and FSSA101
	Medicaid
	National Center on Education, Disability, and
	Juvenile Justice (EDJJ)
	NICHCY102
	Shriners Hospitals for Children
	Specialized Training of Military Parents
	Supplemental Security Income (SSI)
	Women, Infants and Children (WIC)104
	Wrightslaw104
Re	sources for Families with Seriously Ill or Hospitalized
Ch	ildren
	Fisher House
	Make-a-Wish Foundation
	Starlight Starbright Children's Foundation105
	A Special Wish Foundation105
	The Dream Factory
	Give Kids the World Village
Re	cords and Tools107



Introduction Ction

Many parents wish their children came with instruction booklets. For parents of a specially challenged child, this feeling may be magnified. As you learn about your child's disability and interact with medical and educational professionals, remember that you are the expert on your child. Although you may feel bewildered by the challenges you face and may have many questions, no one will know your child as well as you will. Use this module as a guide to help you find solutions for your problems and answers for your questions You are not alone.

Discovering Your Child has a Delay or Disability

Learning that your child is developmentally delayed or has a disability can be a stunning blow. Many parents experience an array of feelings, frequently starting with denial and flowing into anger, fear, and guilt. It can be hard to believe that the diagnosis is true. As this new information is absorbed, anger is often present and may



be directed at medical personnel or whoever provides information about the child's condition. Anger may even spill out onto family members as they try to understand what this diagnosis means. Fear stems from the unknown about what the future holds, as well as the realization that the complex job of raising a disabled child lies ahead. Many parents also experience guilt and worry that they did something to cause the disability. Sadness and disappointment are inevitable as you realize you must revise the hopes and dreams you had for your child.

You may be flooded with emotion, and feel overwhelmed. However, there are constructive actions that can be taken now, and there are many sources of help, support, and reassurance available.

Reach Out

First of all, ask any questions you may have of the professional who is seeing your child. If a doctor or professional is using words you don't understand, ask them to explain. Don't be embarrassed to say, "Would you please explain that again?" A large amount of information is being absorbed and it can be very confusing. If unsure about the diagnosis, ask for a second opinion; you are entitled to one.

Wirth to App Inrec

Some parents feel...

"The first few years after the diagnosis I was struggling with the dire predictions, but I can see now that we are going to be fine."

~Louise, mom to son with autism, Quantico VA

parent to parent

Denial

Often the first reaction people have to any loss is denial. When you have just learned that your child may have a disability, denial may propel you to get a second opinion. That is a good idea; doctors are imperfect.

Anger

Anger is a reasonable reaction to the loss of something precious, and you are entitled to feel angry. You might be asking, "Why me? Why my child?" Eventually, many parents use their anger to energize themselves in the struggle to get the best possible services for their child.

Anxiety and Fear

When you learn that your child is not developing in a typical way, there is good reason to be afraid and anxious. Coping with a child who has a disability or is chronically ill can be exhausting and confusing. Worries about the future and your own ability to be a good parent are common.

Guilt

It is not unusual for parents to blame themselves for having done or not done something that caused their child's impairment. This can be especially difficult for mothers who may look back on their pregnancy and wonder if something they did caused their child's disability or illness.

Sorrow

Sadness and disappointment are inevitable as you realize that the future you had envisioned for your child might never materialize. Grief is the natural reaction to loss, and if you discover that your child is especially challenged, you may need to grieve for the healthy child you had dreamed of.

Acceptance and Hope

Finally, the roller coaster ride starts to level out occasionally. Your child is still disabled or delayed, but you have a greater understanding of his or her condition and you realize that you can take good and loving care of this child. You realize that while your child may not be typical, he or she is loving and lovable.

3

What can I do?

Learn about Your Child's Condition

- Search your library and the Internet for information on your child's condition.
- Ask your doctor any questions you have about your child's condition.
- Jot down questions that occur to you as you go through your day.
- If you don't understand something don't be embarrassed to say so.

Contact STOMP

- Specialized Training Of Military Parents is a valuable online resource.
- You will find support and advice for military parents regardless of special challenges your child may face.
- Join the list serve and correspond with other parents of specially challenged children at www. stompproject.org or call 1-800-5-parent.

Seek Other Parents of Children with Disabilities

- Realize that you are not alone.
- Your Exceptional Family Member Program Representative can help you find other military families who have faced similar challenges.
- To find the closest Family Service Center and EFMP Coordinator, go to www. militaryhomefront.dod.mil/ directories.

Seek Out Your State Parent Training Center

- Every state has Parent Training Centers (PTC).
- PTCs serve families with children with all disabilities, and can help you obtain appropriate educational services for you child.
- PTCs train parents and professionals and can help resolve problems between schools and families.
- To find a Parent Training Center in your state, go to www.taalliance.org.



After many years of research, there is strong evidence that early intervention increases both developmental and educational gains for children, *improves the* function of the family, and provides long term benefits for the community.

Seek other parents whose children have disabilities. Contact your Exceptional Family Member Program representative at the nearest Family Support Center (www.militaryhomefront.dod.mil/directories) and ask for assistance finding families who have dealt with similar challenges.

Family Connections

Keep talking to your spouse. The more you can communicate in challenging times the greater your strength as a couple will be. You will probably not react to this new information about your child in the same way, but try to explain how you feel and listen carefully as your spouse shares feelings as well. Sometimes agreement is less important than understanding. If there are other children in the home, be aware of their needs as well. If talking about the disability is too difficult at this time, ask another adult to try to establish a bond with your child so that your child has someone to talk to about his or her feelings without upsetting mom or dad.

Early Intervention

IDEA

In 1986, Congress recognized the importance of getting early help to children with special needs and their families, so an amendment was made to The Education for All Handicapped Children Act of 1975. This ensured that children with special needs would not have to wait until they were school age to receive services. Today,

the Individuals with Disabilities Education Act (IDEA) Part C requires all fifty states and jurisdictions to have a system of early intervention for all children with disabilities from birth until they turn 3. For more information about IDEA, go to www.wrightslaw.com.

What is Early Intervention?

Every baby and child develops at a unique speed emotionally, intellectually, and physically. When children under the age of 3 are discovered to have, or be at risk of developing, a condition or special need that may affect their development, early intervention services can help the children and their families to identify and minimize these delays.

Goals of Early Intervention

Early intervention provides services with the goal of lessening the effect of any condition that may limit a child's development. It can be remedial or preventive in nature, minimizing delays or preventing their occurrence. Early intervention focuses on the child, but is most effective when the focus is on the child and the family together. Services may begin anywhere between birth and age 3; however, there are many reasons to begin as early as possible.

Why Start so Young?

There are many reasons to introduce an exceptional child to early intervention as soon as possible. The most important reason is that a child's rate of

learning and development is most rapid in the preschool years. If, during these early stages of development, the teachable moments and times of greatest readiness are not taken advantage of, the same skills may take longer to learn when the child is older.

Early Intervention Strengthens Families

Early intervention is also a valuable resource for the parents and siblings of an exceptional child. The families of exceptional children may feel isolated, disappointed, frustrated, or helpless. All of these stresses may affect the whole family's well-being, as well as the child's development. Early intervention helps families to be empowered as they negotiate their way through life with a specially challenged child. It can result in parents having improved attitudes about themselves and their child as well as better information and skills for teaching their child.



To find the early intervention program in your area, you can call The National Dissemination Center for Children with Disabilities (NICHCY) at 1-800-695-0285.

Who Provides the Services?

Early intervention services are required by law and are available throughout the 50 states and territories of the U.S. Each state decides which of its agencies will be in charge of early intervention services for infants and toddlers with special needs.

Most Services are Free

Part C of IDEA requires that the evaluation or assessments, the development of an Individual Family Service Plan (IFSP), and the service coordination be provided free of charge to eligible children and their families. Other services may also be provided at no cost to families, although some fees may be assessed on a sliding scale depending on the income of the child's family. However, the law also states that no family shall be denied services because they cannot afford them. If you have problems with cost or availability of services, contact your service coordinator or your health benefits advisor. Early intervention may be paid for under your TRICARE option, your private insurance, or Medicaid. Each child's family has the final say on what services they will accept, and they may reject services they don't want to pay for.

The Department of Defense also has an early intervention program to meet the needs of children who reside on military bases with DoD schools but are too young to attend. All DoD Early Intervention Services are provided at no charge.



The Department of Defense calls its early intervention services Educational and Developmental Intervention Services (EDIS).



Your service coordinator will work with your family to ensure that the proper evaluations are done and that the services in the IFSP are carried out and will assist 6 you with the transition out of EIS when your child reaches the age of 3.

Referrals and Service **Coordinators**

Referrals for Early Intervention Services are usually made by a child's parents or physician, but they can be made by anyone on behalf of a family. Once a child has been referred for EIS. a service coordinator will be assigned to assist the family by gathering information from the family, arranging for appropriate assessments and evaluations, and eventually creating an Individual Family Service Plan. Your service coordinator will be your contact as evaluations are conducted and meetings are scheduled to discuss the results and will help with assessing and coordinating recommended services.

The Evaluation Process

Within 45 calendar days of the referral, an evaluation must be completed and a service plan put in place if the child is found to be eligible for early intervention. The evaluation will determine whether or not a child needs early intervention services. It consists of a general developmental assessment of the child's abilities, including the following:

- A parent interview to voice concerns about a child's delay(s).
- A review of the child's medical history.
- Assessments by specialists in the areas of concern.

The following areas will be assessed:

- Physical development. The ability to see, to hear, and to move with purpose or coordination.
- Language and speech development. The ability to talk, to understand language, and to express needs.
- Social and emotional development. The ability of a child with typical intelligence to build satisfactory relationships and respond appropriately under normal circumstances.
- Adaptive development. The ability to eat, to dress, to toilet, and to perform other self help skills.
- Cognitive development. The ability to think and to learn; a measurement of intellectual functioning which is related to the child's ability to think, to speak, to read, to write, or to do mathematical calculations.

To minimize anxiety during the assessment process, do not allow your child to be separated from you. The anxiety of separation may cause a child to do poorly. Make sure the child is comfortable with the professional doing the assessment. This may take time and require more than one session. The goal is a fair assessment of the child's abilities and weaknesses.

Discussing Your Child's Special Challenges

Many parents have mixed feelings about discussing their child's area of weakness. It may feel unloving or disloyal to call attention to the child's delays. However, spelling out concerns and noticing the areas of weakness is your responsibility as your child's advocate. Your child will benefit when, because of your shared observations, needed services are made available. Being very honest is a loving choice.



Child development research shows that the rate of human learning and development is most rapid in the preschool years. If the most teachable moments or stages of greatest readiness are not taken advantage of, a child may have difficulty learning a particular skill at a later time.

Who is Eligible?

Babies and children may be eligible for services until they turn 3 if they meet the following criteria:

 The child has a diagnosed physical or mental condition which is likely to result in a delay of development.

- The child has a
 developmental delay in one
 or more of the following
 areas: cognitive (intellect),
 physical development
 (to include vision and
 hearing), social or emotional
 development, self help, or
 adaptive skills.
- The child is considered to be at high risk of developing substantial delays if early intervention is not provided.

The Eligibility Meeting

After assessments have been completed, an eligibility meeting will be held. The evaluations and observations of the child will be compared with the eligibility criteria listed above to determine if he or she qualifies for services. It is at this meeting that a child will or will not be found eligible for services.

Preparing for the Eligibility Meeting

To prepare for this meeting, gather and write down your own information about your child's growth and development and be prepared to share this information with the team. You may want to make a small poster about your child to help the team to better know your child and to remember that he or she is unique and muchloved. It is helpful to bring a family member or friend with you. Often you will have been given the results of the screening of your child. You may be pleasantly surprised, or dismayed by the findings. Don't



The eligibility meeting is where the decision about whether or not your child will receive services will be made.

Checklist for Early Intervention Meetings
A picture of your child.
Copies of prior evaluations.
List of concerns and ideas for your
Cilia.
List of questions developed over time.
Pertinent medical records.
Paper and pen to take notes.
* *
A friend or family member for
company and moral support.

rush through these meetings. Ask questions of the professionals in the room about your child's ability levels or services you believe might be a help to your child or your family. Remember that formal testing is just one component

A sweet snack to share.

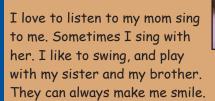
of your child's assessment. Your observations and experiences with your child are an important component of the assessment. Don't give up if the assessment team does not place the same importance on an observation as you do. Talk it over with them so that you are able to understand their point of view, and they understand yours.

A Parent's Perspective

It may feel uncomfortable explaining to a stranger that something is not quite right about your child. It may be tempting to minimize your child's delay because you are so proud of the gains your child has made and because you love your child so profoundly. Keep in mind that in order for your child to qualify for appropriate services there must be a clear and accurate picture of your child's development.

My name is Emma

I was born on March 1st, 2003. I have one sister and one brother. I am the youngest.



I don't like going to bed or eating broccoli.

My daddy calls me his little Emma bug.

Individual Family Support Plans

If a child is found eligible for Early Intervention Services, parents and members of their support team will gather again to write an Individual Family Support Plan (IFSP). This plan will identify what the child's current developmental levels are, what services will be provided to advance those levels, and what goals parents would like to see their child reach. Armed with this information, you will be able to specify the direction you would like to see your child move in and to identify milestones along the way. The IFSP will contain valuable information about your child's strengths, needs, likes, and

Module One: Birth to Age Three

9

dislikes. This information combined with results from assessments and medical information from your child's doctor will provide a thorough description of your child's special needs and goals.

Famlies will revisit this document with their child's service coordinator regularly to assess how goals are being met and to revise or update the steps being taken to assist their child.

The IFSP will include the following components:

- Information about your child's current development.
- Information about family resources, priorities, and concerns.
- Goals of the plan.
- Detailed description of services needed to help your child reach goals.
- Statement about the natural environment where the services will be provided.
- Start date for services and the expected duration.
- Name of the service coordinator who will help obtain the services identified.
- Transition plan for your child.



The IFSP is intentionally family focused. Its purpose is not only to address the needs of the child, but to aid the family in their efforts to support and encourage their child.

The IFSP Meeting

The guiding principal of the IFSP is that the family is a child's greatest resource, and that a baby's needs are closely tied to the needs of the family. The best way to support children and meet their needs is to support and build upon the individual strengths of their family. So the IFSP is a whole family plan with the parents as the most important part of the IFSP team.

Preparing for Your IFSP Meeting

Sitting down with a room full of professionals to discuss challenges and opportunities for your child can be difficult and emotionally draining. However, you are the leading expert on your child and your input is crucial to the quality of the IFSP. To ensure that you remember to discuss all your hopes and concerns, it is helpful to write down observations and areas of concern in the days before the meeting. If IFSP meetings are emotionally difficult and no family member is available to attend with you, ask a friend who is familiar



The most *effective early* intervention programs share the following qualities: the young age of children at start of services, the parental involvement, and the intensity and amount of structure provided by the program.

with your child to accompany you. This person can offer moral support as well as another view point on the situation. The IFSP will be reviewed at regular intervals to monitor your child's progress and adjust goals accordingly.

Types of Services

The IFSP will define what type of intervention will best benefit your child and your family. The services that are required to be available to eligible families include the following:

- Assistive Technology.
 Devices or services that allow or improve independence in daily activities (e.g., a curved handle on a spoon for easier self-feeding or a wheel chair).
- Audiology. Therapy for individuals with hearing loss.
- Family Training. May be counseling to help family understand the special needs of their child and how to best support the child's development.
- Medical Services. For birth to age 3 for diagnostic or evaluation purposes only.
- Nursing Services. May assess health status of your child or administer treatments prescribed by a physician.
- Nutrition Services. Address the nutritional needs of your child and may include

- identifying feeding skills or problems, food habits, or preferences.
- Occupational Therapy.
 Activities designed to improve fine motor skills (e.g., finger, hand, or arm movements).
- Physical Therapy. Activities designed to improve gross motor skills (e.g. leg, back, or whole body movements).
- Psychological Services.
 Administering and interpreting psychological tests and information about a child's behavior and may include counseling, parent training, and education programs.
- Respite Care. Trained care givers who will take care of your child, giving you a little time off.
- Service Coordination.
 Bringing together the people, information, and resources that your child and family may need.
- Specialized Instruction.
 Programs or services
 specially designed to meet
 the needs of children with
 special needs.
- Speech and Language Services. Activities and materials designed to

improve your child's ability to express thoughts and information.

- Transportation. Providing for the travel necessary to enable a child and family to receive early intervention services.
- Vision Services. Identification of, and services for children with visual disorders or delays.

Making the Most of Available Services

As a parent, it is very important to watch how your child is being taught and encouraged while receiving services. By modeling this behavior at home, you are reinforcing the lessons and increasing the speed at which your child will master the new skills being addressed. Every session, whether at home or in a center, offers a chance for the service provider and the family to share information about the child. A child's parents know the child best and can share daily observations. The service provider can offer ideas on how to help the child in the home environment. A cooperative partnership between the family, the service coordinator, the teachers, and the service provider will benefit the child profoundly.

Your Role as Advocate

When a parent first realizes that a child may face more challenges than his or her peers, the reaction can be an emotional one. Over time, the family accepts that it has different



Parents may choose in which natural environment the child will receive services. This may be at home, a preschool setting, or another location.

circumstances than most. The realization that children will need specific services to mitigate these delays turns many parents into advocates.

Parents, are natural advocates for their children. They are their child's first teachers, they know their child better than anyone else, and they have their child's best interests at heart. Children need their parents to play an active role in planning their education. The law gives parents the power to make educational decisions for their child. How can this power be best used to benefit the child? For detailed information about how to become an advocate for your child see module five, Advocating for Your Child, of this Parent Tool Kit.

Your Rights

Parents have certain rights under the Individuals with Disabilities Act. They have the right to do the following:

 Choose whether or not to have a child evaluated and if so, to have it done in a timely manner.

- Go through the early intervention process in their own language.
- Receive full copies of all evaluation results and notice regarding each aspect of the program.
- Refuse any specific service without losing the right to other services.
- Bring or consult an advocate or attorney to any meeting or stage of the process.
- Keep all information regarding the family confidential.
- Examine and correct all records regarding the child and family.
- Withhold or withdraw consent at any stage of the process.
- Be told of any possible changes in the child's evaluation or services before any are made.
- Be involved in all stages of early intervention.
- Not to participate in the Early Intervention Program.

The role as a parent is vital, for parents are the most important people in their child's life and they know their child best. Make sure that early intervention services are doing what is best for your child.

To ensure this, be ready to organize and keep track of all the paperwork throughout the early intervention process. Learn about assistive technology so you will be informed enough to ask for devices that might aid your child. Be aware of your rights and those of your family and be an active participant in all stages of early intervention. For hints on how to keep your child's records organized, see module five, *Advocating for Your Child*, of this Parent Tool Kit.

Challenges and Support

Sometimes, even though parents may suspect their child has a delay, they hesitate to ask for help, perhaps hoping that the child will catch up to his or her peers without additional help. If you are hesitating, consider that there is nothing to lose by asking to have your child screened. Either necessary help will be offered, or you will receive reassuring answers to your questions.

Challenges

Learning how to find appropriate services for your child can be difficult, and military families must also deal with the complication of relocating and starting the process again. It is very important to carry the documentation of your child's early intervention program with you to your new home. Once in the new location, seek early intervention services quickly, as there may be a waiting list or other delays in services. Call The National Dissemination Center for Children

with Disabilities (NICHCY) at 1-800-695-0285 to find who provides early intervention in your area.

Although all states have early intervention services, all programs are not equal and a child may not be eligible for the same services at the new location. Also, you may need to demonstrate residency before you can apply for services. For information about relocating with your exceptional child see module four, *Families in Transition*, of this Parent Tool Kit.

Support

Members of the military have many groups and agencies to turn to for help with their exceptional children. Please take advantage of the many resources that have been put in place. Remember that you are not alone and there are knowledgeable people ready and waiting to help. In module six, *Resources and Support*, of this Parent Tool Kit, there are lists of contacts, ways to connect with support groups, and many other sources of help and information.

Being the caretakers of a child with special needs can be physically exhausting as well as emotionally draining. By finding people to talk to about your life, your child, and your unique stresses, you will be helping yourself as well as your child. Caretakers need care too. If you think you might benefit from counseling, contact your family service center at www. militaryhomefront.dod.mil/directories

or Military OneSource at www. militaryonesource.com or call 1-800-342-9647. Help is close by.

For More Information

Obtain the other modules of this Parent Tool Kit at www. militaryhomefront.dod.mil/efm or from your EFMP coordinator.

- Module Two, Special Education
- Module Three, *Health Benefits*
- Module Four, Families in Transition
- Module Five, Advocating for Your Child
- Module Six, Resources and Support

For parents of babies and toddlers who are newly diagnosed with a developmental delay or disability, the following resources are especially helpful.

STOMP

Specialized Training for Military Parents (STOMP) is a national organization dedicated to educating and training military parents of children who have special education or healthcare needs. STOMP assists military families by providing information, support, and advice. STOMP can also connect you to other military families with exceptional children.

"I started to feel better when I realized that asking for help didn't mean I wasn't a good enough mom."

~Karen, mom to daughter with downs syndrome and SID, Ft. Lewis, WA



Visit the STOMP website and consider joining their list serve at www.stompproject.org.

Parent Training Centers

Another resource is your state's Parent Training Center. Each state has a minimum of one Parent Training Center that is designed to serve families of children and young adults from birth to age 22 with all disabilities. Centers may provide information, training, referrals, and advocacy services to assist parents obtain the needed resources within their communities. To locate the Parent Training Center within your state, visit www.taalliance.org.

NICHY

The National Dissemination Center for Children with Disabilities (NICHY) offers a wealth of information in both English and Spanish. To learn more about early intervention for infant and toddlers and specific disabilities, visit their website at www.nichcy.org.

Wrightslaw

Parents, advocates, educators, and attorneys utilize Wrightslaw for accurate, up-to-date information about special education law and advocacy for children with disabilities. You will find articles, cases, newsletters, and resources about the Individual with Disabilities Education Act (IDEA) and other legal issues at www. wrightslaw.com.

Books

You will Dream New Dreams; Inspiring Personal Stories by Parents of Children with Disabilities, by Stanley D. Klien, Ph.D. and Kim Schive

Special Children Challenged Parents, by Robert A. Naseef, Ph.D.

Introduction CtiOM

Your child may have a disability you are already aware of, or perhaps you suspect your child has learning problems but are unsure of what to do next. Learning how to navigate the Special Education system can be difficult for any family, but for military families whose educational environments are constantly changing, it is an even greater challenge. For any child in a military family where homes, schools, and neighborhoods frequently change, parents are the constant factor. If your child does not receive an adequate education, you and your child will cope with the consequences for years to come. As you learn the system and interact with professionals, remember that you are the expert on your child and that no one else has a greater knowledge or interest in your child than you do.

IDEA

The Individuals with Disabilities Education Act (IDEA) is the special education legislation that guides school systems throughout the United States, its territories, and Department of Defense schools in the education of children with special needs. IDEA Part B establishes educational requirements for children with disabilities from the ages of 3 to 21. IDEA Part B has six major principles that must be met by school systems.



- Free and Appropriate Public Education (FAPE). This means that your child is entitled to an education at public expense, under public supervision and direction.
- Appropriate Evaluation.
 This includes gathering the information necessary to ensure a child is able to be involved in and progress within the general curriculum of the school.
- Program (IEP). This is a written plan for a child with a disability that is developed and reviewed according to the standards detailed in IDEA.
- Least Restrictive
 Environment (LRE). Children
 with disabilities are most
 appropriately educated
 with non-disabled peers.

Separating the child from his or her non-disabled peers should only occur when the nature of the disability is such that education in a regular classroom, even with supplementary aids, cannot be achieved satisfactorily.

- Parents play a key role in decision making. "Congress finds the following:...Almost thirty years of research and experience has demonstrated that the education of children with disabilities can be made more effective by...strengthening the role of parents and ensuring that families of such children have meaningful opportunities to participate in the education of their children at school and at home." (IDEA 2004 Finding)
- Procedural safeguards must be in place to ensure that the rights of the child and the child's parents are protected, and that there are clear steps to follow in the case of a dispute.

The purpose of the law is to ensure that all children with disabilities have access to a free, appropriate public education (FAPE) to ensure the rights of children with disabilities and those of their parents are protected and to ensure that teachers and parents have the tools they need to meet educational goals and to assess the effectiveness of educational efforts being made for the child.



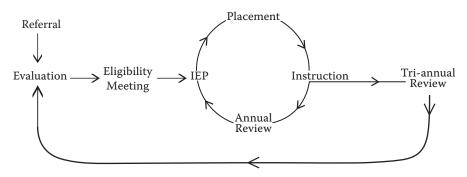
Every state has a Parent Training
Center as well as a Protection
and Advocacy Agency. These
two organizations will help you
learn how to advocate for your
child within the public school
system. If you have a concern
you should not hesitate to
contact these agencies at www.
taalliance.org and www.napas.
org.

The Special Education Cycle

How does a child become involved in Special Education? When a child has an obvious handicap or when a parent or teacher notices that a child is not progressing at the rate of his or her peers, this information is usually given in writing to the school system. This is the referral that begins the special education cycle. As the child moves through the cycle he or she will be assessed. and a decision will be made as to whether or not the child is eligible for special services. If so, a unique Individual Education Program will be written and followed to ensure that the child will get an appropriate education.

Referral

A referral is simply a request, usually in writing, to have a child evaluated by the school system for special education services. Some



Special Education Cycle

school systems have a specific form for this. A referral for special education can be made by a parent, teacher, or doctor, or it can come from a child development program. This happens when someone involved with the child notices that the child is not making progress or is showing signs of physical or behavioral challenges that are interfering with learning. Any of these people can contact the school system, in writing, and request that the child in question be evaluated. Usually, after a referral has been made, a screening committee meets to determine whether or not the child needs a full evaluation. This typically occurs at the child's home school. Should the screening committee decide that the child should have an evaluation, the parents will be notified as the child cannot be evaluated without their permission.

Evaluation

The evaluation is the series of tests and assessments the school system will use as they try to determine whether or not a child qualifies for special education. A student's abilities may be evaluated in these areas:

- Cognitive. A child's intellect (ability to reason, remember, and understand).
- Behavioral. The ability to pay attention, the quality of child's relationships with children and adults, and the behavior at home as well as school and other settings.
- Physical. The assessment of the child's health to include vision, hearing, and the ability to communicate and move purposefully.
- Developmental. The assessment the child's progress in a number of areas such as understanding and responding to language, social and emotional levels, mobility, and ability to be organized.

You are an expert on your child, and the law requires that parents be included in every step of the evaluation process. It is important



Your school system must communicate with you in a understand. If English is hard for you to understand, there must be an interpreter. If reading is hard for you, the school should be read and explained by someone from the school.

Referral for Special Education Request for Evaluation Date:____ Director of Special Education School District School Dear: ____ (Director of Special Education) Re: (Child's name) (Date of Birth) I am writing to refer my child to the Committee on special education. I am requesting a special education assessment in all areas of suspected disability and specifically in the following areas: __ Some of my concerns are based on: If the school district agrees to evaluate my child, I understand I will be presented with a written evaluation plan within fifteen (15) days and that the plan will identify for me the tests to be given, dates for the tests, and the names of the persons who will administer the tests, as well as explanations of the tests and their purposes. Sincerely, Parent/Guardian Signature Parent/Guardian Printed Name Address City, State, Zip Code Telephone Number Received by: ______ Date: _____

that you share your insight about your child. In fact, without your input, the school cannot have a complete picture of your child's personality and capabilities.

Sometimes talking to teachers and professionals about your child's areas of weakness may feel disloyal. However, without your perspective, the school system will not be able to fully understand your child and help him or her overcome or minimize areas of delay.

The school system must have a procedure that assures the following:

- Parental written consent to testing before the child is evaluated.
- Input from parents about their child's growth and development.
- The results of the evaluation will be available to parents.
- A chance to meet with representatives from the school so that parents can question any results they may disagree with.
- An opportunity to examine the child's records.
- The evaluation is appropriate for the child and without a cultural bias or is not inappropriate because of the child's disability.



- The initial evaluation for special education must be completed within 60 days of parental consent for an evaluation, unless your state has established a different time frame.
- If you think the evaluation is incomplete or inaccurate, you can request an independent educational evaluation.
- The evaluation must consist of a variety of tools. No single measure can determine if a child is eligible for special education.
- The assessment is given in the language the child is most comfortable with, unless this is not feasible.

Evaluation from the Child's Perspective

To many children, being evaluated is just another novel experience. The one-on-one attention can be fun. However, should your child feel anxious about the evaluation, spend some time talking about it. Explain that the evaluation is to help the child's teachers know the best way to teach the him or her. On the day of the evaluation, be sure your child is well rested and fed. If



Prior to the evaluation, trusted friend about how you feel about the evaluation process. Write down any *auestions* or concerns you have and contact the evaluator or ask at the Evaluation Conference.



"I wish I had known from the beginning that being assertive doesn't necessarily mean being a witch. You really do catch more flies with honey than you do with vinegar."

~Adriana, mom to daughter with Downs Syndrome, and visual issues, Ft. Huachuca,

parent to parent

you can, give your child a choice such as, "Which breakfast do you think will help you feel strong for your evaluation, oatmeal or eggs?" or "Would you like to wear your favorite shirt for your evaluation?"

When the evaluation is over, ask your child which activities were enjoyable and if there were things he or she didn't like. Praise your child for the effort.

The Evaluation Conference

The evaluation conference is where the findings of the formal evaluation will be discussed. This may be combined with the eligibility meeting. If you are not notified about such a meeting, you should request one. A copy of the evaluation report will be given to you.

What if there is a Disagreement?

At this point, parents and the school system should agree that the evaluation results are accurate, complete, and up-to-date. If there is a disagreement, you can ask informally for more testing to be done. However, even informal requests should be followed up with an email repeating your expectations. If this does not get the desired results, you can request an independent educational evaluation (IEE) of your child at public expense. You do not have to prove that the school's evaluation was faulty. You are entitled to an independent evaluation if there is reason to believe the initial evaluation is incomplete or

inaccurate. An IEE may evaluate any skill related to your child's educational needs. The school may not agree to this independent evaluation and may choose to hold a hearing during which they will try to show that the initial evaluation was valid and complete. Unless they do this, the school system cannot deny your request for a new evaluation. If, after a hearing the school system is not required to pay for an independent educational evaluation, you may still choose to have your child evaluated independently at your own expense. The school system is required to consider the independent evaluation when planning your child's education.

Should you agree with the school system that the evaluation is accurate, begin to discuss whether or not your child is eligible for special education. The Evaluation Conference may be held at the same time as the Eligibility Meeting.

Eligibility

Eligibility refers to the decision about whether or not a child qualifies for special education services based on the established criteria. A committee will make this decision. This committee is required to compare the results of the evaluation with the definitions of various disabilities as defined in the Individuals with Disabilities Education Act (IDEA). The

	- 1	
	"	
	/.	
_	=	

Request	or an Independent Educational Evaluation	
	Date:	
Director of Special Education	n/Principal	
School District		
School		
Re:(Child's Nam (Date of Birt (School))	
Dear: (Director of Speci	al Education)	
•	Assessments are inaccurate or incomplete. Because the sare flawed in their accuracy or completeness they are	
sufficient to guide the IEP to placement.	am to an appropriate identification of disability, service ments, I disagree with the following:	
sufficient to guide the IEP to placement.	am to an appropriate identification of disability, service	
sufficient to guide the IEP to placement.	am to an appropriate identification of disability, service ments, I disagree with the following:	
sufficient to guide the IEP to placement.	am to an appropriate identification of disability, service ments, I disagree with the following: Sincerely,	
sufficient to guide the IEP to placement.	am to an appropriate identification of disability, service ments, I disagree with the following: Sincerely, Parent/Guardian Signature	
sufficient to guide the IEP to placement.	am to an appropriate identification of disability, service ments, I disagree with the following: Sincerely, Parent/Guardian Signature Parent/Guardian Printed Name	
sufficient to guide the IEP to placement.	am to an appropriate identification of disability, service ments, I disagree with the following: Sincerely, Parent/Guardian Signature Parent/Guardian Printed Name Address	



The presence of a disability does not automatically qualify a child for special education services under IDEA. The need for such services must first be supported by the evaluation of the child.

following are the disabilities which qualify children who, because of their disability, require special education in order to benefit from their educational program:

- Mental retardation.
- Hearing, vision, speech, or language impairments.
- Emotional disturbance.
- Autism.
- Traumatic brain injury.
- Orthopedic impairments.
- Learning disabilities.
- Developmental delays for children between the ages of 3 and 9.
- Other health impairments.

Each state, as well as the DoD, has its own categories and definitions of these disabilities. However, all states must follow the regulations under IDEA.

Eligibility Meeting

It is during this meeting that the decision will be made as to whether or not a child qualifies for special education. This meeting may be held at the same time as the Evaluation Conference.

Preparing for the Eligibility Meeting

Before the meeting starts you may want to pass around a picture or two of your child and family. This reinforces that your child is much more than an evaluation can measure. Be sure to ask for copies of the results of the evaluation as well as the official report of the meeting. Have your ideas about your child written down before going into the meeting. Include what you know about your child's way of learning and other information that may be helpful to the team. If desired, ask that your statement be included in the evaluation record.

	Checklist for Eligibility and IEP Meetings
	A picture of your child and family.
	ri protuco or your orma una rammy.
	A list of questions you have developed
	over time.
	Cifil+i
	Copies of prior evaluations.
	Records from Early Intervention, if
	your child participated.
	, ,
	Pertinent medical records.
_	5 1 6 11
	Paper and pen for taking notes.
	A friend or family member for
_	company and moral support.
	oupport
	A sweet snack to share.

What if there is a Disagreement?

If all goes well, you and the school system will agree on the best course of action for your child's education, be that in or out of special education. Problems may arise when you think your child qualifies and would benefit from special education services and the school does not, or if the school thinks special education is appropriate, and you do not. Sometimes the problem is that the school system and the parents of the child cannot agree on the nature or definition of the child's disability.

Should any of these disagreements occur, you may request an administrative review within the school system. If this is not available or if you are not satisfied with the results, there are two options. You may request mediation or a due process hearing, or you may request both at the same time. This will accelerate the process and lessen the amount of time your child must wait for an appropriate education.

- Mediation is a process
 that allows a dispute to be
 resolved without litigation.
 When you mediate you have
 two goals: to resolve the
 dispute and to protect your
 relationship with the school
 system.
- Due process hearings are conducted differently from state to state; however, they provide an opportunity to have your complaint heard in an impartial hearing.
 Before the hearing takes place, the school must hold a Resolution Session to give the parties a chance to resolve their differences before the hearing.

Managing Emotions

As you walk into the meeting that is to determine whether or not your child will qualify for special education services, be aware of your emotions. You may be feeling worried, nervous, or even defensive. Try to put these feeling aside in this and subsequent meetings.

Focus on the goals you have for your child. Be a good listener, and let the others at the meeting know you understand their perspective. That does not have to mean you are agreeing with them.

If someone says something you don't understand, either about your child or the procedures used to qualify for special education, don't hesitate to ask. There is so much to absorb, and it can be overwhelming. If you still don't understand, ask again. While all parents want the best possible education for their children, it can be a blow to realize a child needs special education to grow academically. Bring your spouse, a friend, or a professional who knows your child with you. If your spouse is deployed, bringing someone with you to the meeting is even more important. This person can provide moral support as well as another perspective on your child. It is also nice to have someone with whom you can discuss the meeting.

Once the disagreements, if any, have been worked out, it is time to write your child's Individual Education Program.



When talking to school staff, you will be most successful when you keep your cool, stay positive and clear about your goals, and keep the focus on meeting your child's needs.

How to organize an IEP Notebook

Supplies:

A three ring note book A three hole punch Highlighter Sticky notes #10 envelopes Stamps Dividers for binder Calendar Phone log

- 1. Request a complete copy of your child's school records. See the form letter on page 33.
- 2. Start a photo record of your child adding a school picture to the record each year.
- 3. Label dividers, and organize information in the following way:
- Assessments
- IEP
- Report cards/ interim reports
- Health records, immunizations
- Discipline records
- Calendar
- Phone log
- Correspondence to school system
- Correspondence from the school system
- Addresses

Section 504 of the Rehabilitation Act

Section 504 is a civil rights law that prohibits discrimination on the basis of disability and applies to public schools among other entities. Because Section 504's definition of disability is broader than the IDEA's definition, some children who do not qualify for special education under IDEA do qualify under Section 504. This can be especially helpful for children with invisible conditions, such as learning disabilities or Attention Deficit Hyperactivity Disorder. For a link to more information about Section 504 of the Rehabilitation Act, look in the "For More Information" section at the end of this module.

Individual Education Program (IEP)

An IEP is a written plan describing a detailed program for the child's education. It will contain the following:

- A description of the child's present level of academic achievement and functional performance.
- Consideration of parental concerns about their child's education and progress.
- Goals that are measurable and specific (e.g., David will write a paragraph

with opening and closing sentences, or Becky will feed herself with a spoon).

- A list of the related services the child will receive and details about where the services will be located, who will offer them and for what length of time, and how much time the child will spend in the services.
- Special Education Placement includes a description of how much of the day the student will spend in the regular education classroom with students who are not in special ed, as well as a description of the special education programs and services that will be provided to the student.
- The IEP will include the methods that will be used to determine if the child is meeting goals and objectives.
 This might be classroom observation, test results, or examples of school work.
- The projected date for the beginning of services as well as the frequency, location, and duration of services.

Who Attends IEP Meetings?

The following people must attend the IEP meeting: the parent, a teacher of the child's regular education class (if the child is or will be in a regular class room), a special education teacher, and an administrator who is not only knowledgeable about special education and the general curriculum, but is also able to commit the schools resources to meet the child's needs. Sometimes specialists and other educators attend. It may be appropriate for the child to attend, especially as parents begin to plan their child's transition out of school. Bring a spouse or friend to the meeting. It is a good idea to explain to this person the role they should take during the meeting (e.g., another view point on the child or just moral support and another set of eyes and ears).

Preparing for the IEP Meeting

In order to prepare for this IEP meeting and future meetings, it is a good idea to take a little time to organize your child's school records. Many parents create an IEP notebook, which is kept up-to-date with copies of past evaluations, past IEPs, and correspondence with the school. If creating a notebook seems overwhelming right now, be sure to have a designated folder for all special education paperwork until you have time to create a notebook.

Potential Problems

You may be presented with an IEP that was completed before the meeting. Should this happen, keep in mind that you have a right to participate in the development of your child's IEP. Consider and refer to this IEP as a draft. If you feel pressured to sign it, simply remind the other members of the committee that you need time to

parent barent

"I never go in there alone.
The most productive IEP meetings have been the ones where I have had the necessary moral support."

~ Isabel, mom to son with autism, Quantico, Virginia





If you would like to learn more about advocating for your child, see module five, Advocating for Your Child, of this Parent Tool Kit.

read and digest such an important document, and that you will need a copy to take home with you.

If the school system says a course of action is prohibited by law or regulation, ask politely for help identifying this law or regulation.



If you move to a new state mid year, the school must provide comparable services to the previous IEP until the new school conducts an evaluation and develops a new IEP.

Focus on Your Child's Needs

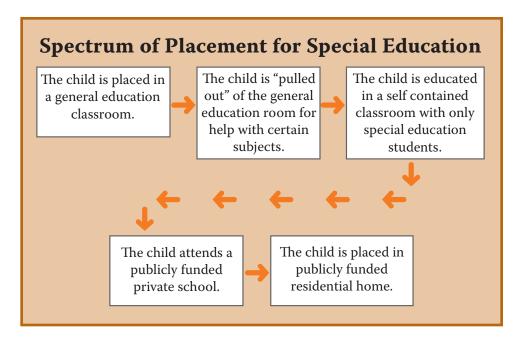
This is another time when emotions can run high because your child's education is so important. Remember to keep the needs of your child the focus of the discussion. When possible, have educational options for your child already in mind. If you feel resistance to your ideas, suggest trying a new idea for eight weeks to see how it works. Look for common ground and be sure the others in the room know you are trying to understand their point of view. Remember that a pleasant attitude is much more productive that a negative one and thank those who have been helpful.

Are You Satisfied With the IEP?

If you are satisfied with the IEP, sign it to show you accept the plan. If you would like a few days to think about it, you can ask for that. If you do not agree with all or part of the IEP, identify which parts are unacceptable. If the school refuses to make the changes, three options are available:

- Sign the IEP but indicate in writing the parts you find objectionable. You will then be on record as stating that you believe the IEP does not meet all your child's needs.
- Sign the IEP but list the parts you find objectionable and write that you plan to appeal those parts. This way your child can begin or continue to receive the services while the appeal is pending.
- Refuse to sign the IEP and indicate in writing that you plan to appeal the IEP. Before doing this, ask what services your child can receive while the appeal is pending since he or she may be denied services until the IEP is signed.

Remember, parental consent for an evaluation is not consent for a child to receive special education services. The school must have an informed consent before providing services.



Your child's IEP will be reviewed each year and rewritten to reflect the gains your child has made and the new goals that have been set. Because your input is crucial to the completeness of the IEP, the school system is required to notify you in writing when a meeting is scheduled. Once your child reaches the age of 16, the school is required to include him or her in meetings to address the transition from high school into post high school life. If you would like to request the IEP team meet mid-year to discuss your child's progress, you need to do so in writing.

Placement

Placement refers to the setting in which a child will be educated, including the school, classroom, and related services, and how much time the child will spend with children who are not disabled. The details of your child's placement

should be spelled out in the IEP. An integral part of IDEA is the concept of the Least Restrictive Environment (LRE). This means that a child with disabilities should be removed from the regular classroom only when the child's disability is of a nature that it is necessary to do so.

Placement Options

School systems are required to provide a range of placement options to ensure differing needs can be met. This spectrum of placement starts with the general education classroom, moving to time in a resource room or "pull out" classes for certain subjects, to self-contained classrooms with only special education students, to private school, and finally to residential placements. Once you know which specific services your child will need, you can address the question of where these services should be provided. The focus is on



Inclusion refers to the schools intent to educate students with disabilities in a regular classroom whenever possible.

how to best educate your child in the least restrictive environment. Least restrictive environment also means that whenever possible your child should be educated in the neighborhood school that he or she would normally attend, unless the IEP requires another arrangement. When appropriate placement cannot be provided by the public school system, a private day or residential school must be paid for at public expense.

Plan-Discuss the assignment with your child and share ideas on how to complete it.

- rganize-Visually identify the steps needed to complete the task. This may be pictures or words to identify the beginning, middle, and end of a story.
- rite-Have your student write the story elaborating on the ideas or pictures of earlier steps.
 - dit—Have student proofread for a single component at a time. Kids tend to read what they intended to write, and may miss holes in the story. If the child is overwhelmed take turns editing. Have the child check for capital letters and periods, and you can check for spelling errors. Learning to edit is a long but valuable lesson.

Revise–Many kids balk at revision. Revision leads to a product the child will be proud of.

Instruction and Related Services

Instruction is the actual educating of a child. It refers to time spent in the general education classroom and in special education, as well as time receiving related services.

Instruction

After all the evaluations and meetings have been held, the instructional time should be structured in such a way that your child's needs for an education are being met. Although the majority of instructional time is spent in school, parents have an important part to play as back up for their child's teacher. It is up to you to create a homework routine that will work for your child and family and to help your child remain motivated and feel successful.

Remember that children learn best when they are relaxed. If your child is stressed about an assignment, he or she may not be able to do the work for worrying about how to get it done or fear of not doing it well. Help your child by showing how to break the task into more manageable parts. Some teachers call this "chunking." The first step might be to read the directions, gather supplies, and then perhaps make an outline of what the child will do to complete the assignment.

If learning a new concept, be sure the child understands the vocabulary involved. Instead of asking, "Do you understand these words?" say, "Can you tell me what

Location

- Help your child choose a distraction free work space that will be regularly available for homework.
- Your child should have a comfortable chair and good lighting. Some children concentrate better with total silence, others with low music.
- A chewy snack, like sugar free gum may help with concentration.

Fatigue

- Be aware that your child may need a break; this could mean physical activity, or relaxing with a snack. Avoid TV. Use a timer to let your child know the break is over and it is time to get back to work.
- If your child is spending an unusually long time doing homework, contact the teacher and see if some modification can be made. Make sure your child's teacher knows how hard this is for him or her.

Organization

- If the work space is used by others during the day, fill a basket with school supplies and let your child pull it out at homework time.
- Supply your child with different color folders for different subjects.
- Help your child prioritize assignments.
- Teach your child that his or her homework is not finished until it is in the correct folder and put in a backpack by the door.
- Provide your child with a calendar for tracking test dates and project due dates.

Encouragement

- Use concrete statements of praise like, "The way you drew that tree makes it look like the branches are waving in the wind. I like that!"
- Give non verbal reassurance with a squeeze of a shoulder or a kiss on the head.
- Let your child hear you praise him or her to another adult.

germination is?" A good place to start is to find out what the child already knows. Ask the child, "What can you tell me about George Washington?" Almost any answer can be used as a good beginning to start a conversation. Children will remember new information better if they can relate it to something they already know.

Writing can be especially challenging to a child who learns differently. To write, the child must do many things at once. First, the child must hold the story in his or her head, tell it in the correct order, remember punctuation and spelling, and once all this is done the child may feel defeated because the end result looks so messy. Brainstorm with your child before writing begins about words that might be used and have them listed near by. Another way of helping a child tackle a writing assignment might be to teach and then post the POWER strategy on page 28. This will help the child to break the assignment into smaller, more manageable parts.

Related Services

In order to adequately educate your child, his or her IEP may specify services other than those provided by the classroom teacher. The following are some of the related services your child may receive:

 Assistive Technology. Any piece of equipment that improves a child's ability to communicate, to be independent, and to learn.



It could be an augmentative communication board or a wheel chair.

- Audiological. Services
 to identify children with
 hearing loss and to help
 with language improvement,
 speech, lipreading,
 conversation, or the
 appropriate use of hearing
 aids.
- Counseling. School counselors who work to improve behavior, selfcontrol, and self-esteem of students.
- Medical. Available for diagnostic reasons and to make recommendations for special ed services based on the child's disability.
- Occupational Therapy.
 Activities focus fine motor skills, such as writing,

- sorting, eating, and other skills that assist in improving daily life.
- Orientation and Mobility.
 Assistance for any child who needs to be taught how to travel around the school building, perhaps because of visual impairment.
- Parent Counseling and Training. Helps parents of children with special needs to understand how their child is developing, and also refers to other groups who can offer financial planning or other professional services.
- Physical Therapy. Provided by a licensed therapist, this service concentrates on gross motor functioning. That is, large body movements like sitting, standing, and moving.
- Psychological. School psychologist gives testing, interprets results, and acts as a consultant to school staff.
- Rehabilitative Counseling. Independence training, employment preparation, vocational training, and integration into the work place.
- School Health Services.
 Nursing services that are necessary to assist a child so he or she will benefit from the educational plan must be described in the IEP, and may be services such as

- administering medication, providing assistance with catheterization, or breathing therapy.
- Social Work. Provides group or individual therapy and helps with problems in the child's home that may affect the child's adjustment in school.
- Speech. Diagnoses speech and language disorders, provides therapy, and counsels parents and teachers regarding speech problems.
- Transportation. Schools are responsible for transportation of special education students to and from school and in and around the building.

There may be other services that the IEP team identifies that are not on this list. Specific goals will be written for related services, just as goals are written for class work.

Finally, You Have a Plan

Now that you are past the evaluation stage and have a written plan and a comfortable routine, relax a little. You deserve it. It is a good idea to give your child's teachers a little time to get the program running smoothly before checking on it. Once the school year is underway and the teacher has had a chance to get your child's program up and running, establish an atmosphere of cooperation with the teacher. This is essential to keeping

track of your child's academic, behavioral, and social activity in the classroom. Some parents and teachers stay in touch by way of a notebook that is passed back and forth everyday, by telephone, or by frequent conferences. Probably some combination of the above is best. Be as positive as you can be and let the teacher know that you appreciate the work done on behalf of your child.

Annual Review

Once a year the school system is required to review your child's Individual Education Program. This is called the annual review. Your school system is required to notify you in writing of the purpose of the meeting and who will attend. It should be attended by at least three people: the parent, the teacher, and a representative of the school system who is authorized to commit the school resources. If your child spends time in a regular classroom, the teacher of that class must attend. In addition, specialists such as the school psychologist, an occupational therapist, or the school nurse may attend. The meeting must be at a time and place that is convenient for you. Also, if you need assistance with English, they must provide an interpreter.

There is an option in some states to replace the annual review with a review every 3 years. The benefit may be that teachers spend less time on paperwork this way. However, children grow and change a lot in 3 years, and if you are not

comfortable with this idea you may opt for an annual review. As with the evaluation conference and the eligibility meeting, have your thoughts, ideas, and questions written down before the meeting begins. You may want to bring someone with you, a spouse or friend, who has seen your child progress.

Triennial Review

Every 3 years the school system is required to conduct an extensive review of your child's progress. This is called the triennial review. There may be entirely new evaluations done, and there will be a new eligibility decision about whether to continue special education. There will be a thorough review of existing data to determine which new evaluations may be needed. If there are any new areas of suspected disability, you may request certain evaluations, and unless they provide rational for refusing, the school is required to provide them.

Records

Many school systems keep three types of records:

 Cumulative File. This file contains report cards, standardized test scores, teacher reports, and a copy of your child's Individual Education Plan (IEP) if your child is already in special

v)	
≺	
U	A.

Re	equest for School Records
	Date:
Director of Special Education or	Principal
School District	
School	
Re: (Child's name) (Date of Birth) (School)	
Dear:(Director of Special Ed	ducation or Principal)
	ne file for my Child's Special Education information. I am all school records, cumulative and confidential, within my child's name,
Please include copies of all eva Record, Health Record, Disciple Assessments, Individual Educat If the school district charges a fe	luations and actual test scores, the Cumulative Record, Psychological Record, Confidential Record, tional Plans, and Teacher Record. The for this service, please alert me as soon as possible. The my request contact me at
Please include copies of all eva Record, Health Record, Disciple Assessments, Individual Educat If the school district charges a fe	luations and actual test scores, the Cumulative Record, Psychological Record, Confidential Record, tional Plans, and Teacher Record.
Please include copies of all eva Record, Health Record, Disciple Assessments, Individual Educat If the school district charges a fe	luations and actual test scores, the Cumulative Record, Psychological Record, Confidential Record, cional Plans, and Teacher Record. ee for this service, please alert me as soon as possible. Emy request contact me at
Please include copies of all eva Record, Health Record, Disciple Assessments, Individual Educat If the school district charges a fe	luations and actual test scores, the Cumulative Record, Psychological Record, Confidential Record, cional Plans, and Teacher Record. ee for this service, please alert me as soon as possible. It may request contact me at Sincerely,
Please include copies of all eva Record, Health Record, Disciple Assessments, Individual Educat If the school district charges a fe	luations and actual test scores, the Cumulative Record, Psychological Record, Confidential Record, cional Plans, and Teacher Record. The for this service, please alert me as soon as possible. The many request contact me at Sincerely, Parent/Guardian Signature
Please include copies of all eva Record, Health Record, Disciple Assessments, Individual Educat If the school district charges a fe	luations and actual test scores, the Cumulative Record, Psychological Record, Confidential Record, cional Plans, and Teacher Record. Ree for this service, please alert me as soon as possible. The my request contact me at Sincerely, Parent/Guardian Signature Parent/Guardian Printed Name
Please include copies of all eva Record, Health Record, Disciple Assessments, Individual Educat If the school district charges a fe	luations and actual test scores, the Cumulative Record, Psychological Record, Confidential Record, cional Plans, and Teacher Record. Ree for this service, please alert me as soon as possible. The my request contact me at Sincerely, Parent/Guardian Signature Parent/Guardian Printed Name Address



For more information about raising a special needs child while in the military, see module four, "Families in Transition," of this Parent Tool Kit.

education. You can get a copy of this through your school office.

- Confidential File. This may
 be kept at the school or in
 an administrative office. It
 has all the reports written
 about your child's evaluation,
 medical records if available,
 summaries of meetings held
 by the evaluation team, and
 sometimes a record of your
 correspondence with the
 school. Ask the principal to
 see this file.
- Compliance File. Some school systems keep a separate file with all reports, records of meetings, and all correspondence. You can ask the principal if this file exists.

To receive copies of any of these files, ask your school system what the procedure is. If you request copies of your child's records, the school must provide them, but there may be a charge for the cost of copying. You must request a copy of your child's records in writing

Transition to Adulthood

If your child has been involved with special education for several years, you have a good understanding of the IEP process. Transitioning out of school and into the world has a different focus. Instead of identifying and working to minimize your child's challenges, you are looking toward the future

and exploring what it will take for your child to learn a job or live on his or her own.

Once a child graduates or leaves the school system, there is no guaranteed program to pick up where IDEA leaves off. However, starting between the ages of 14 and 16, your child's IEP will begin to address the transition process. Transition services are a coordinated set of activities that will aid a child with a disability as he or she moves from school to post school activities. These activities should be based on the child's needs, taking into account his or her strengths and interests.

Your child should be assisted in developing post school living objectives concerning employment or daily living skills. Time in school might be spent with an emphasis on practical life matters, like reading job applications or menus and



learning money skills. Ask your child what kind of work he or she would like to do. Is it realistic? Is there a compromise that can be made so that your child's desires can be met? Perhaps a child who wants to be a veterinarian could work in a vet's office.

These transition services should start no later than the first IEP in order to be in effect when the child turns 16, and should be updated annually there after. Also, no later than 1 year before reaching the age of majority under state law, your child must be informed of his or her rights under IDEA, if any, that will transfer to him or her upon reaching the age of majority.

What options are there for your child?

- College. Whether two or four year, colleges offer opportunities for students with disabilities to continue their education. Because of the Americans with Disabilities Act (ADA), colleges cannot discriminate against otherwise qualified students with disabilities.
- Continuing and Adult Education. These courses range from computer skills to cooking and offer a way to expand your child's horizons.
- Vocational Training. There are trade schools that typically prepare students for specific occupations, such

- as beautician or electrician and requires a high school diploma to attend.
- On-the-Job Training. Is short-term training that allows a child to learn a job while working on the site. Many vocational rehabilitation agencies, disability organizations, and large companies provide this sort of training and placement.
- Competitive Employment.
 These are jobs in the mainstream of everyday life.
 Competitive employment describes jobs for which your child would get paid the going rate. The law prohibits discrimination and requires reasonable accommodations be made if the person is qualified for the job.
- Supported Employment.
 This is paid employment for people with severe disabilities, who have a job coach that provides guidance by helping the employee improve job skills or any other job related needs. Generally the coach is involved heavily in the beginning of employment, but is less involved as the employee gains in skill and comfort.
- Adult Day Programs. These programs provide a work environment in a supervised setting with other disabled



If you are considering obtaining guardianship for your child, learn about the state, and begin the process well 36 child turns 18.

- workers. They will usually receive training in life skills and recreation.
- Centers for Independent Living. Here people with disabilities develop self help and advocacy skills like balancing a check book, cleaning, and cooking nutritious foods.

Guardianship and Declaration of Incapacitation

Usually when a child reaches the age of majority, 18 in most states, it is assumed that he or she will be able to make decisions about health, finances and the future. However, for some children this is not the case. Once your child reaches the age of majority you will have no control over educational, financial, or health related decisions your child might make. If you are concerned that your child will not be capable of making these decisions responsibly, consider asking the courts for guardianship. The age of majority varies from state to state. Check www. militaryhomefront.dod.mil/efm to find out information about your state.

Guardianship is a court approved relationship between a legal guardian and the person with a disability. The court will define the degree of legal authority that the guardian will have to act on behalf of the disabled person. Detailed documentation from a physician

will be needed to show that your child is not mentally capable of becoming independent.

Laws concerning guardianship vary from state to state, so if you move to another state, you will have to reapply in the new state.

For More Information

Obtain the other modules of this Parent Tool Kit at www. militaryhomefront.dod.mil/efm or from your EFMP coordinator.

- Module One, Birth to Age Three
- Module Three, Health Benefits
- Module Four, Families in Transition
- Module Five, *Advocating for* Your Child
- Module Six, Resources and Support

Parenting Advice

The National Dissemination Center for Children with Disabilities www.nichcy.org

Visit the STOMP (Specialized Training for Military Parents) website and consider joining their list serve. This group can help you find other military families with exceptional children.

www.stompproject.org

Module Two: Special Education

Writing A Successful IEP www.ldonline.org

Advocacy Information

State by state list of Protection and Advocacy Agencies as well as information on advocacy strategies. www.reedmartin.com

Your Rights

Section 504 of the Rehabilitation Act www.ed.gov (search 504)

IDEA

www.wrightslaw.com

37



Introduction Ction

Caring for a disabled child can be exhausting physically, emotionally, and financially. There are obvious expenses (e.g., ongoing medical treatment, assistive technology, and skilled nursing), but other less obvious expenses take their toll as well (e.g., time off from work to attend frequent medical appointments, special diets, and more time lost due to sick days). Few families can provide adequate care to disabled family members without medical and financial assistance from a variety of programs. Disabled family members of eligible uniformed personnel have the benefit of participating in the Department of Defense's healthcare system, known as TRICARE. You may also qualify for further benefits through state or federal programs.

TRICARE

TRICARE is the Department of Defense's healthcare system for members of the military and their families in the U.S. and all over the world. TRICARE is an organization that includes military healthcare resources as well as civilian healthcare providers who have been authorized by TRICARE to receive reimbursement. The following are authorized civilian providers:

- Network providers who have discount agreements with TRICARE.
- Participating providers who are not part of the TRICARE network but who have agreed to accept TRICARE allowable charges as payment in full.
- Non-participating providers who do not accept TRICARE allowable charges as payment in full. These providers may

be paid up to fifteen percent more than the allowable charges and may require



The Defense Enrollment Eligibility Reporting System (DEERS) is a computerized database of military sponsors, families, and others worldwide who are eligible for TRICARE benefits. DEERS registration is required for TRICARE eligibility. To be sure your **DEERS** information is current you may go to your nearest uniformed services ID card center (to find, go to www. dmdc.osd.mil and search by zip code) or contact the Defense Manpower Data Center Support Office (DSO) at 1-800-538-9552.

seneits



In all military facilities, active duty service members have priority for care, followed by active duty family members enrolled in Prime.

beneficiaries to file their own claims and wait for reimbursement.

TRICARE is organized into four geographic regions: North, South, West, and Overseas. The three regions located within the United States offer the same options for healthcare plans and coverage. If you are a TRICARE beneficiary living overseas, you have fewer options. Visit the TRICARE website, www.tricare.osd.mil, to find helpful links to TRICARE regional websites.

TRICARE Options for Active Duty Family Members

To meet the diverse needs of active duty families, TRICARE offers several healthcare plans.

TRICARE Prime

Prime is TRICARE's managed-care option, similar to a civilian health maintenance organization. Active duty service members are required to be enrolled in TRICARE Prime and may choose to enroll their families. This is the only TRICARE option that requires enrollment and the service member must enroll each family member. The beneficiaries receive medical care from a local military treatment facility or from a network approved healthcare provider. Active duty family members who are enrolled in Prime enjoy enhanced clinical preventive benefits. As a Prime enrollee, you must follow some

well-defined rules and procedures, such as seeking care first from your primary care manager and receiving a referral from him or her as well as authorization from your regional contractor when seeking specialty care. Failure to follow these steps may result in costly Point of Service (POS) charges.



The TRICARE Prime pointof-service option (POS) allows TRICARE Prime enrollees to receive nonemergency, TRICARE-covered services from any TRICARE-authorized provider without a referral from their primary care manager or authorization from a healthcare finder. Using the TRICARE Prime point-of-service option is more costly to the enrollee and POS charges incurred after the catastrophic cap has been met are the beneficiary's responsibility.

TRICARE Prime Remote

If you are a family member living with an active duty service person, and you live either fifty miles or a one hour drive from the closest military medical treatment facility, you may enroll in TRICARE Prime Remote for Active Duty Family Members. Enrollment is required, and once enrolled you must select or be assigned a local primary care

manager (PCM) where network primary care providers are available. If no network primary care provider is available, you may use any TRICARE authorized provider for primary care. Contact your TRICARE regional managed care support contractor for help locating a provider.



Enrollment forms for TRICARE
Prime and TRICARE Prime
Remote must be received by the
regional/overseas contractor
by the 20th of the month for
coverage to start the first day of
the next month.

TRICARE Standard

Standard is a fee-for-service option that gives eligible family members the option to see any TRICARE-certified/authorized provider (e.g., doctor, nurse-practitioner, lab, clinic, etc.).

TRICARE Standard can be used simultaneously with Extra (discussed in following section). If you see a non-network provider you will incur greater out of pocket costs and have to file your own claims. However, Standard affords you the greatest choice of providers and may be the only option to family members in some locations. It is not an option for active duty

service members. To see a cost comparison of TRICARE options see the chart at www.tricare.osd.mil.

TRICARE Extra

TRICARE Extra is a preferredprovider option that allows active duty family members using the TRICARE Standard benefit to receive care from TRICARE network providers with lower out of pocket costs.

With TRICARE Extra there are no claims to file, but the choice of providers is limited to those in the network. TRICARE Extra is not available to active duty members, nor is it available overseas.

Pharmacy Benefit

The TRICARE pharmacy benefit offers multiple ways to have a prescription filled. The most costeffective way to receive prescription drugs is through the nearest uniformed services military medical treatment facility (MTF). If unable to visit a uniformed services MTF pharmacy, you have three other options: TRICARE mail order pharmacy (TMOP), TRICARE retail network pharmacies, and non-network pharmacies. For more information on how to save costs and make the most of this benefit use the pharmacy link www.tricare. osd.mil/pharmacy.



Eligible family members are covered under TRICARE Standard unless they enroll in TRICARE or Prime Remote.



The term "beneficiary" refers to the person who is entitled to the services. Frequently, this is your child.

TRICARE Plan Options for Active Duty Family Members				
	Prime	Extra	Standard	
Annual Deductible	None	E-5 & above — \$150/person or \$300/ family E-4 & below — \$50/person or \$100/ family	E-5 & above – \$150/person or \$300/ family E-4 & below – \$50/person or \$100/ family	
Annual Enrollment Fee	None	None	None	
Civilian Outpatient Visit	No cost	15% of negotiated fee	20% of allowed charges	
Civilian Inpatient Admission	No cost	\$14.35/day (\$25 minimum)	\$14.35/day (\$25 minimum)	
Civilian Inpatient Mental Health	No cost	\$20/day	\$20/day	
Civilian Inpatient Skilled Nursing Facility Care	No cost	\$11/day (\$25 minimum)	\$11/day (\$25 minimum)	

This informations is current as of March 2006. Rates are subject to change on an annual basis: go to the TRICARE website for current cost information.

TRICARE's Benefits for Families with Special Needs

To help families in the military who face the extra challenges that come with caring for a special needs family member, TRICARE offers additional programs to those who are eligible.

Extended Care Health Option (ECHO)

In 2005, TRICARE introduced the Extended Care Health Option (ECHO) to replace the Program For Persons With Disabilities (PFPWD). TRICARE ECHO offers most of the benefits that PFPWD did, with the addition of home respite care and an increase in the allowable cost share from the government from \$1,000 to \$2,500. The purpose of the ECHO program is to provide financial assistance and additional benefits for services, equipment

or supplies beyond those available through TRICARE Prime, Extra, or Standard.

Who Qualifies?

Active duty family members who have one of the following conditions may qualify for ECHO benefits:

- Moderate or severe mental retardation.
- A serious physical disability.
- An extraordinary physical or psychological condition that leaves the beneficiary homebound.
- Multiple disabilities involving two or more body systems.

How Do I Register?

To participate in TRICARE ECHO the beneficiary must first do the following:

- Enroll in the Exceptional Family Member Program (EFMP) of the sponsor's military service.
- Once enrolled in EFMP, register with the regional TRICARE office.

You can enroll in the Exceptional Family Member Program at your nearest Family Support Center. To find this go to the www.militaryhomefront.dod. mil/directories. Here you will be able to find your nearest Family Support Center as well as an EFMP coordinator.

To enroll in EFMP you must complete Department of Defense (DoD) form 2792, which is a medical summary, and if your child is school age you must also complete DoD form 2792-1, which is a summary of special education or early intervention services. Submit these completed forms to your EFMP coordinator for processing. Once form 2792 is completed and approved by the EFMP coordinator, you must then show proof of enrollment to the Managed Care Support Contractor (MCSC). In most cases, a copy of the approved 2792 form is considered proof. The MCSC is the one who will approve ECHO coverage and update the DEERS system to indicate that your

TRICARE Regional Offices:

- North Region: Health Net 1-877-874-2273
- South Region: Humana Military Healthcare Services 1-800-444-5445
- West Region:
 TriWest
 1-888-874-9378
- Overseas: 1-888-777-8343

child is eligible for ECHO. You can expect this process to take four to six weeks.

In the meantime, contact the Regional TRICARE contractor with proof of enrollment in EFMP. The proof of enrollment can be a copy of your application form for EFMP.

Eligible family members may be granted provisional ECHO status for a period of no more than 90 days while they wait for their application to be completed.

What Benefits are Available? The following are ECHO benefits:

 Medical and rehabilitative services, prosthesis, orthopedic braces, and appliances.

parent parent

"Talking to other moms with disabled kids is really *important to* me and it helps me be a better mom. When I talk to moms with similar challenges we blow of steam, share ideas. and know that we aren't alone."

~ Marcie, mom to twin girls with Downs Syndrome, Fort Lewis, WA





The purpose of respite care is to benefit the whole family by proving a rest for the primary caregiver, while ensuring the dependent child is cared for by a competent care giver.

- Durable equipment and maintenance.
- Training for families to use assistive technology devices.
- Training for families to provide home administered medical interventions.
- Special education.
- Institutional care when residential care is required.
- Transportation under certain conditions.
- Assistive communication services (e.g., interpreters, readers for the blind).
- 16 hours of respite care services per month if the beneficiary is receiving another ECHO benefit.
- ECHO Home Healthcare(see next section).



For more information about ECHO benefits, visit the TRICARE website, www. tricare.osd.mil, or call your regional office.

Respite Care

Some families are interested in respite care but are concerned about the individuals who will care for their child in their absence. Respite care providers are all hired through Medicare certified home health agencies. This means that there have been background checks and screening done to help assure the quality of the caregivers. Meet your caregiver before they care for your child to determine your comfort level with the individual. If the caregiver does not seem to be a good fit for your family, ask for another applicant from the agency.

ECHO Cost Shares

Sponsors will pay part of the monthly authorized ECHO expenses for their family members based on their pay grade.

After the monthly cost share is paid, TRICARE will pay up to \$2,500 per month for authorized ECHO benefits, except for the ECHO Home (EHHC) benefit. If costs exceed \$2,500 per month, the sponsor is responsible for the additional costs. If more than one family member with the same sponsor qualifies for ECHO, TRICARE will pay up to \$2,500 for each eligible beneficiary.

ECHO Home Healthcare (EHHC)

EHHC provides home bound family members with intensive home services and supplies if they generally require more than 28 hours per week of home health services or respite care.

ECHO Cost-Shares		
Sponsor Pay Grade	Monthly Cost-Share	
E-1 through E-5	\$25.00	
E-6	\$30.00	
E-7 and O-1	\$35.00	
E-8 and O-2	\$40.00	
E-9, WO/WO-1, CWO-2 and O-3	\$45.00	
CWO-3, CWO-4 and O-4	\$50.00	
CWO-5, O-5	\$65.00	
O-6	\$75.00	
0-7	\$100.00	
O-8	\$150.00	
O-9	\$200.00	
O-10	\$250.00	



If you think you have been incorrectly denied services, you may appeal. When services are denied, you will receive a letter explaining the reason for the denial and the steps necessary to appeal the decision.

Occassionally mistakes are made, so be prepared to question any denial you think has been made in error.

Beneficiaries are considered home bound if their condition generally prevents them from being able to go out because of the considerable and taxing effort of leaving the home.

Any absence of the beneficiary due to treatments or adult day care programs will not disqualify beneficiaries from being considered home bound and eligible for EHHC. This can be of use to beneficiaries who stay home to avoid living in institutional facilities, acute care facilities, or skilled nursing homes.

Your child may qualify for the following benefits:

 Nursing care from a registered nurse or by a licensed or vocational nurse who is under the direct supervision of a registered nurse.



- Services provided by a home health aid under the direct supervision of a registered nurse.
- Physical therapy, occupational therapy, speech and language services, or medical or social services under the direction of a physician.
- Teaching and training activities.
- Medical supplies.

following requirements:

How Do I Qualify For EHHC? To qualify for EHHC the family member must meet all of the

- Be registered in ECHO.
- Physically reside in the United States, the District of Columbia, Puerto Rico, the Virgin Islands, or Guam.
- Be homebound.
- Be case managed, to include required services as specified in a physician certified plan of care, and receive periodic assessments of needs.
- Receive home services from a TRICARE authorized home agency.
- Require medically necessary skilled services beyond the level of coverage provided

- by the TRICARE Home Prospective Payment System benefit.
- Require more than two medical interventions during the eight hour period that the primary care giver(s) would normally be sleeping.

EHHC Respite Benefit

Respite care is a break from duty for parents of specially challenged children. This benefit is offered to help primary caregivers as well as their children. It provides rest for parents as well as skilled supervision for children. The goal is to promote well-being for the whole family. This benefit is geared to help families with home bound children who have medical conditions that require frequent interventions by their primary caregivers. These beneficiaries may receive 8 hours of respite care 5 days a week. A Medicare certified home health agency will provide information on caregivers, whom you can meet before they care for your child. It is intended for family members whose medical conditions require frequent interventions so that the primary caregiver has time to sleep. This is separate from the 16 hours of respite care offered by ECHO and cannot be used with the ECHO respite care program. Respite benefits cannot be used for sibling care, employment, deployment, or pursuing education, and they are not accumulative.

Home Healthcare

Home healthcare may be authorized for an active duty family instead of EHHC if the need is intermittent or part time. Services include skilled nursing and home health aid care.

Skilled Nursing Facility Care

TRICARE will provide coverage for care delivered in a skilled nursing facility (SNF) when nursing and rehabilitation services are determined to be medically necessary. They are provided by licensed nurses, physical therapists, occupational therapists, etc., and they are performed under the general supervision of a Medicare/ TRICARE-authorized physician. For TRICARE to cover your child's admission to a skilled nursing facility, the child must have had a medical condition that required hospitalization for at least three consecutive days. Admission to the skilled nursing facility is covered



as long as your child is admitted within 30 days of discharge from the hospital. Your doctor's plan of care must demonstrate your child's need for medically necessary, skilled services for TRICARE to pay for the care.

Hospice Care

Hospice care is designed to comfort terminally ill patients and their families once the patient is not expected to live longer than 6 months. The goal of Hospice care is to provide dignity and comfort to the dying, and eighty percent of hospice care is in home or in nursing homes. TRICARE will cover most of the costs of hospice care, and there are no limits on custodial care or personal comfort items under hospice rules. Beneficiaries must elect hospice in lieu of basic benefits.

Mental Healthcare

Unless the beneficiary has a serious mental illness that qualifies for care under ECHO, mental healthcare benefits can be confusing. Mental healthcare covered under the TRICARE program has the following restrictions:

The provider must establish the medical necessity, and the TRICARE contractor must preauthorize the following mental healthcare services.

- Inpatient care, up to authorized annual limit.
- Care at residential treatment facilities.



The sixteen hour respite benefit available under ECHO cannot be used at the same time as the forty hours a week available under ECHO Home Health Care.



TRICARE provides 8 routine therapy sessions per fiscal year without the necessity of a PCM referral. Family members may self-refer.

- Extensions to TRICARE annual limits on inpatient care.
- Outpatient mental care exceeding 2 outpatient visits per week or 8 outpatient visits per year.

The following are annual limits for inpatient care:

- 30 days for patients over age 19.
- 45 days for patients under age 19.
- 150 days for inpatient care in residential treatment centers (available only to those under age 21).
- 7 days detox and 21 days rehabilitation for substance abuse.

The disorders that qualify for TRICARE mental healthcare benefits include conditions such



Active duty family members who need counseling for behavioral or emotional difficulties that are not covered under TRICARE should visit www.militaryonesource.com or call 1-800-342-9647.



TRICARE has developed a record keeping system called Special Care Organization Record (SCOR) which is designed to help families like yours keep their child's medical records organized and easy to access. Visit SCOR at www. tricare.osd.mil.

as depression, anxiety, obsessivecompulsive disorder, bi-polar disorder, schizophrenia, attention deficit disorders, and autism.

TRICARE mental health benefits do not cover treatment for weight loss, sexual dysfunction, certain personality disorders, or special learning disabilities.

Case Management

Case management is offered as a system for organizing and integrating the many services that are often required for the management of complex physical or emotional illnesses. It is designed to improve the quality of care, control costs, and support patients through catastrophic medical situations by providing a bridge between acute-care and long-termcare services. TRICARE offers case management to beneficiaries who are receiving care for chronic or high risk health issues. Beneficiaries with catastrophic or terminal illnesses may also qualify for case management. If you are

Module Three: Health Benefits

49

interested in case management, ask your primary care provider for information.

Help and Information

You can access TRICARE program information twenty-four hours a day, seven days a week by visiting the TRICARE website, www. tricare.osd.mil. From the site you can get regional contractor contact information, including toll-free numbers and links to regionspecific Web pages. You can find important TRICARE information and get your questions answered regarding eligibility, TRICARE Prime enrollment, benefits and co-payments, services that require a referral or prior authorization, claims payment, and any other type of TRICARE question.



TRICARE Online is the Department of Defense Internet medical portal that provides TRICARE beneficiaries with secure, interactive, one-stopshopping access to a host of unique and exciting services, tools, and resources. You can make appointments for primary care, check claims information, access a medical library, find links to information about health and wellness as well as information about facilities and providers. See www. tricareonline.com.

Should you need help with TRICARE issues, have all information about your case at hand when you talk to a customer service representative or your case manager. This includes referrals and authorizations, TRICARE Explanation of Benefits (EOBs), medical/dental bills from providers, letters regarding denials, debt collection notices, etc. The information you provide will help your case manager move quickly to understand and resolve your problem. The representatives/case managers will work with you and provide other agency points of contact to help you with your case.

TRICARE Service Center (TSC) Directory

TSCs are located throughout the regions and are staffed with customer service representatives to provide help on a walk-in basis. There is a TSC locator available through the TRICARE website, www.tricare.osd.mil.

Beneficiary Counseling and Assistance Coordinators (BCACs)/Health Benefits Advisors (HBAs)

Regional Offices and most military treatment facilities are staffed with beneficiary counselors/benefit advisors whose job is to advocate for you and advise you about the TRICARE system. These counselors can provide information, assistance on benefit options, enrollment questions, status of claims information, as well as help with referrals and appointments. The benefits counselor can



The DCAO is there to help people with issues concerning the complex legalities of medical finances.



If you lose your TRICARE coverage because of separation from the military, divorce, or a dependent child reaching the age of 21 or 23, you will be issued a Certificate of Creditable Coverage (CoCC) which is proof to your next healthcare plan that you had previous healthcare and limits the amount of time your new healthcare plan can exclude your participation because of preexisting conditions.

aid communication between beneficiaries and the military treatment facility and help find answers to questions that can't be found through the usual channels, as well as help with the appeals process. There is a BCAC Directory at www.tricare.osd.mil/bcacdcao.

Debt Collection Assistance Office Program

TRICARE provides Debt Collection and Assistance Officers (DCAO) whose role it is to advocate for beneficiaries who need help dealing with the confusion of multiple medical or dental bills. If you have received a notice from a collection agency concerning a medical bill or have a dispute about a medical bill, do not hesitate to contact the closest DCAO. They will help

research your claim and provide you with a written explanation of how to resolve your collection problem.

Should you need the assistance of a DCAO, you should bring any documentation you have concerning the collection action or billing dispute. This includes debt collection letters, TRICARE Explanation of Benefits (EOBs), and medical/dental bills from providers. The more information you can provide, the easier it will be to determine the cause of the problem.

The DCAO will research your claim with the appropriate claims processor or other agency points of contact and provide you with a written explanation of how to resolve your collection problem. The collection agency will be notified by the DCAO that action is being taken to resolve the issue.

The DCAO cannot provide you with legal advice or fix your credit rating, but can help you through the debt collection process by providing you with documentation for your use with the collection or credit reporting agency in explaining the circumstances relating to the debt. You may locate the nearest DCAO by contacting your TRICARE contractor or online at www.tricare. osd.mil/bcacdcao.

Catastrophic Cap

The TRICARE catastrophic cap limits the amount of out-of-pocket expenses a family will have to pay for TRICARE covered medical services. The cap applies to all allowable charges for covered services to include annual deductibles. Prime enrollment fees, pharmacy co-pays, and other TRICARE allowable cost shares. Not included are out of pocket expenses paid under TRICARE Prime Point of Service option (POS). Also, any POS charges incurred after the catastrophic cap has been met are the beneficiaries responsibility.

For Prime enrollees the catastrophic cap for active duty members and their families is \$1,000. For families using Standard and Extra the catastrophic cap is \$1,000 for family members of active duty service members and \$3,000 for other beneficiaries.

IDEA and TRICARE

The Individuals with Disabilities Education Act (IDEA) is legislation that ensures all children with disabilities are provided with a free and appropriate public education. This includes services necessary to meet the educational goals described in their Individual Education Program (IEP). Infants and toddlers who are, or may become, delayed due to impairment may receive Early Intervention Services (EIS) or Educational Developmental and Intervention Services (EDIS) if they are in a DoD school system. The services these

children receive are often medical, diagnostic, or therapeutic in nature and are provided by healthcare providers. These services must be identified in either an Individual Family Service Plan (ISFP) or an Individual Education Program (IEP). IDEA policy intends for these services to be provided at little or no cost to families.

The most recent legislation stipulates that TRICARE will pay its share of early intervention services that are medically or psychologically necessary and would otherwise be a TRICARE benefit. Cost sharing decisions are made on a case by case basis. Services identified in an IEP for special education students between the ages of 3 and 21 are paid for by state educational agencies, and TRICARE will be involved only when it can be shown that the necessary services are not available or adequate to meet the child's needs.



In many states, eligibility for Supplemental Security Income (SSI) qualifies the individual for Medicaid.



For more information about Early Intervention or Special Education, see modules one and two of this Parent Tool Kit.



Federal and State Programs with Benefits for Special Needs Families

The federal, state, and local governments offer programs designed to aid disabled children and to ensure they receive the medical and educational assistance they need. These benefits may be used by military families to augment TRICARE benefits, and several are listed here. For more information about these benefits you may look under "Federal and State Programs" in module six, *Support and Resources* of this Parent Tool Kit.

Supplemental Security Income (SSI)

SSI is a monthly payment to those with low incomes and few resources, and who are disabled, blind, or 65 or older. Children may qualify. If you think you or your child might qualify, visit your nearest Social Security Office or call the Social Security Administration Office at 1-800-772-1213.

Medicaid

Medicaid is a program that pays for some individuals and families with low income and few resources. Military families who are struggling with the cost of care for a disabled family member should apply for Medicaid. Benefits may exceed those offered by TRICARE. To apply, go to www.cms.hhs.gov.

Medicare

Medicare is a basic health insurance program for Americans over the age of 65 and those with disabilities. Qualification for Medicare is based on the Medicare tax paid through work; however, a worker's spouse, minor children, and disabled adult children may also qualify. To learn more, contact www.medicare.gov.

Food Stamps and Women, Infants and Children (WIC)

Food stamps and WIC are programs designed to provide families with low incomes a nutritious diet. Eligibility is based on income and resources. TRICARE manages a WIC program for Active Duty Family Members (ADFMs) who are overseas. For information about these nutrition programs, contact www.fns.usda.gov.

Acronyms

ADFM	Active Duty Family Member
ADSM	Active Duty Service Member

BCAC Beneficiary Counseling and Assistance Coordinator

CoCC Certificate of Creditable Coverage

DCAO Debt Collection Assistance Officer

DEERS Defense Enrollment Eligibility Reporting System

ECHO Extended Care Health Option

EDIS Education Development and Intervention Service

EIS Early Intervention Services

EFMP Exceptional Family Member Program

EHHC ECHO Home Healthcare
EOB Explanation of Benefit

IDEA Individuals with Disabilities Education Act

IEP Individual Education ProgramIFSP Individual Family Service PlanMCSC Managed Care Support Contractor

MTF Military Treatment Facilities

PCM Primary Care Manager

POS Point of Service

SNF Skilled Nursing Facility

SSI Supplementary Security Income

STOMP Specialized Training of Military Parents

TRO TRICARE Regional Office
TSC TRICARE Service Center

TMOP TRICARE Mail Order Pharmacy

WIC Women and Children (nutrition program)

For More Information

Obtain the other modules of this Parent Tool Kit at www. militaryhomefront.dod.mil/efm or from your EFMP coordinator.

- Module One, Birth to Age Three
- Module Two, Special Education
- Module Four, Families in Transition
- Module Five, Advocating for Your Child
- Module Six, Resources and Support

For further information regarding ECHO and EHHC, visit www. tricare.osd.mil/echo or call your TRICARE Regional Office (TRO):

- North Region: 1-877-874-2273
- South Region: 1-800-444-5445
- West Region: 1-888-874-9378
- Overseas: 1-888-777-8343

For more details about TRICARE health benefits go to www. tricareonline.com.

For information on a variety of topics, go to one of the following websites:

www.militaryhomefront.dod.mil/efm

www.militaryhomefront.dod.mil/directories

To contact other parents with children with disabilities, visit www. stompproject.org and consider joining their list serve.

amilies in Transition

Introduction CtiOn

For military families, change is certain. All families want to make the changes that accompany relocating, deploying, or separating from the military as easy as they can for their children. However, families whose children have special needs must work even harder to help their children weather the changes with as little stress as possible.

Relocating

Moving is an integral part of life as a military family. There are belongings to pack, a move to plan, expenses to be tracked, and a new home to find. When a family has a child with special needs, these experiences are even more complicated and emotion filled. As part of the military community, there is a lot of help available, such as financial help for the move and, if desired, a sponsor waiting to help at the new duty station. It will benefit the entire family to take advantage of these resources.

The Exceptional Family Member Program

It is very important that a child with special needs be enrolled in the Exceptional Family Member Program (EFMP). To enroll in EFMP, contact the Family Support Center aboard the nearest military installation. This will ensure that your child's medical and educational needs will be considered as a duty station is selected. Service members will be assigned to an area where their EFM's educational and medical needs can be met, provided there

is a valid personnel requirement for the service member's grade and specialty.

Service members have the option of accepting assignments where services for EFMs do not exist. Choosing this option usually means that the service member must live apart from the family so that the child can continue to have his or her needs met. Contact the EFMP office at the new duty station to let them know that you are coming and what your family's needs might be. If respite care or specialized daycare is needed, the EFMP coordinator can help provide available resources.



You can find a listing of Family Support Centers as well as EFMP Coordinators at www. militaryhomefront.dod.mil/ directories.



Once you are moved in, you may want to make an appointment with your new healthcare provider so your child will have a chance to become familiar with 56 him or her before an illness occurs.

Family Support Centers

Once you know you are moving, contact the nearest Family Support Center and ask to speak with a relocation specialist. The Relocation Assistance Program offers a wealth of information for the relocating service members and their families. Be sure to discuss your moving allowances and understand how they are computed. This is also a good place to look for resources to help meet the needs of an exceptional child. The Family Support Center can also connect you to the Exceptional Family Member Programs and to available respite care programs. To find a family center near you go to www.militaryhomefront.dod.mil/ directories.

SITES

SITES (www.dmdc.osd.mil) is a website specifically designed with relocating military families in mind. There is up-to-date information about duty stations and the surrounding areas as well as help with planning a move. There is even a feature that will help estimate expenses and provide information about travel allowances and entitlements.

Schools

Ask your child's current teacher to write a letter introducing your child to the new teacher. An overview of what the teacher sees as strengths and weaknesses, as well as a description of what works well with your child will help the new teacher. Contact the new state's Parent

Training and Information Center (www.taalliance.org) for information on schools in the new area.

Medical Concerns

Before moving, check to see what medical care is available at the new duty station. The Provider Directory on the TRICARE website (www. tricare.osd.mil) can help locate specialty services. Phone numbers are provided so that providers can be contacted in advance to be sure that they are still network providers and are currently accepting new patients.

If a child has special physical needs, take extra care to ensure that the child's records are kept safe. Before moving, make copies of the child's important documents and leave copies of important papers with grandparents or close friends if possible.



Moving with Special Needs Checklist Copies of important records, such as IFSP, IEP, letters from doctors or FFMP confirming Category Four

- as IFSP, IEP, letters from doctors or EFMP confirming Category Four status for priority housing (Navy and Marine Corp), birth certificates, and passports.
- ☐ Refilled prescription.
- Contact information for medical connections in the new location.
 - Contact information for the doctor you already have a relationship with, in case you need advice from someone who already knows your child.

Tell the Kids

For some families, the news that the family is moving is best presented in a family meeting. If you think the reaction is likely to be a positive one, this is probably a good idea. If, however, you think your kids are going to be upset, it may be a good idea to tell them one on one before the family meets to discuss this. This will allow time to react to each child individually, and may avoid a scene where one upset child sets the tone and then negatively influences the other children.

Before telling the kids about the move, arm yourself with some of the positive aspects of your new home.

- Is it closer to friends or family?
- Are there beaches? Is it near an amusement park?

- If your kids are old enough, show them your new home on a map and begin the discussion of your journey to your new home.
- Should your child have a special interest, find out if there is a museum on the way to your new home that your child would not be able to experience otherwise.

Decide the best way to present the move and give thought to how you will handle various emotional responses.

- Discuss ways your children can keep in touch with friends, or have a visit planned before you move away so the good-bye won't be so final.
- Be positive. If you are upbeat about your move, your kids will be reassured that all will be well.



You can call Military
OneSource (1-800-3429647) for a "Know Your
Neighborhood" report. This will
give you some information in
hand as you discuss your new
home with your children.



Consider your child's developmental level. Will a visual aid help your child keep track of the plan for your move? A count down on the calendar might help, along with a picture of boxes on the day the packers come, or a truck on the day the movers соте.



Moving day can be hectic, and children are not immune to the excitement and nervousness that may come with it. Consider asking a friend to keep your kids for the day.

- If your child has concerns, or is grieving for his or her old home already, it is very important that you show your child that you understand this sorrow, and that it is natural and normal. You might share some of your own sorrow coupled with some aspect of the new home that you are looking forward to.
- Remind your child that the present home was once new, and yet they made friends.
 This will happen again.
- A calendar or time line with pictures of things that will be happening leading up to, during, and after the move may help calm the fears of younger or special needs children who rely on daily reminders to help them prepare for what each day will bring.

Moving Stories
for Kíds
<i>Moving Day</i> by Robert Kalan
W/ 16 / 1 Tr / 1 Tr
 We're Moving by Heather Maisner
Boxes, Boxes Every Where
 by Crystal Bowman
by Crystar Downlan
Berenstain Bears Moving Day
by Stan and Jan Berenstain
 <u> </u>
Alexander, Who's Not (Do you hear
me? I mean it!) Going to Move
by Judith Voist



MTOM (www.defenselink. mil/mtom) is a website designed for Military Teens On the Move. This website was specifically designed for children 6 to 18 years old. It uses humor, empathy, testimonials, and upbeat visuals to provide a wealth of relocation information and to address the challenges facing military children and youth as they cope with the strains of moving.

- Have a family meeting to discuss the children's feelings: whether they are excited, angry, or worried. Reassure your children that all these feelings are normal.
- Find time in normal rituals of meal preparation or bed time to have one-on-one conversations with your children, so they can share their thoughts and feelings about the move.
- Plan a farewell party. Take lots of photos and collect addresses, email addresses, and phone numbers.
- If your child is old enough, provide a scrapbook for the child to assemble.



Medically required equipment can be shipped in the same manner as the sponsor's professional papers and books and does not count against your household weight allowance.

Visit your Transportation Office (TO) or Traffic Management Office (TMO) for more information. You will need a letter from your physician stating that the equipment is medically necessary.

Moving away from the familiar and into the unknown can be scary. Give your children opportunities to express their feelings. Happy and excited feelings are much easier to accept and deal with, but negative feelings, like sorrow or anger are just as valid. If your children feel that only happy thoughts should be expressed, the negative emotions will just go underground and may well surface as negative behaviors. This does not mean your child is entitled to set a negative tone for the whole family or that poor behavior is acceptable, but honest talk may diffuse some of the difficulty.

Packing

Before the movers arrive, set aside the following items in a room with a big sign on the door asking movers to stay out:

- Important documents such as school records, dental records, any medical records, birth certificates, insurance policies, copies of PCS orders, and a copy of the household inventory form.
- Medicine and medical equipment that will travel with you.
- Comfort needs, like a pillow or some favorite music or DVDs.

Overseas Suitability Screening

Before being stationed overseas or to a remote assignment, all families of service members are screened for overseas suitability. The screening is mandatory and is used to determine if the member or family member(s) have any special needs that may require special medical or educational attention. The presence of a special need does not mean a family is not eligible to travel overseas; however, it does mean extra care is necessary to be sure the family is living in an area that is suitable to all family members.

Traveling with Kids

Whether traveling by plane, train, or automobile, traveling with children takes some planning.



Command sponsorship is required for families to participate in TRICARE Overseas Program Prime

parent to parent

"As parents we

are our family's

best advocates."

~Katrina, mom

to a daughter with downs

Quantico, VA

syndrome,

The following tips will help make the trip go smoothly:

- Be sure to inform TMO if a child has special needs.
- Be proactive in contacting the airlines or other services to assure there are arrangements for wheelchair storage and to find out the locations of accessible bathrooms. If a wheelchair is needed at the gate, make the calls yourself to be sure this happens.
- Keep security items within reach.
- Have healthy snacks at hand.
- Bring plastic bags for trash.
- Bring books, cards, and games to help pass the time. A few new items may hold a child's attention longer than an old favorite.
- A child might enjoy being in charge of his/her own travel bag; however, regulate how much is put into this bag so that it doesn't get too heavy!
- Bring an inexpensive umbrella stroller; these can be especially helpful in airports and train stations.
- Tape emergency contact information in children's clothing or have them wear a medical alert bracelet.

- Take a portable DVD player if possible, along with the child's favorite DVDs as well as comforting music for bedtime.
- Keep hand wipes ready for frequent hand cleaning after stops and before eating.

Air Travel

The Air Carrier Access Act prohibits airlines from prohibiting passengers on the basis of disability and actually requires U.S. air carriers to accommodate the needs of passengers with disabilities. For more information contact www. disabilityinfo.gov.



Each service has a system to screen families so that any special needs will be identified and can be taken into consideration as the service member is assigned to a new duty station.

Army-Family Member Deployment Screening

Navy-Suitability Screening

Marine Corps—Suitability Screening

Air Force–Family Member Relocation Clearance Process Keep the following things in mind as you prepare for the trip:

- Contact the airline 48 hours in advance of the flight if special services are needed, such as a respirator hook up or transportation of an electric wheelchair.
- Ask if the bathrooms are accessible if flying on an older or small aircraft.
- devices do not count toward the limit on the number of pieces of carry on luggage.

 Wheelchairs (including collapsible battery-powered wheelchairs) and other assistive devices have priority for in-cabin storage space (including in closets), as long as you take advantage of preboarding.
- Ask your physician about the safety of flying if a family member suffers from seizures. Get the physician's



It might help to prepare your kids for going through security. Practice with a toddler walking through a doorway one at a time and handing over that precious backpack to be X-rayed.



If you choose to check your car seat, you can ask that it be put into a large plastic bag that is available at the airport. This will prevent it from becoming soiled.

recommendation in writing and carry it with you as part of your family's medical records.

- Consider bringing a stroller to gate check, as there can be a lot of ground to cover between gates.
- Use a backpack instead of a diaper bag as it will leave your hands free to hold on to kids.
- Bring snacks for the kids, as few self-respecting toddlers will eat airplane food, and on many flights only a small bag of pretzels is offered anyway.
- Decide if boarding early would be the best choice for your family. Air-conditioning is generally not turned on until just before take-off, so a squirmy child would have to remain still longer than necessary in an overheated plane. Some families tag team, with one parent



If your child requires oxygen and is traveling by air, arrange to have oxygen provided by the airlines as you will not be allowed to use your own.



If your child is likely to run or wander off, be sure you have a copy of the child's identifying informatio<u>n</u> with you at all times. If your child is not verbal, you may want to put identifying *information* on the child. Remember to use a phone number other than the home phone.

boarding early with the bags and the other parent boarding later with the kids.

 Be sure the car seat you have is compatible with airline seats. Check the airline's website for car seat information.

Traveling by Train

If you are traveling by train, Amtrak will assist those in wheelchairs in the case of high or low platforms or bi-level trains. Your child may remain in the wheelchair en route or the chair may be stowed. Should your child require oxygen, you must make reservations in advance and give notice of your need to bring oxygen aboard at least 12 hours before you board. Please call 1-800-USA-RAIL (1-800-872-7245) for more information about bringing oxygen on an Amtrak train, as well as station accessibility.

Train travel means that more interaction with children is possible than in a car, especially if there is only one driver. Be sure to bring activities your child enjoys, such as favorite stories, card games, and healthy snacks.

Traveling by Car

Traveling in a car affords a family greater flexibility than in a plane or a train. You can stop and explore or stretch your legs when you would like to. To make the most of the journey, plan a route with places of interest to stop along the way. Provide children with a map with the route to the new home clearly



Amtrak allows trained service animals accompanying passengers with disabilities in all customer areas in the stations, trains, and Amtrak Thruway motor coaches. If the train schedule permits, you may walk your service animal at station stops. However, if you plan to walk your animal during the trip, please notify the conductor when you first board the train.

marked, and stops along the way marked as well. Car games will help pass the time. Download a map of the United States (www.eduplace. com) and have the children color in a state each time they spot a license plate from that state. Have a scavenger hunt with each family member trying to spot items on a list.

Temporary Lodging

For information about temporary lodging, go to www.military.com and click on "Travel" and then "Military Lodging Options." Make reservations as far in advance as possible. Mention your family's EFMP status as some bases have special accommodations. Be sure to ask if they have wheelchair accessible rooms or rooms with TTY for the deaf or hearing impaired if necessary.

Ideas for your Scavenger Hunt

- flashing red light
- bus
- signs in foreign languages
- food store
- police car
- person using a cell phone
- school
- someone on a bike
- statue
- church
- pickup truck
- dog in a car
- silo
- train tracks
- a car just like ours
- cows
- pond or lake
- dirt road
- tractor
- gas station
- horses
- barn deer

A Toddler's Scavenger Hunt

- tall building
- lake or pond
- bike
- bridge
- red car
- animal
- truck
- stop signs
- store

Some families find the time in transit, while waiting for belongings to catch up with them, to be a bit of a break from the usual household responsibilities. When there is only a suitcase of clothes, the amount of work necessary to keep up the family is diminished. Take this time to find fun in the new area. Help kids to enjoy themselves and get a positive feel for their new home.

Housing

Should your family live on base or off? Five percent of on base housing has the advantage of being wheelchair accessible, a feature that can be hard to find off base. Life on base has the added advantage of other military families close by. Becoming part of a supportive community may be easier on base than it is off, where neighbors may not understand or be interested in the military lifestyle. A big factor in this decision is the wait for housing, which varies from base to base. Some Services offer priority housing to eligible families with EFMs.

Schools

An important factor in your decision about housing is schools. Investigate both on base, if available, and off base schools. Contact these schools well in advance of the move to begin the discussion of how your child's unique needs will be met. Meet with administrators of both systems to share your child's IEP, and see what is available in each system. Your child's IEP should be honored until a new IEP is written, but



The Army calls their special needs childcare resource the Special Needs Accommodation Process (SNAP), The Navy and Marines call theirs the Special Needs Evaluation Review Team 64 (SNERT), and the Air Force does not have this service.

available services may vary, as might the individual school's approach to special education. Even on a base with a DoD school, the child might be transferred off base if it is determined that the civilian school is better suited. This is more likely if the child has severe or profound challenges. For more information about special education and schools, see module two, Special Education, of this Parent Tool Kit.



For state specific education information check www. militaryhomefront.dod.mil/efm.

Childcare

For working parents, finding highquality care is a high priority. As a military parent of a special needs child, finding childcare that can accommodate shift work, extended hours, and weekend duty and can meet the unique needs of a child can be challenging.

Look for childcare that is inclusive. Inclusive childcare allows children to learn together in an educational atmosphere that supports and nurtures the individual strengths of each child, and each child participates in the daily routines and activities of the class regardless of cognitive or physical impairments.

Every child deserves the opportunity to interact with other people regardless of his or her ability level. Most military installations have special resource teams to help parents of special needs kids find appropriate childcare. These teams may be comprised of childcare specialists, an EFMP advocate, a public health nurse, and the parents. The purpose of this team is to explore childcare and youth activities for children with certain special needs who are involved in installation childcare or youth programs. The team will identify the care options available to best meet the child's needs as well as consider any increased technical support, special services, or staffing that may be necessary to care for the child appropriately.

For more information about childcare, check with the installation's Resource and Referral Office. A resource specialist can guide you through the registration process, accreditation and fees, and the exploration of both on and off base options to choose the best care for your child. Installations have different names for the office that manages the childcare programs, so if the name of the office is unknown, the best place to start is at the home installation's Child Development Center (CDC) ask which office provides local childcare resource and referral services. Telephone numbers of all CDCs and school-age programs at can be found at www. militaryhomefront.dod.mil/efm.

Questions to Ask About Childcare

What are the priorities for placement on the list at this installation?

I have more than one child. What is your policy on placing siblings?

What process do you use for keeping my data up to date?

Will you get in touch with me, or will I be responsible for periodically updating you?

What is the range of time that I might have to wait for a space to open up in my child's age group?

I will need childcare in the interim. Will you help me find it?

What is your child/provider ratio?

Will the center adapt the physical environment to meet my child's needs with the goal of increasing his or her participation?

Will the providers adapt materials and curriculum to promote independence and capitalize on my child's favorite activities?

Do the providers have experience working with adaptive devices? What types of training have the providers had?

How will the center implement and monitor my child's IFSP or IEP?

What is your provider/child ratio?

Will the center allow me to work with the care providers to show proper positioning, use of equipment, medication administration, etc?

Will therapists have a quiet area to work with my child?

How will the center facilitate diapering? (Sometimes centers will not have changing tables in rooms for 3 and 4 year olds.)

Do you have staff members who know American Sign Language (ASL) or have experience working with augmentative communication devices?

What are your emergency medical procedures? How close are they to a medical facility? Do you have a nurse on staff?

Does the center have a discipline policy? (Ask for a copy.)

Does the center have a method for filing complaints? Whom would I speak with?

Do you provide Emergency Respite Care?



Every military childcare program has a Parent Advisory Board (PAB) in which parents are able to voice concerns and make recommendations for improving service.

Moving In

Move in day is exciting. The new house starts to feel like home, and everyone is relieved to have familiar objects back. Give thought to creating moving day traditions. They can be a simple as having Chinese take out the first night in a new home, or eating the first meal on boxes, even though the table is back. Because of the excitement, pay special attention to children who may wander or find danger in unfamiliar surroundings. If respite care is needed, contact the family support center.

Safety in a New Home

Look over a new home with an eye for hazards such as busy roads or creeks near by. Hold a family meeting to discuss these hazards with children and establish firm boundaries defining where they are allowed to go.

If a child is likely to run away from the house, talk to the local police or the Military Police (MPs) about this. Provide them with a current photo and a description of the child. Explain how the child is different and might react if confronted. Be sure to include all contact information in the sheet and give copies to the MPs or local police. Remember to update the photo and contact information as necessary.

You may want to make several copies of this to have on hand in case of emergency and to take with you when you travel.



This is our son Michael.

We work very hard to keep him safe, but sometimes he gets out of the house

without our knowledge. If you see him, please call us, as he should never be out alone. He is autistic, and may not respond if you talk to him. He may run away from you if he is scared. He has asthma and is allergic to peanuts and peanut oils. If he is having trouble breathing, call 911 and do not offer him snacks that contain peanuts or peanut products.

Name: Michael Smith

Medical conditions: Autism, Asthma, and peanut allergy

Contact information:

Home phone:

Mother: Mary Smith Work phone: Cell phone:

Father: Joe Smith Work phone: Cell phone:

Thank you very much.

If concerned that despite much vigilance a child may leave the house unobserved, consider installing extra locks or an alarm system. Ask your physician for a letter explaining the medical necessity for these modifications and bring it along with a request to the base housing office or landlord to ask permission to install extra locks.

Talk to neighbors about concerns for your child. Give them your phone number and ask them to call if they spot your child moving away from the house alone. If a child is deaf or blind, contact the base or local authorities and ask for a sign alerting drivers to the presence of a deaf or blind child.

If oxygen tanks are in the home, the local fire department needs to know about them. Also, if a child is likely to hide in the case of an emergency, tell the fire department. A copy of the child ID page that was made for the police would be appropriate for the fire department as well.

If a child is not verbal, consider keeping identification and contact information on the child, perhaps on a bracelet or sewn into clothes.

Spouse Employment

Frequent relocation, extended deployments, and other unique aspects associated with the military lifestyle can create significant career and employment challenges for military spouses. Having a special needs child brings even

further challenge. You may desire employment due to financial necessity or to fulfill personal goals. Fortunately, there are resources available to assist you.

Military Spouse Career Center

To enhance employment and career opportunities for military spouses, the Department of Defense partnered with Monster.com to develop the Military Spouse Career Center. This virtual resource found at www.military.com/spouse can provide assistance to you regardless of your location. The center was created to provide career networking services, employment services, and information to military spouses. The center provides information on spousefriendly employers, education and scholarships, licensing and certification, job search skills, and much more. The center enables employers to post jobs for military spouses at no cost. Additionally, resumes can be created and posted, and thousands of job openings around the world can be explored.

MilitaryHOMEFRONT (www. militaryhomefront.dod.mil) also has information on spouse employment in the "Troops and Family" section.

Installation Support

Many installations have a family support center that offers professional family member employment readiness training and support services. Installation-based employment assistance programs provide job search training and



Talk to your children about the deployment before it occurs. Children are quick to sense when something is about to happen and will worry more when information is 68 withheld.

assistance and serve as a source of information for local job fairs and job search databases. Training and other support services for spouses may include the following:

- Resume writing.
- Skills assessment.
- Career interests assessment.
- Access to computers and the Internet.
- Individual counseling and career planning.
- Job search skills.
- Information about local job listings.
- Career seminars.
- Support and encouragement.

Deployment

Waiting for a loved one to deploy is hard on children as well as spouses. Children may not understand why a parent must leave and may fear the parent is leaving forever. Because children are not very good at expressing their worries verbally, they tend to express them behaviorally. Be sure your children have many chances to express how they are feeling. The following ideas may help your family prepare for and get through a period of separation due to deployment:

- Use your own words to help children find theirs. For example, "I don't want Daddy to leave, and waiting for him to leave makes me feel sort of sad and worried. Do you ever feel that way?"
- Explain that although many things will be different, many things will be the same.
- If the child plays imaginary games with dolls or animals, try to introduce the idea of one member of the doll family leaving. Let the other dolls say how they feel about this.
- Use a map or a globe to show where his or her parent will be.
- Use a calendar to show children when the deployment will take place, as they may not understand how long three weeks is.
- Be sure that the departing parent has time with each child before deploying. Hug often. Take photos of each child with the departing parent.
- The departing parent might schedule a trip to the child's school to meet with the teacher. The point of this trip is to be sure the teacher knows about the change in the family dynamics. Let the child show you around his or her school world and perhaps

hear you tell the teacher how proud you are of him or her. You will be able to ask better questions about your child's day if you are familiar with his or her school.

- Have a family meeting about ways to keep in touch during the deployment. Letters, pictures, tapes, and movies are all good ways to stay connected.
- Remember to occasionally send children their own letters. Children enjoy few things more than receiving their own mail! A letter to the family pet will also bring a smile to a child's face.
- Find the best way for the child to mark the end of the deployment. This may be making Xs on the calendar or ripping links off a paper chain.
- Remember that just because a child doesn't express his or her feelings, it doesn't mean they are not troubled. If a child is acting out, it may be the result of unexpressed emotions. Help the child name these feelings.
- It is fine and even healthy for children to see you have sad feelings too, but if you are really about to fall apart, try to do this away from your kids. Strong emotions in a parent can be scary to a child.



- Remind children that they are still safe, and that a deployed parent is still a member of the family.
- Do not minimize the child's grief. To a child it may feel like a parent is lost forever. Grief without understanding is difficult to work through.

Help is Available

If you or your children are having a particularly difficult time adjusting to the deployment, counseling is readily available through several sources. Call the family service center or contact www. militaryonesource.com. Through TRICARE you are entitled to 8 sessions of counseling without a referral from your Primary Care Manager. If more is needed, an authorization can be obtained. Another source of support may be a chaplain. It is important to ask if the chaplain is licensed for marriage or family therapy. The parent at home has a heavy load to carry. As a parent of a disabled child, things can be difficult enough when both parents are available, but now it may seem overwhelming. Taking care of yourself has never been more important. Do not hesitate to contact your EFMP coordinator to ask for respite care. The entire



In case of an evacuation, be sure your extended family knows where to find you and have a plan in place for your family pets.

family will benefit if the parent at home has the chance to recharge his or her batteries.

Coming Home

When the deployed parent returns, children may feel worried and stressed, as well as happy and excited. Depending on the child's developmental level, he or she may feel uncomfortable around the returning parent, almost as if they were strangers. For some children, even good change is unsettling. Remind your returning spouse of this and help him or her understand that the child's behavior is a reaction to change, and not a rejection of the returning parent.

Make sure children have time to let their excitement out with the returned parent before having quiet time with your spouse. However, once the excitement has subsided, do schedule time to reconnect. Maintaining a strong marriage is one of the best things parents can do for their children.



Many respiratory illnesses can be aggravated by stress; plan to have breathing aids such as inhalers, nebulizers, or oxygen tanks within reach.

Disaster Preparedness

Families with special needs must be prepared for evacuation or other emergencies. Careful preparation will reduce stress and hardship. Remember that more time may be needed to evacuate.

You may want to include the following when packing for an evacuation:

- 30 days medication supply.
- Important documents (medical records, insurance papers, birth certificates).
- Enough diapers and clothing for 7 days.
- Bed rail.
- Special eating utensils.
- Special food.
- Entertainment for children (e.g., games, cards, books).
- Comfort items.
- Battery operated flash light and radio.
- A current photo and physical, behavioral, and medical description of your child including a list of necessary medication.
- Contact information for your child's physician.



If you are experiencing financial difficulty because of a natural disaster or other crisis, your military aid society may be able to help:

Air Force Aid Society: 1-800-769-8951

Army Emergency Relief Society: 1-866-878-6378

Navy/ Marine Corps Relief Society: 1-703-696-4904

Or call the American Red Cross: 1-202-303-4498

Service Animals

Federal law allows guide dogs into emergency shelters. In your packet of important papers be sure to include the dog's rabies tag and license. Remember that in a disaster the guide dog may become confused, and may need more attention than usual.

Power Loss

In times of disaster, extended power outages may last for weeks. If you live in military housing and require electricity for vital medical equipment, contact the EFMP coordinator or housing manager. If generators are not available, contact the Primary Care Manager

to discuss if your child should be moved to a hospital or other facility where power is available.

Transition to Adulthood

Between the ages of 14 and 16, a child's IEP will begin to address the transition process. During transition planning, students and their families find out about community agencies and programs that provide services to persons with disabilities after high school. Some of these adult services include job training and placement, assistance in getting housing, and programs on healthcare and independent living. These transition services should start no later than the first IEP to be in effect when the child turns 16, and should be updated annually thereafter. Also, no later than 1 year before reaching the age of majority under state law, a child must be informed of his or her rights under IDEA, if any, that will transfer to him or her upon reaching the age of majority. Remember to include an older child in the IEP process.

Independent Living

As a parent, you began teaching self-help skills very early in your child's life. Self advocacy skills are also important. Whenever possible, let the child speak for him or her self. This might be encouraging a child to order his or her own food in a restaurant or to explain to a new teacher his or her need to tape record lessons.



Bring the following when evacuating with a service animal:

- Food.
- Bowls.
- Records of licensure and rabies shots.
- Disposable bags.



Service members who are retiring must be aware that while children of retirees are still entitled to healthcare under TRICARE, they are not entitled to ECHO/EHHC benefits. These benefits are reserved for active duty members only.

The time to begin thinking about assisted living facilities is when a child is young, as the waiting lists can be years long. Contact the state you will retire to and inquire about what services are available.

One of the most important adult services, vocational rehabilitation, is available in most states. Vocational rehabilitation services include planning, assistance, support, and training that helps a person get ready for and find a job. Contact the state's Parent Training Center, www.taalliance.org, and ask about programs that help with transition.

It is important to remember that unlike the special education system, a person with disabilities does not automatically get free vocational rehabilitation services. A person must meet certain qualifications, and some agencies also charge fees for their services. Because there is no central system of adult services like there is for special education,

it may be necessary to deal with an assortment of adult services and government programs.

Caring for Your Adult Child

Parents of healthy children can usually plan on their children living independently and becoming financially independent. However, if your child has a life long disability you will need to plan not only for childhood care, but adult life as well. Will the child be able to make decisions about health care or finances? For an adult child to qualify to receive Supplemental Security Income or Medicaid, he or she cannot have more than \$2,000 in assets. So how can you insure a child's well being and financial security?

Supplemental Security Income (SSI) and Medicaid

The Supplemental Security Income program is a minimum monthly cash payment for categorically aged, blind, and disabled individuals. Eligibility is based on the limitation of assets and should not be confused with other Social Security benefits. Medicaid is frequently tied to SSI approval and is a program to pay for health care for certain low-income or disabled individuals or families. Medicaid does not pay money to you; instead, it sends payments directly to health care providers. Depending on the state's rules, it may be necessary to pay a small part of the cost (co-payment) for some medical services. Many states have special



If because of separation from the military, divorce or a dependent child reaching the age of 21 or 23, you lose your TRICARE coverage you will be issued a Certificate of Creditable Coverage (CoCC) which is proof to your next healthcare plan that you had previous healthcare, and limits the amount of time your new healthcare plan can exclude your participation because of preexisting conditions.

Medicaid programs for people with disabilities, and not all are income based.

The Special Needs Trust

Special Needs Trusts are discretionary trusts created for people with disabilities to supplement, but not replace public benefits. This type of trust will allow a disabled individual to continue to receive SSI, Medicaid, Section 8 housing, and other public programs while benefiting from trust fund money. The money from this trust can be used to purchase special wheelchairs, handicapped accessible vans, as well as to pay for vacations, a personal attendant, or recreational and cultural experiences. SSI is designed to pay for food, clothing, and shelter. Medicaid will pay for medical bills. The trust fund can be used for all other needs that are identified in the trust document. Contact a lawyer who has experience with Special Needs Trusts. Don't hesitate to act because of concerns about paying for the service. Make some calls and explain your situation. Many lawyers will consider reducing their fees or allowing payment on a monthly basis for their services. If you think you do not have the assets needed to fill a trust, remember that life insurance is an asset, as is a home if you own it.

Letter of Intent

This letter provides parents with an opportunity to speak to whoever will be caring for and making decisions for their child after they have died. This may be the person who is the trustee for the Special Needs Trust. You may want to write out your child's story in the letter, including medical history and educational background. Describe the child's favorite activities, foods and people. Include places he or she has gone, and places he or she would like to visit. This tool will help whoever is taking care of your child to better know you and your child. It will provide information to help them understand your wishes and expectations as they make decisions about your child's future.

Guardianship and Declaration of Incapacitation

Usually, when a child turns 18, it is assumed that he or she is capable of making decisions about health, finances, and the future. Once your child turns 18, you will no longer be able to talk to your child's physician about his or her health. You will



If you are considering obtaining guardianship for your child, you should begin the process before your child turns 18.



For more information about wills, guardianship, and Special Needs Trusts, contact STOMP.

have no control over financial decisions or contracts your child might sign. If you are concerned that a child will not be capable of making these decisions responsibly, consider asking the courts for guardianship.

Guardianship is a court approved relationship between a legal guardian and the person with a disability. The court will define the degree of legal authority that the guardian will have to act on behalf of the disabled person. Detailed documentation from a physician will be needed to show that your child is not mentally capable of becoming independent. Be aware that if you move to another state, it is necessary to apply for guardianship in the new state.



If your child has more than \$2,000 of his or her own, SSI and Medicaid will be affected. Should you or a grandparent die and leave a child money, the child will lose these public benefits unless the money is left to the child's Special Needs Trust.

ID Cards for Adult Children

Unmarried children of military sponsors who are age 21 and over, severely disabled, and are disabled due to a condition that

existed prior to the child's 21st birthday are entitled to TRICARE benefits. These adult children are eligible to retain their military ID cards as well. In the Navy and the Marine Corps, this program is called The Incapacitated Dependents Program and in the Army the program is called Incapacitated Children Over 21.

Army families can call: 317-510-2774/2775

Navy families can call: 910-874-3360

USMC families can call: 703-784-9529/30 If you are retired or a former spouse, call 1-800-336-4649

Air Force famlies can call: 210-565-2089

Hospice Care

Hospice care is available for terminally ill patients and their families when the patient has been given a terminal, life-limiting prognosis. The goal of Hospice care is to provide dignity and comfort to the dying. Eighty percent of hospice care occurs in homes or in nursing homes, and TRICARE will cover most of the costs.

If you live on base and your child is in hospice care, arrange a meeting with the Military Police, your chaplain, and your EFMP coordinator. This will help ensure all parties understand your wishes for your child. This is very important,

Module Four: Families in Transition

75

as without this meeting, well meaning but misguided Military Police or emergency response personnel may insist on trying to resuscitate your child against your wishes. Module three, *Health Benefits*, of this Parent Tool Kit contains detailed information about hospice and long-term care.

For More Information

Obtain the other modules of this Parent Tool Kit at www. militaryhomefront.dod.mil/efm or from your EFMP coordinator.

- Module One, *Birth to Age Three*
- Module Two, *Special Education*
- Module Three, *Health Benefits*
- Module Five, *Advocating for Your Child*
- Module Six, Resources and Support



Introduction CtiOn

When you already do so much to help your child, discovering that there is yet another job to do may be discouraging. This may be especially true for military parents who are already coping with frequent separations and relocation. You may not realize it, but advocating for your child is a job you are probably already doing. Advocacy is learning about about your child and his or her condition, keeping track of records and correspondence, and making sure your child receives the health care and education that he or she is entitled to.

Remember as you advocate for your child that no parent is perfect. Meetings are sometimes missed, or papers lost. Talk to other parents, but trust yourself. Keeping a positive perspective can be a challenge when you are tired and frustrated. Understand that your child is not entitled to every intervention that he or she could benefit from, and that the healthcare and educational professionals you interact with can help you create positive outcomes for your child

Effective Communication

Whether you are interacting with your child's healthcare provider or school system, effective communication is the cornerstone of successful advocacy.

Stay Cool, Communicate Clearly

Good communication includes direct eye contact, an even and modulated voice, and open body language. If you are pleasant to work with, you will not only draw more people to your way of thinking, but you will feel better about yourself. There is a difference between being polite to someone and agreeing with them. Remaining calm, pleasant, and focused can be a challenge for parents who are

working hard on behalf of their children. When interacting with medical professionals and school personnel, be aware of emotions. You may be anxious or worried. Keep as positive a demeanor as you can muster. Even if you expect a



Advocacy is by nature a thoughtful activity. Parenting is an active and emotional activity. Blending the two can be difficult, but when done well, educated, organized, and loving parents are formidable advocates.

dvocating for Your Child



Speak clearly, smile when you can, and remember that a pleasant attitude is much more productive that a negative one.



Relationships with healthcare providers and the school system are important to you and your child. Creating and preserving good relationships benefits everyone.

meeting to be contentious, try to set a positive tone. Make good use of your manners, your smile, and direct eye contact. If you want the others to be patient, prepared, and educated about your child's needs, you must set the standard.

If you do not understand what someone has said, or if it rubs you the wrong way, politely say, "Did I understand you to say that ______?" This can clear up a

______?" This can clear up a misunderstanding early on or help define an area of disagreement. Don't not be embarrassed to ask for further explanations. It is a parent's job to understand as much as possible about their child's education and medical condition. Look for common ground and be sure the others in the room know you are trying to understand their point of view. Thank those who have been helpful.

Despite the frustration and anger you may feel if a situation concerning your child is not heading toward consensus, it is advantageous to remain calm. You do not want to be seen as unreasonable, inconsistent, or volatile. Angry outbursts will undermine your credibility and thus your ability to advocate well.

Letter Writing

You may need to write letters for several reasons such as to request copies of school records, to request a meeting, or to document a problem. Some people are very comfortable with this, but if you are not, the following are some tips for effective letter writing:

- Use clear, everyday language.
- Keep it brief.
- State the purpose of the letter in the first paragraph.
- Explain what action you would like to see.
- Finish the letter politely.
- Include contact information.



Several sample letters can be found in module two, *Special Education*, of this Parent Tool Kit.

Remember that once the letter is mailed, there is no going back. If a letter is written when you are angry, wait several days before mailing it. You may be rightfully upset, but the expression of your anger may hurt your cause, namely, the education of your child.

If no reply is received after 2 weeks, write again and include a copy of the first letter. If this letter brings no response, go higher up the chain of command.

Getting Organized

Corresponding with healthcare agencies and school systems generates a lot of paper. To complicate things further, military families relocate every few years which means you must often navigate through a new school system. Also, with each move comes the possibility of lost paperwork. What is needed is a system for organizing this paperwork because it is crucial to your ability to effectively advocate for your child.



A Shopping List for Getting Started
Two three-ring note books
Three-hole punch
Highlighter
Sticky notes
#10 envelopes
Stamps
Dividers for binders
Calendar

To avoid the frustration of searching for lost letters or records, it is a good idea to have a system for keeping track of papers concerning your child's disability. For those with only a few papers, this might be as simple as a folder in which to keep letters from the school, for others it will be several binders, one for educational information and another for medical information. With well organized records, you will be empowered as you go into meetings concerning your child's health or education.

Before you begin to organize these files, give thought to your child's needs. Are they primarily physical or educational? How many agencies have individual records for your child? Make a list of people and agencies in order to request records if needed. If you have a child with special educational needs as well as frequent medical needs, consider starting files in two separate binders: medical and educational.



A key component to effective advocacy is record keeping.

The Medical File

The first binder will be primarily for medical information. Organize the sections in the following way:

- Phone log.
- Research and information on the child's disability.
- Copies of correspondence to TRICARE.
- Correspondence from TRICARE.
- Other insurance information.
- Important pages from medical and dental records.
- Immunizations.



The phone log is an important component of your file. This is where you will keep notes regarding when and with whom you have spoken about appointments and healthcare coverage. Phone calls come at all times of the day, and a few notes jotted here will help you keep an accurate record. It is a good idea to follow particularly important phone calls with an email or a letter.

If you would like copies of medical records, request them from the military treatment facility. The first copy should be provided free of charge. The policy for receiving copies of records varies in different facilities, but your request should be made in writing, and you may be asked to wait as long as 6 weeks to receive copies of your records.

Educational File

In the second binder, keep information about your child's educational history. Use the sample letter found in module two, *Special Education*, in this Parent Tool Kit to request a complete copy of your child's educational records. You may want to start a photo record of your child on or in this binder, adding a school picture as each year goes by. Label dividers and organize information the following way:

- Phone log.
- Assessments/evaluations.
- IEPs.
- Discipline reports.
- Report cards/interim reports.
- Correspondence to school system.
- Correspondence from school system.
- Immunizations and pertinent health records.

 Contact information for service providers and agencies.



TRICARE has a Special Care Organizational Record (SCOR) that is helpful when organizing your child's medical records. It can be found at www.tricare.osd.mil.

Remember to copy all letters you send to the school and include them in your file. Consider using certified mail when corresponding with the school system so there will be no question about if and when the school received your mail. Do not underestimate the value of an accurate phone log. Follow up important conversations with a note (e.g., "Thank you for talking with me today about my daughter's education. I understand that you have agreed to (provide/change) by (date). Please let me know if my understanding is not accurate."). Keep your notes from IEP meetings in this file, as well as any in school suspension slips or notes from the school. Keep all documents in chronological order.

Medical Advocacy

As you adjust to the news that your child has a physical or educational diagnosis, you may feel overwhelmed. Many parents react by learning all they can about their child's condition. Begin by asking your child's doctor and other professionals who know your child any questions you may have. Write down questions as they occur to you during the day. Then, at the next appointment, your questions will be ready. A thorough understanding of your child's condition will help you become aware of what you can expect from your child.

It may be empowering by to learn all you can, but don't become overwhelmed with new information. Take time to adjust to the emotional impact of a new diagnosis. Remember that the diagnosis is only part of who your child is.



If you don't understand what your doctor is saying, you should say so. It is your job as a parent to understand what the doctors and other professionals are telling you, and it is their job to help you understand.



There can be an overwhelming amount of new information to be absorbed, so beware of burning yourself out.

Getting the Referral You Need

A referral may be needed for a specific type of therapy or for special equipment for your child. Do not assume your doctor is aware of the best way to word the request.

A wonderful resource is the STOMP list serve, www.stompproject.org. STOMP is a Parent Training and Information Center for military families providing support and advice to military parents whose children have special challenges. Here you can interact with parents who have already experienced much of what you are going through. They are happy to help.

Armed with this information, you and your doctor can write a referral in the way most likely to be approved. If a piece of durable equipment is needed for your child, work with your healthcare provider to write a very thorough and complete description of how a piece of durable equipment is going to lessen the functional loss caused by the disability.

Appealing TRICARE Decisions

If an application for Extended Care Health Option (ECHO) or Extended Home Health Care (EHHC) has been denied, the letter of denial will include the specific information you need about whether or not the decision is eligible for appeal, and if so where to send the letter of appeal and what the time limitations are. The appeal process varies depending on the reason for the denial. Even if the letter

says the decision is not eligible for appeal, you may want to question it any way. Does the letter state the reason for the denial? Is it accurate? Can your child's circumstances be described in such a way as to make things more clear to TRICARE?

If your letter of denial states that an appeal is not available do not give up quite yet. Question your TRICARE regional contractor as to the reason for the denial. Post a description of your problem on STOMP, www.stompproject.org, and see how other families have handled similiar situations.

For help with TRICARE appeals, contact your regional contractor by going to www.tricare.osd.mil and clicking on the applicable TRICARE region. You can also contact the Beneficiary Counseling and Assistance Coordinator (BCAC) at the TRICARE regional office or military treatment facility.

Educational Advocacy

It is especially important that parents whose children have special needs be aware of the legislation that affects how their children are educated.

Legislation

IDEA is the special education legislation that guides school systems throughout the United States, its territories, and Department of Defense schools in the education of children with special needs. The purpose of the law is to ensure that all children

with disabilities have access to a free appropriate public education (FAPE), to ensure the rights of children with disabilities and those of their parents are protected, and to ensure that teachers and parents have the tools they need to meet educational goals and to assess the effectiveness of educational efforts being made for the child. For more information about IDEA and Special Education, of this Parent Tool Kit.

Section 504 of the rehabilitation act is a civil rights law that prohibits discrimination on the basis of disability and applies to public schools as well as employers or organizations that receive financial assistance from any federal department or agency. These organizations and employers include many hospitals, nursing homes, mental health centers, and human service programs. Because Section 504's definition of disability is broader than IDEA's definition, some children who do not qualify for special education under IDEA do qualify for special help under Section 504. This can be especially useful for children with "invisible" conditions, such as learning disabilities or Attention Deficit Hyperactivity Disorder. For more information about Section 504 of the Rehabilitation Act go to www. ed.gov.

The Americans with Disabilities Act (ADA) gives civil rights protection to individuals with disabilities similar to those provided to individuals on the basis of race, color, sex, national origin, age, and religion. It guarantees equal opportunity for individuals with disabilities in public accommodations, employment, transportation, state and local government services, and telecommunications. For more information about the ADA, visit www.usdoj.gov.

Nondiscrimination on the Basis of Handicap in Programs and Activities Assisted or Conducted by the Department of Defense, DoD Directive 1020.1, prohibits discrimination based on handicap in programs and activities receiving federal funds through the Department of Defense. For more information about this directive, go to www.dtic.mil.



Avoid writing directly on original documents as you may need them for official business in the future, perhaps as exhibits at a due process hearing. Instead, use stick on notes for your comments.

For further information or assistance contact your state's Protection & Advocacy Agency. The National Disability Rights network lists state agencies at www.napas. org.



Some children who do not qualify for special education under IDEA do qualify for help under Section 504.

The School System

One of the basic principles of IDEA is that procedural safeguards must be in place to ensure that the rights of children and their parents are protected and that there are clear steps to follow in the case of a dispute. Contact your school system for information concerning appeals within the system. Ask for copies of these policies and procedures and take a well read copy with you to your meetings. This will signal to the school that you are serious about your child's education, and that you know the rules. It is a good idea to contact your state Parent Training and Information Center and Community Parent Resource Centers. To find yours, contact Technical Assistance Alliance for Parent Training Centers, www. taalliance.org.

Assessments

A variety of tools may be used to help you and the school system identify your child's areas of strength and weakness. These often include IQ (or cognitive) tests or academic achievement tests given to your child in order to better define your child's intelligence or level of academic achievement. In either of these types of tests, a series of tasks are presented to the child being evaluated, and the child's responses are graded according to carefully prescribed guidelines. After the test is completed, the results are compiled and compared to the responses from other children of the same age or grade level as the

child being evaluated. There are many assessments used, several are described below.

- Differential Ability Scales (DAS). This is a nationally normed and individually administered group of cognitive and achievement tests. Its age range includes children from 2 years and 6 months to 17 years and 11 months.
- Leiter International
 Performance Scale. This
 is a totally nonverbal
 test of intelligence and
 cognitive abilities. It is easily
 administered and quickly and
 objectively scored. Its gamelike administration holds a
 child's interest.
- Peabody Individual
 Achievement Test (PIAT).
 This is an efficient individual
 measure of academic
 achievement. Reading,
 mathematics, and spelling
 are assessed in a simple,
 nonthreatening format that
 requires only a pointing
 response for most items.
- Stanford-Binet Intelligence Scales. This measures several types of reasoning, knowledge, and memory testing both verbally and nonverbally in order to accurately assess individuals with deafness, limited English, or communication disorders.

- Wechsler Intelligence
 Scale (WISC). This is an
 intelligence test for children
 between the ages of 6 and
 16 that can be completed
 without reading or writing.
- Woodcock-Johnson III (WJ III). This consists of two distinct batteries. Together they provide a comprehensive system for measuring general intellectual ability.

Speech and Language Tests

Speech and language issues are not separate from academic concerns, as speech and language form the basis for a child's ability to understand what is heard and to respond meaningfully. Children who have difficulty expressing themselves with spoken words may have difficulty putting their thoughts into words on paper. There are many tests that can assess whether your child has trouble with receptive language (understanding what is heard) or with expressive language (making oneself understood to others).

Understanding Scores

By examining your child's scores on norm referenced tests over time you will be able to gauge whether your child is attaining the goals or milestones with his peer group or falling behind. A criterion referenced test can show if your child's score improves each year. However, if your child is steadily losing ground compared to peers, you may want to make some key changes to the IEP.



"Battery" refers to a grouping of similar things intended for use together, such as achievement tests.

"Cognitive" refers to conscious intellectual activity such as thinking, reasoning, imagining, remembering, or learning words.

"Criterion referenced tests" will tell you if your child achieved a certain mark (e.g., if your child can count to ten), but it will not give you information about how your child compares to his or her peers.

"Normed tests" are those that compare your child's score to those of other children within the same peer group. This is usually age based, but may be grade based as well.

Grades given by teachers are an important piece of information, but may be quite subjective. Remember your teacher may give your child better grades than his or her work deserves out of kindness, as a reward for sincere effort, or because failing grades will increase the pressure on the teacher. For a clear picture of your child's progress, standardized norm referenced tests are a good evaluation tool.



Many parents find IEP and eligibility meetings to be positive and productive, as teachers and educators care deeply about each child's success.

If there is a steady decline in your child's progress as compared to peers, and you believe that a more effective educational plan could change it, consider making a chart of your child's standardized test scores. Bring the chart to the next IEP meeting as a visual image sometimes has more impact than spoken words.

The composite score is the combination of all subjects assessed and may be misleading as it will not show variation between subjects. The composite score will not show you variation between subjects. Beware of looking only at composite scores from the battery of tests your child has taken. If you have a child with an obvious strength in one area and a weakness in another, the scores may blend into an average composite score that seems to show that your child is of average capability and offers no explanation for any educational frustration. If you look at the sub tests scores you might see that your child has an area of weakness that is interfering with his or her education.

The Bell Curve and Standard Deviations

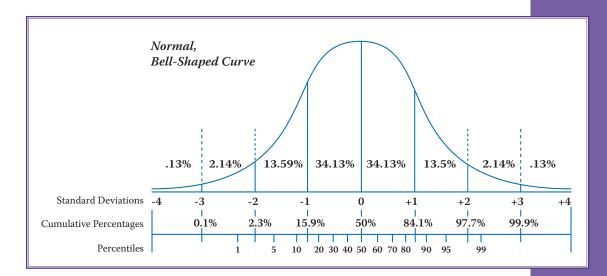
The bell curve is a visual way of organizing data, in this case test scores. The center of the bell, where it is the highest, shows the average test score or the fiftieth percentile. Those who did better than the average score will fall to the right of center and those who did less than the average score will fall to the left. So, within the bell curve you will find the entire spectrum of scores of

the population that was tested. As there are few children who do very well or very poorly, the size of the bell diminishes as it moves outward.

To describe how far a score falls from the center, or average, we use standard deviations. The phrase "standard deviation" refers to the distance between a certain score and the average score. The average score will be in the center of the bell at 0 standard deviations. The next markers move away from the center and are -1 and +1, -2 and +2, and -3 and +3. The percentage of scores that fall between the deviations is always the same, so that between -1 and +1 standard deviation is where 68% of the population will fall. In a normal distribution, about 68% of the scores are within one standard deviation of the mean and about 95% of the scores are within two standard deviations of the mean. So, if your child scored at the +1 standard deviation, she has scored at the 84th percentile.

Independent Educational Evaluations

Before an IEP or eligibility meeting, ask for copies of any new evaluations. If you think that the evaluation conducted by the school is either out of date or incomplete, you have several options. You may ask your school to re-administer a test, or have it administered by another person. If you are still dissatisfied, you can request an independent educational evaluation (IEE) of your child at public expense.



You do not have to prove that the school's evaluation was faulty. You are entitled to an independent evaluation if there is reason to believe the initial evaluation is incomplete or inaccurate. An IEE may evaluate any skill related to your child's educational needs. The school may not agree to this independent evaluation and may choose to hold a hearing during which they will try to show that the initial evaluation was valid and complete. Unless they do this, the school system cannot deny your request for a new evaluation. A sample letter requesting an independent evaluation can be found in module two, Special Education, of this Parent Tool Kit.

If, after a hearing, the school system is not required to pay for an independent educational evaluation, you may still choose to have your child evaluated independently at your own expense. Private evaluations are not cheap, but can be very useful. School district evaluations are school

district material, and in the case of an independent hearing they are important evidence. You may be reassured if the independent testing reinforces what the school system has found or dismayed if there is a discrepancy, but you need not question the veracity of the independent evaluation.

IEP and Eligibility Meetings

IEP and eligibility meetings can be emotionally laden. Even if you have a good relationship with your child's teachers and school system, learning that your child is lagging behind his or her peers can be a devastating blow. On the other hand, trying to convince the school system to provide services for



IDEA requires that independent evaluations must be considered when writing an IEP.



It is a good idea to read and become familiar with the results of any evaluation well before the IEP meeting. You cannot expect to read and understand complex assessments at the same time you are trying to be a meaningful participant in a meeting.



You may want to audio tape the meeting, especially if there is no one to accompany you. The IDEA statute does not mention tape recording meetings, but many states have regulations about this. Contact your Parent Training Center for state specific information. If your state allows for taping meetings, you should still notify the school district in advance of your intentions.

your child when the school system is resistant can be profoundly frustrating as well. Keep the focus on your child, and not on the school district's resources or any individual personalities in the room. There may be tension between your wishes and expectations as a parent and the school district's resources. As a parent, you want the best for your child. But the school district must provide services from within a clearly stated budget.

If both parents cannot attend the IEP meeting, it is a good idea to bring a friend or family member who has experience with your child to the meeting. The moral support can be invaluable. Also, when the meeting is over it is very helpful to have someone who was there and who can offer a different perspective with whom you can discuss the meeting.

Writing an Effective IEP

To write an effective IEP, you must first have an accurate understanding of your child's present level of achievement and functional performance. By reviewing the assessments your child has taken, you will be able to see the areas of need that arise as a function of your child's disability. Have a clear idea of your ultimate goals for your child. What are the steps that your child must take to reach these goals? Think about the skills your child needs to progress. What does your child need to learn? Does your child need to learn to communicate, to get along with peers, or to read?

	Checklist for Eligibility				
	and IEP Meetings				
	A picture of your child and family.				
	A list of questions you have developed over time.				
	Copies of prior evaluations.				
	Records from Early Intervention, if your child participated.				
	Pertinent medical records.				
	Paper and pen for taking notes.				
	A friend or family member for company and moral support.				
	A sweet snack to share.				
	A tape recorder if you want to record the meeting.				
	Knowledge of procedural safeguards				
_	prior to the meeting.				

A good IEP will specifically identify the following:

- Areas where growth is needed.
- Activities and services the child will receive to help encourage growth and learning.
- How often your child will participate in these activities and where.
- How your child's progress will be measured, and at what intervals.

A well constructed IEP will state goals and objectives that are well defined and measurable. "Joey will improve his reading and skills" is not specific, does not give a time limit, and does not tell us how the improvement will be measured. Better would be an IEP that states,



The IEP cannot be a general statement about what your child should accomplish in a year. It must be a detailed document that identifies your child's areas of need and describes how the school will meet these needs, the time frame involved, and the method that will be used to measure your child's progress.

"In six months time, Joey will increase reading skills to the third grade level, as measured by..."

Disagreements

If an IEP that was completed before the meeting began is presented keep in mind that you have a right to participate in the development of your child's IEP. Consider and refer to this IEP as a draft. If you feel pressured to sign it, simply remind the other members of the committee that you need time to read and digest such an important document, and that you will need a copy to take home with you.

If you have serious concerns about the IEP, put them in writing and return them to the school along with the unsigned IEP. You may want to request another IEP meeting. An IEP meeting request sample letter is in module two, *Special Education*, of this Parent Tool Kit. Remember that your child cannot begin to receive services until you have given permission. If necessary, you can agree in writing to part of the IEP, but not all. This way your child can begin to receive the agreed upon services.

It may happen that the meeting ends before you have finished the IEP. The school may ask you to sign this. You are taking a risk if you sign an unfinished document. Consider saying you are not ready to sign such an important document yet and would like wait until it is completed before you read it over and sign it.



The IEP is a needs driven process; you must help define your child's needs or the school system will do it for you.



If the school system says a certain course of action is prohibited by law or regulation politely ask for help identifying this law or regulation.

Should any of these disagreements occur, you may request an administrative review within the school system. If this is not available or if the results are not satisfactory, you have two options: mediation or due process.

- Mediation is a process that resolves disputes without litigation. When you mediate you have two goals: to resolve the dispute and to protect your relationship with the school system.
- Due process hearings are conducted differently from state to state; however, they provide an opportunity to have your complaint heard in an impartial hearing.

 Before the hearing takes place, the school must hold a Resolution Session to give the parties a chance to resolve their differences before the hearing.

You may request mediation or a due process hearing, or you may request both at the same time. This will accelerate the process and lessen the amount of time your child must wait for an appropriate education. Your state Parent Training Center (www.taalliance.org) can help.

If you are involved with a DoD school, you can find the details about your rights in DoDI 1342.12, The Provision of Early Intervention and Special Education Services to Eligible DoD Dependents (www. dtic.mil).

Even if you are considering it, avoid threatening to ask for a due process hearing. The school has heard this many times before, and the threat is unlikely to have the effect you hope for. Also, on further reflection you may decide you do not want to file for due process after all.

Benefits Advocacy

In addition to the benefits available to military families, there are also federal and state benefits that your child may be eligible for.

Supplemental Security Income (SSI)

SSI is a monthly payment to those with low incomes and few resources who are 65 or older, blind, or disabled. Children may qualify. If



If your application for benefits from a government agency is denied, or if your benefits are reduced, the agency involved must offer an appeals process, as well as a detailed explanation of their decision. For helpful information about responding to a denial or reduction in government benefits see the article "Your Medicaid or SSI Benefits were Terminated—Now What?" that can be found in EP MAGAZINE at www.eparent.com.

you think you or your child might qualify, visit your nearest Social Security Office or call the Social Security Administration Office at 1-800-772-1213. If your application is denied, it is good practice to appeal the decision. Keep in mind that the appeal should be timely, no later than 30 days from the date of the notice or 10 days if you are requesting to receive benefits during the appeal. This is referred to as "aid paid pending." Be aware that you may be asked to repay the benefits if the outcome is not in your favor. Also, as you move from state to state you will find that eligibility requirements vary.

Medicaid

Medicaid is a program that pays for health care for some individuals and families with low income and few resources. Medicaid is a national program with broad guidelines, but each state sets its own eligibility rules and decides what services to provide. Be aware of this as you move from state to state. States can also choose to cover other groups of children under the age of 19 or those who live in higher income families.

Many states qualify children though a program called TEFRA (Tax Equity and Fiscal Responsibility Act of 1982, also known as the Katie Beckett Waiver) or the Home and Community Based Waiver. These programs allow children to qualify without considering their parents income. To find information on Medicaid and Medicaid waivers in your state go to www.cms.hhs.gov.



In many states, eligibility for SSI qualifies the individual for Medicaid.

Military families who are struggling with the cost of care for a disabled family member should consider applying for Medicaid. Benefits may exceed those offered by TRICARE. To apply, contact www.cms.hhs.gov/medicaid.

Teaching Your Child to Self Advocate

As a parent you know how important it is to teach your child as much as possible about taking care of his or herself. This may mean teaching personal hygiene, how to safely cross a street, or how to avoid a classmate who always causes trouble. Teaching self advocacy is not very different. If we expect our children to grow as people, we must give them the chance to speak for themselves and to make their own decisions.

Self advocacy begins with teaching your child to ask for help and to accept responsibility for his or her own actions. Part of this is being an active participant in planning his or her life. It means helping your child feel confident enough to speak out when something is bothering him or her. This can be

parent parent

"The reality is that our children are likely to outlive us. If we don't give them the skills to survive when we are gone, what are we doing?"

~Heather, mom to two sons, one with downs syndrome and one with learning disabilities, Ft. Lewis, WA



practiced at home or at school. Self advocacy can take many forms, such as explaining to a new teacher the need to tape record the lesson, informing the waiter that he made a mistake on the order, or learning to use public transportation. It can begin with letting your child pay for purchases or plan a birthday party. It is very important for students with disabilities to develop or improve self-advocacy skills because they will need these skills in all life settings.



Unlike the special education system, a person with disabilities does not automatically get free vocational rehabilitation services. A person must meet certain qualifications, and some agencies charge fees for their services. Because there is no central system of adult services like there is for special education, a student and his or her family may need to deal with a complicated assortment of adult services and government programs.

The transition process at your child's school can help. Transition is when the focus of your child's education begins to shift from identifying and working to minimize your child's challenges to looking toward the future and exploring what it will take for

your child to learn a job or live on his or her own. Your student should be an integral part of this process, expressing needs, wants, and desires. To have a full life, your child must be part of the plan. For more information about transition see module two, *Special Education*, of this Parent Tool Kit.

One of the most important adult services is vocational rehabilitation and is available through your state. Vocational rehabilitation services include planning, assistance, support, and training to help disabled people get ready for and find a job. Most states have a vocational rehabilitation agency with regional offices that provide these services. If you know you will retire in a different state, contact them. Remember that waiting lists for assisted living homes can be years long. Contact your state Parent Training Center (www. taaliance.org) to find out what programs are available in your state.

Influencing Public Law

With day to day life as full as it is, keeping track of new and proposed legislation may be low on your list of things to do; however, you have the power to influence the legislation that will impact your child's education, health, and quality of life.

What can a busy parent do? The first step is to be informed. Many parents find list serves a place to not only share tips on how to get through the day, but also a place

to become informed about public issues that may affect their child. Your state Parent Training Center is another source to ask about current issues.

When an issue of importance to you comes up, a quick phone call or a one-page letter to an elected official's office is all it takes to express a view. Elected officials pay attention to communications from constituents. Tell your family's story. If you are sending a letter or an email, include a picture of your family. This will put a face on the issue at hand for your representative who will likely know the details of the legislation but may need to hear about how it will affect the lives of his or her constituents.

Parents can share personal stories about what public education and other health government services have done for their family. In addition, they can explain about their need for additional services and funding.

For More Information

Obtain the other modules of this Parent Tool Kit at www. militaryhomefront.dod.mil/efm or from your EFMP coordinator.

- Module One, Birth to Age Three
- Module Two, Special Education
- Module Three, *Health Benefits*

- Module Four, *Families in Transition*
- Module Six, Resources and Support

Seek Other Parents of Children with Disabilities

The Exceptional Family Member Representative can help you find other families who have faced similar challenges. The knowledge that you are not alone can be of great comfort. Find your EFMP representative through your Family Service Center at www. militaryhomefront.dod.mil/directories.

Also available through Military Homefront is the Family Connections Forum at www. militaryhomefront.dod.mil.

Contact STOMP

Specialized Training Of Military Parents (STOMP) is a valuable resource. They provide support and advice to military parents without regard to the type of medical or educational condition the child may have. STOMP also has many excellent publications on their website. You can join their list serve and correspond with other parents of specially challenged children. Go to www.stompproject.org or call 1-800-5-parent.

Find Your State Parent
Training and
Information Center
Each state is home to at least one
parent center (www.taalliance.
org/centers). Parent centers serve

families of children and young adults from birth to age 22 with all disabilities: physical, cognitive, emotional, and learning. They help families obtain appropriate education and services for their children with disabilities; work to improve education results for all children; train and inform parents and professionals on a variety of topics; resolve problems between families and schools or other agencies; and connect children with disabilities to community resources that address their needs.

Books

From Emotions to Advocacy, second edition by Pam and Pete Wright (This is an excellent source for advocacy information.)

Writing Measurable IEP Goals and Objectives by Barbara D. Bateman and Cynthia M. Herr

The Goal Mine: Nuggets of Learning Goals and Objectives for Exceptional Children (Paperback) by Donald Cahill, Maureen Cahill

How Well Does Your IEP Measure Up? Quality Indicators for Effective Service Delivery by Dianne Twachtman-Cullen and Jennifer Twachtman-Reilly with foreward by David L. Holmes, Ed.D.

The Complete IEP Guide, 4th Edition; How to Advocate Your Special Ed Child by Attorney Lawrence M. Siegel

EP Magazine www.eparent.com

Resources and Support

Introduction CtiOn

Life in the military is challenging. When you have a child with special needs it is even more so. Families in the military have an array of resources available to them, from within and beyond the military community. Help yourself and your family by becoming educated about the support services and resources that are available.

Military Community Resources

Family Support Centers (FSC)

Family Support Centers throughout the military exist to help military families. Most military installations have Family Support Centers that offer a variety of free services and support designed to assist service members and families with the unique challenges of military life. Available offerings may vary due to the size and mission of the installation. Types of assistance offered may include the following:

- Relocation counseling and lending lockers.
- Information and referrals for special needs.
- Employment workshops.
- Volunteer coordination.
- Parenting classes.
- Individual and family counseling.

- Personal financial management.
- Spouse education and support programs.
- Deployment support.
- Family life education and workshops.



When military members are in receipt of orders to a new duty station, they can request and be assigned a sponsor. Ask the EFMP coordinator at your new duty station for a sponsoring family with similar special needs.

Family Support Centers can connect you with the Exceptional Family Member Program. This will ensure that your child's medical and educational needs will be considered as a duty station is



There are resources and referrals available from the Child Development Center to help parents find childcare when arrangements cannot be met on the installation.

selected. Your FSC is also a good place to ask for information about local organizations and support groups concerned with specific disabilities. To find the Family Support Center nearest you, go to www.militaryhomefront.dod.mil/directories.



Most military installations have special resource teams to help parents of special needs kids find appropriate child care. The purpose of this team is to explore childcare and youth activities for children with certain special needs who are involved in installation childcare or youth programs. The Army calls this service the Special **Needs Accommodation Process** (SNAP), the Navy and Marines use Special Needs Resource Team (SNERT), and the Air Force does not have this service.

New Parent Support Program

The New Parent Support Program (www.militaryhomefront.dod.mil) assists expectant and new parents through a variety of services.

Services are matched to the needs of individual families and include home visitations, education, counseling, and referrals to other resources to include special needs organizations and services aboard the installation and within the

local community. Parents who take advantage of the classes offered will gain hands on training that will help them make informed and responsible decisions for their children.

Family Advocacy Program (FAP)

The military community is not immune to personal or family problems. Problems may range from experiencing stress due to a deployment to experiencing domestic violence including spouse or child abuse. Fortunately, vital services and support are available to military families. FAP sponsors activities and services to include public awareness briefings, individual and couples counseling, crisis intervention, support groups, stress management, and other well-being workshops. FAP services may be found at military medical facilities or at installation Family Support Centers. For more information, go to www. militaryhomefront.dod.mil/ directories.

Child, Youth and Teen Development Programs

Military families face greater challenges than most other families. Shifting work schedules that are often longer than the typical eight hour day and the obligation to be ready to deploy anywhere in the world on a moment's notice requires a child development system that is flexible, yet maintains high standards. Add to these challenges

a child with special needs, and finding quality childcare can be a formidable challenge.

- Child Development Centers. DoD Child Development Centers (CDCs) provide care for children 6 weeks to 12 years of age. To help ensure the needs of your exceptional child are met in the daycare setting, the Army, Navy, and Marine Corps offer special needs resource teams. Contact information for all DoD CDC's is available at www. militaryhomefront.dod.mil.
- Family Child Care (FCC). FCC homes operated on base are certified by the military child development program. These providers deliver critical services to service members on shift work, working extended hours or weekends, and for those who prefer a homebased environment for their children. A family childcare home may be the best option for special needs children who need the consistency of a single caregiver or who require complex procedures that must be learned by the caregiver.
- Youth Centers. Ask about available youth programs at your FSC. You will find an array of programs that will help your child become involved and make friends. Frequently available are

- sports leagues for soccer, basketball, and baseball and a center where your child can play Ping-Pong or video games. For information regarding Child Youth and Teen services contact www. militaryhomefront.dod.mil.
- Summer Camps and Recreation. Several bases have special camps and activities for children with special needs. Camp Lejeune offers Camp Special Time several weekends a year, giving parents some well deserved time off. Fort Campbell offers Camp We Can. Ask about what is available on your base and in your community.

School Liaison Officers

The Army sponsors a program providing a school liaison officer at each Army installation whose role is to work with local schools in support of children from military families. The School Liaison





Ask your CDC about summer camps and activities. You may find an array of activities for your children ranging from sports camps to fishing tournaments.

Officer is particularly helpful when a student is transitioning from one school system to another and may be able to advocate on the parents' behalf when they believe their child's special education needs are not being met. For more information about this program, go to www.militarystudent.dod.mil.

Relief Societies

Military communities pride themselves on taking care of their own. Relief societies exist to help families with unexpected problems or financial emergencies. Help may be available for the following needs:

- Emergency transportation.
- Funeral expenses.
- Disaster relief assistance.
- Childcare expenses.
- Essential vehicle repairs.
- Unforeseen family emergencies.
- Food, rent, and utilities.
- Medical/dental bills (patient's share).

Each of the Armed Forces has established its own relief society.

Army Emergency Relief Society www.aerhq.org 1-866-878-6378 Navy/Marine Corps Relief Society www.nmcrs.org/intfreeloan.html 1-703-696-4904

Air Force Aid Society www.afas.org 1-800-769-8951

Service Sponsored Websites

Each branch of the military sponsors a website that provides an overview of programs and support available to military personnel and family members. These websites also provide news articles and information relating to life in the military and online tutorials.

U.S. Army MyArmyLifeToo.com www.myarmylifetoo.com

U.S. Navy LIFELines Services Network www.lifelines.navy.mil

U.S. Marine Corps Marine Corps Community Services www.usmc-mccs.org

U.S. Air Force Air Force Cross Roads www.afcrossroads.com

Additional Military Resources

MilitaryHOMEFRONT's
Special Needs/EFMP Module
Military HOMEFRONT's (www.
militaryhomefront.dod.mil/efm)
Special Needs/EFMP module is
the Official Department of Defense
website that was designed to help
troops and their family members

who have special needs. This site is packed with information. MilitaryHOMEFRONT maintains a Military Community Directory that has a searchable list of family center addresses, websites, phone numbers, and email addresses world-wide. Here you will also find resources to support the following:

- Exceptional Family Member Program.
- Parenting.
- Relocation.
- Tip sheets.
- Military Spouse Resource Center.
- Military Saver.
- List of benefits and services.
- Pre-separation guide.
- Military Teens on the Move.
- General legal information.



For access to a vast amount of information on a wide variety of support websites dealing with disease, disorders, and syndromes go to www. militaryhomefront.dod.mil/efm.



Do you need to talk? Military OneSource is available to you 24 hours a day.

From the US: 1-800-342-9647

International Toll Free: 1-800-3429-6477

International Collect: 484-530-5908

- Deployment connections.
- Employment and transition assistance.

Military OneSource

Military OneSource (www. militaryonesource.com) provides information, referrals, and assistance to the military community. Accessed by telephone or the Internet, Military OneSource provides special needs consultation, research, resources, and materials intended to enhance current military services available to families with special needs.

A Military Education Specialist is available and is devoted to military families who need assistance with issues related to educating your children. Services are provided on a scheduled appointment basis via telephone and are focused on special needs children ages

"The Military
OneSource
consultant
spoke to me
calmly and
with a good
sense of humor,
and helped me
find my sense
of humor. If
it weren't for
them, I probably would still
be stressing."

~Navy parent of child with behavioral challenges.



birth to 21. Specialty services can be accessed through the main telephone number for Military OneSource, and an appointment with a military special needs specialist should be requested.

Many tip sheets covering a wide range of topics of interest to military families with needs are available. All services are free of charge.

Military Teens on the Move (MTOM)

MTOM (www.dod.mil/mtom) is a website specifically for military teens and kids who are facing yet another move. Here they will find age appropriate information about how to deal with the feelings they have about moving, information about the new installation, and advice on handling the move and how to begin to fit in at their new home.

SITES

Visit SITES (www.dmdc.osd.mil) to create your own personalized Relocation Booklet. Read through the list of categories, topics, and tip sheets. Ask yourself questions about your particular moving needs. Will you be traveling separately from your family? What are the needs of your children? Do you have pets? Do you have elder care needs? Are you moving your own household goods? Then check the appropriate boxes to indicate which information you want to be part of your Relocation Booklet and click "submit." Your SITES booklet will then be prepared to download and print.

TRICARE

TRICARE offers several programs to assist families with special needs. Extended Health Care Option (EHCO) offers financial assistance and additional benefits for services, equipment, or supplies beyond those available through TRICARE Prime, Extra, or Standard. Also available is ECHO Home Health Care (EHHC). EHHC provides home bound family members with intensive home health care services. For more information, go to www.tricare.osd. mil or see module three, Health Benefits, of this Parent Tool Kit.

Federal, State and Community Resources

American Red Cross

Today's American Red Cross is keeping pace with the changing military. The Red Cross sends communications on behalf of family members who are facing emergencies or other important events to members of the U.S. Armed Forces serving all over the world. Both active duty and community-based military can count on the Red Cross to provide access to financial assistance, counseling and assistance to veterans, and emergency communications that link them with their families back home. Contact the Red Cross at www. redcross.org or 1-202-303-4498.

Computer/Electronics Accommodations Program (CAP)

The Computer/Electronic
Accommodations Program
provides assistive technology and
services to people with disabilities,
federal managers, supervisors, IT
professionals, and wounded service
members. "We buy it, we pay for
it, we get it to the users, it's just
that simple." — Dinah Cohen, CAP
Director. You can find additional
information about CAP's EFMP
initiatives at www.tricare.osd.mil/cap
or call 1-703-681-8813 (voice) or 1703-681-0881 (tty).

Disabilityinfo.gov

This website, www.disabilityinfo. gov, exists to connect people with disabilities to the information and resources they need to pursue their personal and professional ambitions. Disabled individuals can look here for information about travel, work place support and fair housing.

Cadre (National Center on Dispute Resolution)

Cadre encourages the use of mediation and other collaborative strategies to resolve disagreements about special education and early intervention programs. Cadre offers a spectrum of services including promoting ways to prevent conflict and help with early dispute assistance, education about conflict resolution options, mediation, resolution sessions, and due process hearings. To contact Cadre, go to www.directionservice.org or call 1-541-686-5060 (voice) or 1-541-284-4740 (tty) or send a fax to 1-541-686-5063.

Food Stamps and FSSA

The Food Stamp Program (www. fns.usda.gov) serves as the first line of defense against hunger. It enables low-income families to buy nutritious food with Electronic Benefits Transfer (EBT) cards. Food stamp recipients spend their benefits to buy eligible food in authorized retail food stores, including the commissary. To prequalify online, go to the website and click on "Pre Screening Tool."

Food stamps are not available for military families stationed overseas. However, you can apply for the Family Subsistence Supplemental Allowance (FSSA). Although



NICHCY welcomes communication in English or Spainish. this allowance does target those families currently using food stamps, all total force members may apply because it is based upon household income and family size, not whether one is currently receiving food stamps. Nothing in the law prohibits service members from receiving both FSSA and food stamp benefits at the same time. However, the FSP will count any FSSA benefits as income, just like any other military income in determining eligibility and allotment amounts under the FSP. For more information, go to www. dmdc.osd.mil.

Medicaid

Medicaid (www.cms.hhs.gov) is a program that pays for health care for some individuals and families with low income and few resources. Medicaid is a national program with broad guidelines, but each state sets its own eligibility rules and decides what services to provide. Be aware of this as you move from state to state. In most states, children who qualify for SSI will also qualify for Medicaid. States can also choose to cover other groups of children under the age of 19 or those who live in higher income families.

Many states qualify children though programs that allow disabled children to qualify without considering their parents income. To find information on Medicaid and Medicaid waivers in your state go to www.cms.hhs.gov.

National Center on Education, Disability, and Juvenile Justice (EDJJ)

EDJJ is concerned by the number of youth with disabilities at risk for contact with the courts or already involved in the juvenile delinquency system. They provide assistance, conduct research, and disseminate resources in three areas: prevention of school failure and delinquency, education and special education for detained and committed youth, and transition services for youth returning to schools and communities. For more information, go to www.edjj.org or call 1-301-405-6462.

NICHCY

NICHCY (www.nichcy.org) has a wealth of information on disabilities. NICHCY stands for the National Dissemination Cen

the National Dissemination Center for Children with Disabilities and serves the nation as a central source of information on the following:

- Disabilities in infants, toddlers, children, and youth.
- IDEA, which is the law authorizing special education.
- No Child Left Behind (as it relates to children with disabilities).
- Research-based information on effective educational practices.



NICHCY is a valuable resource for all parents of disabled children and is linked to the BrowseAloud text reader. This means all the information on this site can be read to you.

Shriners Hospitals for Children

Shriners Hospitals are a network of 22 pediatric hospitals in the U.S., Canada, and Mexico that provide specialized care for orthopedic conditions, burns, spinal cord injuries and cleft lip and palate. All services are provided at no charge.

If you know of a child, Shriners Hospitals might be able to help. Please call the toll-free patient referral line.

In the U.S.: 1-800-237-5055

In Canada: 1-800-361-7256.

Specialized Training of Military Parents

STOMP is the only National Parent Training and Information Center for military families that provides support and advice to military parents regardless of the type of medical condition their child has. The STOMP Project hosts a list serve for military families and professionals to use to share ideas. The list serve enables military families all over the world to connect, learn, and help each other as they raise their special needs children in military communities.

On STOMP parents can ask question and get answers about the resources available to them, as well as receive advice on educating their children and navigating the healthcare system. STOMP offers workshops addressing an array of topics. You can contact STOMP at www.stompproject.org or 1-800-5-PARENT (v/tty).



STOMP offers workshops addressing an array of topics. You can contact STOMP at www.stompproject.org or 1-800-5-PARENT (v/tty).

Supplemental Security Income (SSI)

SSI (www.ssa.gov) is a Federal supplement program that can provide a monthly payment to

those with low incomes and few resources who are 65 or older, blind, or disabled. Children may qualify. If you think you or your child might qualify, visit the nearest Social Security Office or call the Social Security Administration Office at 1-800-772-1213. If the application is denied, it is good practice to appeal the decision.

Women, Infants and Children (WIC)

The WIC website (www.fns.usda. gov) has a link to toll free numbers across the country. If you can't access the Internet, call the state Nutrition Counseling office or nearest military family support center. WIC offers nutritional help to women and children who are low-income and nutritionally at risk. This includes women who are pregnant, postpartum, or breastfeeding and infants and children up to their 5th birthday. WIC provides nutrition education, nutritious foods, as well as screening and referrals to other health, welfare, and social services.

Service members living overseas may be eligible to participate in the WIC Overseas program. For more information about this program, go to www.tricare.osd.mil/wic.

Wrightslaw

Parents, educators, advocates, and attorneys go to Wrightslaw (www.wrightslaw.com) for reliable information about special education law and advocacy for children with disabilities. Wrightslaw includes thousands of articles, cases, and free resources on dozens of special education topics. This an excellent source for parents who are learning to navigate through the Special Education System.

Resources for Families with Seriously Ill or Hospitalized Children

Fisher House

Members of the military and their families with loved ones who are hospitalized because of illness or injury must often travel far from home for specialized medical care. To help ease this difficult time, Fisher House[™] Foundation donates "comfort homes," which are built on the grounds of major military and VA medical centers. There is at least one Fisher House[™] at every major military medical center providing families in need with the comforts of home in a supportive environment. The average cost of staying at a Fisher house is less than \$10 a day, and many locations offer rooms at no cost. For more information, go to www.fisherhouse. org or call 1-888-294-8560.

Make-a-Wish Foundation

The mission of the Make-A-Wish Foundation® is to grant the wishes of children between the ages of 2½ and 18 with life-threatening medical conditions. Children must be referred to the Foundation and determined to be medically eligible for a wish by their physician. All wish expenses are fully covered, and family income is not a consideration in determining whether a child is

eligible to receive a wish. Contact Make-A-Wish at www.wish.org or call 1-800-722-WISH(9474).

Starlight Starbright Children's Foundation

Starlight Starbright Children's Foundation is a non-profit organization dedicated to making a world of difference for seriously ill children and their families. Starlight Starbright softens the hard edges of what a family experiences when a child has a serious illness. They work hard to meet a family's needs by building playrooms and teen lounges in hospitals and providing PC Pals and Fun Centers so kids can play games, e-mail, chat with friends, and even do their homework from their hospital bed. They bring in entertainers and sponsor parties for kids who are in the hospital. When the kids get to go home, Starlight Starbright helps keep them connected through online chat rooms and special outings for the entire family. For more information, go to www.starlight.org or call 1-800-315-2580.

A Special Wish Foundation

A Special Wish Foundation, Inc. is a non-profit charitable organization dedicated to granting the wishes of children who have been diagnosed with a life-threatening disorder. A Special Wish Foundation is the only major wish-granting organization in the United States that grants wishes to qualifying infants, children, and adolescents from birth through and including the age of 20 years.

For more information, go to www. spwish.org or call 1-800-486-WISH(9474).

The Dream Factory

The Dream Factory, Inc. began with an idea to create a volunteer organization dedicated to granting the dreams of children with critical or chronic illnesses. Currently, there are more than 30 chapters across the United States with over 5,000 volunteers who work to produce and deliver dreams, visit children and their families in the hospital and their homes, arrange special celebrations, and conduct fundraising events for individual children. For more information, go to www.dreamfactoryinc.com or call 1-800-456-7556.

Give Kids the World Village

Give Kids the World Village is a non-profit resort that creates magical memories for children with life-threatening illnesses and their families. Wish-granting organizations coordinate transportation to Orlando, while Give Kids the World provides accommodations at its whimsical resort, donated attractions tickets, and meals for a week-long fantasy vacation. For more information, go to www.gktw.org or call 1-800-995-KIDS(5437).



I Spoke With	Phone Number	none Log	
-	Filone Number	Date	What We Discussed

Records and Tools

	for Special Education uest for Evaluation		
	Date:		
Director of Special Education			
School District			
School			
Dear:(Director of Special Educ	cation)		
Re: <u>(Child's name)</u> (Date of Birth)	- -		
	ommittee on special education. I am requesting a areas of suspected disability and specifically in the		
Some of my concerns are based on:			
If the school district agrees to evaluate my child, I understand I will be presented with a written evaluation plan within fifteen (15) days and that the plan will identify for me the tests to be given, dates for the tests, and the names of the persons who will administer the tests, as well as explanations of the tests and their purposes.			
	Sincerely,		
	Parent/Guardian Signature		
	Parent/Guardian Printed Name		
	Address		
	City, State, Zip Code		
	Telephone Number		
Received by:	Date:		

1	7	٢	١	(
I	U	L	J	D
		7		

Reques		
	Date:	
Director of Special Educat	ion/Principal	
School District		
School		
Re: <u>(Child's Na</u> (Date of B (School)	rth)	
Dear:(<u>Director of Spe</u>	cial Education)	
sufficient to guide the IEP placement.	nts are flawed in their accuracy or completeness they are noted team to an appropriate identification of disability, services, ssments, I disagree with the following:	
sufficient to guide the IEP placement.	team to an appropriate identification of disability, services,	
sufficient to guide the IEP placement.	team to an appropriate identification of disability, services, ssments, I disagree with the following:	
sufficient to guide the IEP placement.	ssments, I disagree with the following: Sincerely,	
sufficient to guide the IEP placement.	ssments, I disagree with the following: Sincerely, Parent/Guardian Signature	
sufficient to guide the IEP placement.	Sincerely, Parent/Guardian Signature Parent/Guardian Printed Name	
sufficient to guide the IEP placement.	Sincerely, Parent/Guardian Signature Parent/Guardian Printed Name Address	

Request for School Records			
	Date:		
Director of Special Education or Pri	incipal		
School District			
School			
Re: (Child's name) (Date of Birth) (School)			
Dear: (Director of Special Educ	ation or Principal)		
I am developing a personal home file for my Child's Special Education information. I am requesting a complete copy of all school records, cumulative and confidential, within the school district that contains my child's name,			
Please include copies of all evaluations and actual test scores, the Cumulative Record, Health Record, Disciple Record, Psychological Record, Confidential Record, Assessments, Individual Educational Plans, and Teacher Record.			
_	for this service, please alert me as soon as possible. y request contact me at		
	Sincerely,		
	Parent/Guardian Signature		
	Parent/Guardian Printed Name		
	Address		
	City, State, Zip Code		
	Telephone Number		
Received by:	Date:		