

Introduction

Introduction to Module 5

As the parent of a child with special needs, you have been working to understand your child's special needs. You may not realize it, but you are probably already advocating for your child. Advocacy is learning 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 to which he or she is entitled.

Remember as you advocate for your child that you are the best person to decide what your child may need. Talk to other parents, but trust yourself. Keep a positive perspective. Understand that while your child may not be entitled to every intervention that he or she could benefit from, the health care 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 health care provider or the school system, effective communication is the cornerstone of successful advocacy. Speak clearly, smile when you can, and remember that a pleasant attitude is much more productive than a negative one.

Stay Cool, Communicate Clearly

Good communication includes direct eye contact, an even and modulated voice, and open body language. When interacting with medical professionals and school personnel, be aware of your emotions. You may be anxious or worried. Keep your demeanor as positive as you can. If you are pleasant to work with, you will draw more people to your way of thinking. There is a difference between being polite to someone and agreeing with him or her. Remaining calm, pleasant, and focused can be a challenge for parents who are working hard on their child's behalf.

If you do not understand or agree with what someone has said, politely ask, "Did I understand you to say that _____?" This can clear up a misunderstanding early on or help define an area of disagreement. Do not be embarrassed to ask for further explanation. It is a parent's



Whenever possible, address your letter to a specific recipient, rather than "To Whom It May Concern." This may require a few phone calls ahead of time.

job to understand as much as possible about his or her child's education and medical condition. Look for common ground and be sure others 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 being resolved as you had hoped, remain calm. You do not want to be seen as unreasonable, inconsistent, or volatile. Angry outbursts will undermine your credibility and 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 writing, but if you are not, the following tips can help you write an effective letter:

- use clear, everyday language
- keep it brief
- state your purpose in the first paragraph
- explain what action you would like to see
- finish the letter politely
- include contact information

Remember that once the letter is mailed, you cannot take it back. If you write the letter 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 (i.e., furthering your child's education or ensuring appropriate health care).

If you do not receive a reply after two weeks, write again and include a copy of the first letter. If this letter brings no response, go higher up the chain of command.



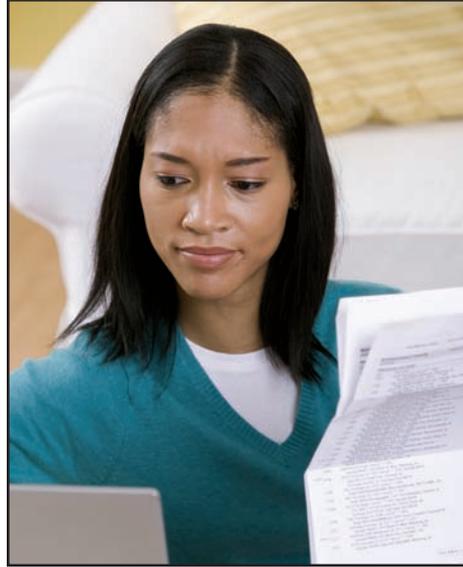
When you need clarification on the information provided by health care providers and professionals, do not hesitate to ask any questions you may have to ensure that you understand the information.



Advocacy is a thoughtful activity. Parenting is an active and emotional activity. Blending the two can be difficult. When done well, educated, organized, and loving parents become formidable advocates.

Getting Organized

Corresponding with health care 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. Each move brings the possibility of lost paperwork. You will need a system for organizing this paperwork because it is a crucial component of effectively advocating for your child.



For those with only a few papers, this might be as simple as a folder to keep letters from the school. Other people might have multiple binders. 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 to contact for 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.

The Special Care Organizational Record

The Department of Defense (DoD) Special Care Organizational Record (SCOR) for Children with Special Health Care Needs is a tool for caregivers, providing a central repository for recording and tracking information about their family member's ongoing support and health needs. Families can use their SCOR in a number of ways:

- track changes in medicines or treatments
- list telephone numbers for health care providers and community organizations
- prepare for appointments
- file information about health history
- share information with primary care doctors, school nurses, day care staff, and other caregivers

Keeping organized records will help you become a more effective advocate.

Each SCOR can be tailored to the unique needs of your family member. For example, the SCOR includes sections for copies of a child's Individualized Family Service Plan (IFSP) or Individualized Education Program (IEP) paperwork.

Military families can order a hard copy of the SCOR for Children with Special Health Care Needs from Military OneSource by calling (800) 342-9647. The hard copy of the SCOR also comes with a CD that has the SCOR and the *DoD Special Needs Parent Tool Kit* files included. The SCOR comes in a professionally designed binder that has pockets for business cards, receipts, and other important items. You can also download a copy of the SCOR from MilitaryHOMEFRONT at www.militaryhomefront.dod.mil/tf/toolsforfamilies/scor.

Medical Records

Medical records can be requested from the military treatment facility (MTF). The first copy should be provided free of charge. The policy for receiving copies of records varies among facilities, but always make your request for records in writing. You may be asked to wait as long as six weeks to receive copies of your records.

Education File

The education file should contain your child's education history. [Module 2, Special Education](#), contains a sample letter for requesting your child's education records. You may want to start a photo record of your child on or in the binder, adding a school picture for each year. When creating the file, consider the following sections for organizing information:

- phone log
- assessments/evaluations
- IEP
- discipline reports
- report cards/interim reports
- correspondence to the school system
- correspondence from the school system
- immunizations and pertinent health records
- contact information for service providers and agencies



The phone log is an important component of your education file. The phone log is where you will keep notes regarding when and with whom you have spoken about appointments and health care coverage. A few notes jotted here will help you keep an accurate record.

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 regarding 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 thanking the school staff for speaking with you. For example, “Thank you for talking with me today about my daughter’s education. I understand that you have agreed to [action to be taken] 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 disability. Talk to your child’s health care provider and other professionals who know your child. Write down questions as they occur to you during the day, then ask them at the next appointment. Understanding your child’s condition may help you know what you can expect.

It may be empowering to learn all you can, but do not become overwhelmed with new information. Take time to adjust to the emotional impact of a new diagnosis. Remember that the diagnosis does not define your child.

Getting the Referral You Need

You and your health care provider can effectively request the equipment or specific therapy your child needs. For example, if you need durable equipment for your child, work with your health care provider to write a thorough and complete description of how the 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 ECHO Home Health Care (EHHC) is denied, the denial letter will include the specific information you need to determine eligibility for appeal. If eligible, information on where to send the letter of appeal and time limitations will also be included. The appeal process varies depending on the reason for the denial. Even if the letter states the decision is not eligible for appeal, you may want to question it anyway. Does the letter state the reason for the denial? Is it accurate? Can your child’s circumstances be explained more clearly to TRICARE? Ask your TRICARE regional contractor why you have been denied.

Your TRICARE regional contractor can assist you with appeals. You can also contact the Beneficiary Counseling and Assistance Coordinator (BCAC) at the TRICARE regional office or at your installation MTF. For more information, visit www.tricare.mil.

In your phone log, include the date of the conversation, the name of the person you spoke to, and a description of the conversation.

Post a description of your problem on HOMEFRONT-Connections and see how other families have handled similar situations.

Early Intervention Services

Families have legal rights when they participate in Early Intervention Services (EIS) provided in accordance with the Individuals with Disabilities Education Act (IDEA). These procedural safeguards and due process rights are intended to protect the interests of families and children with special needs, as well as the early intervention systems. Procedural safeguards are not a separate system but part of the provision of EIS. Each right and safeguard relates to your family's experience with EIS and communicates the law's principles of your role as informed members of the early intervention team. Your EIS procedural safeguards include the following rights:

- **Right to confidentiality and release of information** — The early intervention program cannot share information related to you and your child with anyone, unless you give your permission. In addition, your permission is needed for the early intervention program to obtain information and records from other programs or professionals.
- **Right to examine records** — You have the right to see anything in the early intervention program records about you and your child.
- **Right to prior written notice** — You must receive written notice, in advance, whenever EIS proposes to begin or change any services.
- **Right to understand** — You have the right to understand information about all EIS activities and written records. The early intervention program will provide the information in another language or way of communicating, if at all possible, so that you can be an informed team member.
- **Right to accept or decline services** — All EIS are voluntary. Before evaluation or services, you will be asked to give your consent in writing. You can accept or decline any or all EIS. If you do not choose to participate in one service, it will not affect services you choose to accept.
- **Right to disagree** — You have the right to disagree about any aspect of EIS your child and family receive. You also have the right to timely resolution of your complaints.
- **Right to continued services during dispute** — You and your child will continue to receive the EIS currently being provided during any type of dispute resolution.

Sometimes, parents and providers have different ideas about a child's EIS. If you find that you have a concern or a question, discuss it with your service coordinator or provider right away. You can ask to have an IFSP meeting at any time to talk about what is working or what may need to change. Talking together can solve most disagreements.

When a disagreement continues, all states and jurisdiction, as well as military Educational and Developmental Intervention Services (EDIS) programs, have a dispute resolution process or due process procedure. Mediation is generally offered as a voluntary first step to help you and the early intervention program reach an agreement that satisfies you both. When informal discussions do not work, you may submit a written request for a due process hearing. For specific information about state EIS procedural safeguards and due process procedures, visit www.nectac.org/topics/procsafe/stateonlinec.asp.



Avoid writing directly on original documents as you may need them for official business in the future. Instead, use stick on notes for your comments.

For information about military EDIS procedural safeguards and due process procedures, visit www.edis.army.mil/safeguards.htm.

Visit www.militaryinstallations.dod.mil for specific information about your local EDIS program.

Educational Advocacy

It is especially important to be aware of the legislation that affects how your children with special needs are educated.

Legislation

Module 2, Special Education, provides detailed information about the IDEA, the guiding special education legislation for school systems throughout the United States, its territories, and DoD schools. The IDEA ensures that all children with special needs have access to a free and appropriate public education (FAPE), that the rights of the child and of the child's parents are protected, and that teachers and parents have the necessary tools to help the child meet his or her educational goals.

Section 504 of the Rehabilitation Act is a civil rights law that protects qualified individuals from discrimination based on their disability. It prohibits organizations and employees from excluding or denying individuals with disabilities an equal opportunity to receive program benefits and services. The non-discrimination requirements of the law apply to public schools as well as employers or organizations receiving financial assistance from federal departments or agencies. These organizations and employers include many hospitals, nursing homes, mental health centers, and human service programs.

"As parents, we are our family's best advocates."

Katrina, mom to a daughter with Down syndrome, Quantico, VA

parent
to parent

Some children who do not qualify for special education under the Individuals with Disabilities Education Act may qualify for help under Section 504.

Under this law, individuals with disabilities are defined as the following:

- persons with a physical or mental impairment which substantially limits one or more major life activities
- people who have a history of, or who are regarded as having, a physical or mental impairment that substantially limits one or more major life, such as include caring for one's self, walking, seeing, hearing, speaking, breathing, working, performing manual tasks, and learning

Because Section 504's definition of disability is broader than the IDEA's definition, some children who do not qualify for special education under the IDEA may 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, visit www.militaryhomefront.dod.mil/tf/efmp.

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.militaryhomefront.dod.mil/tf/efmp.

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

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

The School System

One of the basic principles of the IDEA is that procedural safeguards must be in place to ensure the rights of children and their parents are protected and that clear steps are in place if there is a disagreement regarding the child's evaluation, eligibility, and instructional program. As a parent, you have the right to be a fully participating member of the school team throughout the special education process. You are encouraged to play an active role in your child's education and to know your rights within the special education process.

Parental Responsibilities

Along with your rights as a parent come responsibilities. By being actively involved in the education planning process, you can ensure your child receives the services he or she needs to succeed in school and at home:

- participate in meetings regarding your child and be prepared to discuss issues of concern
- ask questions to ensure you understand what is happening
- provide all relevant information needed for planning and program development
- let the school personnel know about any changes in your child's life, both positive and negative, including areas of growth, changes in health and medication, and difficulties your child is having
- educate yourself regarding the rules and regulations governing special education services

If you have any concerns related to your child's special education program, or at some point you disagree with a recommendation made by the school, several options exist to help you work effectively with the school to reach a resolution. The first step is to talk with your child's teachers. The school administrator is also available to assist in resolving issues at the school level. It is often easiest if you can resolve any concerns in the least formal setting. Strategies to assist you in facilitating an early resolution before moving to more formal steps in the dispute process include the following:

- **Organize your thoughts.** Before going into a meeting, ask yourself questions about the big picture. What is my perspective or point of view about the actual concern or potential dispute? How does this concern or dispute affect my child? What can be done that will improve the situation? How can I clarify the points of agreement and disagreement?
- **Consider the other side's perspective.** Listen carefully and try to consider the situation from the perspective of the teacher or the school. Give them an opportunity to explain their position and be sure you understand what they are saying. What is causing the school or teacher to take this position? What is getting in the way of resolution?
- **Reframe the issues.** Ask yourself how you can restate the problem in a way that does not place blame. How can this issue become more manageable? How can everyone share responsibility and credit for success?

As an active member of your child's special education team, you have a role in shaping his or her Individualized Education Program. For more information, refer to Module 2, *Special Education*.

Problem Solving

When the family and school do not agree on some issue affecting the child's education, it is important that both sides discuss their concerns and try to compromise. There are several informal approaches parents and school staff can use to help resolve the concern. The first option is to review the child's IEP and the second is to hold a facilitated IEP meeting.

Informal Problem Solving

Individualized Education Program Review

If you have concerns about your child's rate of progress, services provided, or your child's educational placement, you have the right to request an IEP meeting at any time. At this meeting, you can discuss your concerns with the school and, as collaborative members of the IEP team, work toward a solution that is agreeable to everyone.



It is most effective to resolve any concerns in the least formal setting possible.

The solution reached at the IEP review meeting does not have to be permanent. It is not uncommon for IEP teams to agree on a temporary compromise, such as to try out a particular plan of instruction or classroom placement, for a certain period of time. During that time period, you and the school can see how well the temporary compromise addresses your concern. This trial period will help you and the school come to an agreement that is comfortable for everyone and still meets your child's needs.

Facilitated Individualized Education Program Meeting

A facilitated IEP meeting is used to help IEP teams reach agreements. This meeting includes an impartial facilitator who is not a member of the IEP team, but rather is there to keep the team focused on developing the child's program while addressing concerns as they arise. The facilitator helps promote communication among the team members and helps support full participation of the parent and the school in working towards a solution to the stated concern. The facilitator does not impose a decision on the team. He or she clarifies points of agreement and disagreement, and models effective communication and listening skills for the team members. When disagreements arise, the facilitator encourages you and the school to look at new options. Most importantly, the impartial facilitator ensures that the meeting stays focused on the child.

When preparing for either IEP meeting, it is important to think about how concerns can be addressed. Ask yourself if there are assumptions that do not seem appropriate in this situation, how you and the school can build on each other's

goals and priorities, and what benefits for your child you can anticipate from working in partnership with the school.

In the event that concerns are not resolved through these informal approaches, you can take further steps to address them, including a formal conference, requesting mediation or a due process hearing, and filing a state complaint. Contact your school or the local education agency (district office) for information on your due process procedures. You can also contact your state Parent Training and Information (PTI) Center or your Community Parent Resource Center for information on the process for resolving disputes.

Formal Problem Solving

Conference

A conference provides you an opportunity to address your issues or concerns with a school administrator and your child's teachers or service providers. These conferences and other communications with the school are most productive when you can clearly explain your concerns and the changes you are requesting. You should work closely with school personnel to clearly define the areas of disagreement and possible solutions. When a conference produces mutually agreeable solutions, the school will prepare a memorandum for the record outlining the disagreements and explaining how the disagreements were amicably resolved. If the conference fails to produce a mutually agreeable solution, either you or school personnel may request mediation. You may also waive mediation and request a formal due process hearing.

Mediation

Mediation 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. You may request formal mediation with the assistance of a neutral third person to help you and the school reach agreement over disputes regarding your child's special education services. Mediation is voluntary and conducted at no cost to you. Discussions that occur during the mediation process are confidential and may not be used as evidence in any subsequent due process hearings or civil proceedings.

The National Center on Dispute Resolution (CADRE) encourages the use of mediation and other collaborative strategies to resolve disagreements. Visit CADRE at www.directionservice.org/cadre.

Due Process Complaint

A due process complaint is a written complaint filed by a parent or a school district involving any issue relating to the identification, evaluation, educational placement, or provision of a FAPE to a student with a disability. Due process complaints must be filed within two years of the issue in dispute, unless the state has set a different time limit.

Mediation leaves you and the school in full control of the process and permits both you and the school to achieve agreements to which you are both fully committed.

Resolution Session (Meeting)

The IDEA gives you the opportunity to meet with the school to explain your due process complaint and gives the school the opportunity to resolve your complaint. Within fifteen business days of receiving your petition requesting due process (also known as a complaint notice) a school must hold a resolution session. This session is a meeting involving you, relevant members of your child's special education team who have specific knowledge of the facts identified in the complaint, and a representative of the school system who has authority to make a decision concerning your complaint. The resolution session must occur unless both you and the school agree, in writing, to waive the resolution session or to participate in mediation instead of the resolution session.

Due Process Hearing

When conferencing and mediation have failed to satisfactorily resolve a disagreement involving your child's identification, evaluation, placement, IEP, or right to a FAPE, you or the school may request a due process hearing.

State Complaint

A state complaint is a written complaint that can be filed by any organization or individual claiming that a school district within the state has either violated a requirement of Part B of the IDEA (the part that includes all requirements regarding the delivery of special education services) or the state's special education laws or regulations. State complaints must be filed within one year of the alleged violation.

Independent Education Evaluation

If you disagree with the results of your child's evaluation, you have the right to request an independent education evaluation (IEE) at public expense. An IEE is an evaluation conducted by a qualified examiner who is not employed by the school responsible for your child's education. If you ask for an IEE, the school must provide you with, among other things, information about where an IEE may be obtained. [Module 2, *Special Education*](#), contains a sample Request for Independent Education Evaluation.

The school may grant your request and pay for the IEE, or it may initiate a hearing to show that its own evaluation was appropriate. If the school initiates a hearing and the final decision of the hearing officer is that the school's evaluation was appropriate, then you still have the right to an IEE but not at public expense. If you obtain an independent evaluation at public or your own expense, the school will consider that evaluation in any decision made concerning your child's FAPE. However, obtaining an IEE does not mean that the school must make

a decision consistent with the findings of your IEE. The school must consider all available information in making a decision affecting a child's eligibility, placement, IEP, services, or FAPE.

Revocation of Consent for Services

Parents may unilaterally withdraw their children from special education and related services by revoking their consent for the continued provision of all services or of a particular service. Your revocation of consent must be in writing. Discontinuing services is a change in the child's educational placement. When the school receives the revocation notice, they must notify you in writing before ceasing the provision of special education and related services. The notice will advise you of the following:

- changes in placement and services that will result from the revocation of consent
- whether the school believes that the withdrawal of services is inconsistent with the best interest of the child

Note: In order to modify the IEP, the special education committee must determine the removal of the service will not inhibit the child's right to a FAPE. If there is no agreement, the parent may use the due process procedure to seek a different ruling.

- the date on which the school will terminate the child's special education and related services
- the child may be disciplined as a general education student and will not be entitled to IDEA discipline protections
- parents maintain the right to subsequently request an initial evaluation to determine if the child has a disability and needs special education and related services; the child will not receive special education and related services until eligibility has been determined
- the school will not challenge, through mediation or a due process hearing, the revocation of consent to the provision of special education or related services

Helping Your Child Be a Successful Learner

Children enter school with a natural curiosity for learning and exploring their world. Learning experiences should be meaningful and relevant, helping children make connections between what is being taught and their own life and experiences. You can guide your child in exploring and drawing from educational experiences and applying this knowledge to daily life outside of the classroom.

In coordination with the classroom teacher, you can provide challenging opportunities at home that will maximize your child's achievement level.

Take an Active Interest in Your Child's Daily Life

Your child will be excited when he or she comes home from school each day. Take time to talk with your child about school experiences. Make it obvious that what he or she has to say is important. Ask yourself how you can help your child make these daily activities meaningful. Ask questions about activities and let your child explain what he or she did and how activities were completed. Your enthusiasm and interest will result in a positive attitude towards school.

Review Schoolwork

Your child will be proud of his or her schoolwork. Take time to look at it and to ask questions about how he or she went about completing it. Praise your child and emphasize that he or she should be proud of the work. If the work is unacceptable, guide him or her through considering how to make it better. Let your child know that making mistakes is normal, and that we should learn from our mistakes so that we can do a better job next time. Your child will be thrilled when you display his or her work in your home (e.g., hanging papers on the refrigerator).

Encourage Curiosity and Motivation

Your child will continue to explore the world and will have questions about daily discoveries. Encourage natural curiosity by helping your child find answers to his or her questions. Make learning fun and meaningful. If your child sees purpose in learning, he or she will be more likely to leap ahead and discover new interests.

Promote Understanding

For your child to fully understand the purpose of learning, he or she needs to realize how it applies to his or her own life. Help your child make this connection by providing experiences with clocks, money, calendars, following directions, reading signs or directions, writing short notes or lists, and word games.

Read, read, and read some more each day!

Be Prepared

Children who are organized are better equipped to learn. Develop clear homework habits and provide structure for your child. Set up a daily homework schedule. Be sure the work area is well lit and quiet. Having materials readily available maximizes learning time. Let your child take responsibility for completing homework. If he or she forgets the routine, a reminder is appropriate.

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 him 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 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 children with disabilities to develop or improve self-advocacy skills because they will need these skills in all life settings.

Benefits Advocacy

In addition to military benefits, your child may be eligible for federal and state benefits.

Supplemental Security Income

Supplemental Security Income (SSI) is a monthly payment for those with low incomes and few resources who are sixty-five or older, blind, or disabled. Children may qualify. If you think you or your child might qualify, visit your nearest Social Security Office or call the Social Security Administration at (800) 772-1213. If your application is denied, you should consider appealing the decision. Keep in mind that the appeal should be timely, no later than thirty days from the date of the notice, or ten days if you are requesting 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. As you move from state to state, keep in mind that eligibility requirements vary.

Medicaid

Medicaid pays for health care for some individuals and families with low income and few resources. It is a national program with broad



In many states, eligibility for Supplemental Security Income qualifies an individual for Medicaid.

“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 Down syndrome and one with learning disabilities, Ft. Lewis, WA

parent
to parent

guidelines, but each state sets its own eligibility rules and decides what services to provide. Keep this in mind as you move from state to state. States can also choose to cover other groups of children under the age of nineteen or those who live in higher income families.

Many states qualify children under the Tax Equity and Fiscal Responsibility Act of 1982, also known as the Katie Beckett Waiver or the Home and Community-Based Services (HCBS) Waiver. This allows children to qualify without considering their parents' income. To find information on Medicaid and Medicaid waivers in your state, visit www.militaryhomefront.dod.mil/tf/efmp/resources.

Military families struggling with the cost of care for a family member with a disability should consider applying for Medicaid and the Home and Community-Based Services Waiver. Benefits may exceed those offered by TRICARE.

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. You, however, 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 online discussion boards to be an invaluable resource for both sharing tips on how to get through the day and for becoming informed about public issues that may affect their child. Your state PTI Center can also be a great resource for current information on issues relevant to you and your family.

When an important issue surfaces, a quick phone call or a one-page letter to an elected official is all it takes to express your opinions and concerns. 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 for your representative who may know the details of the legislation but may need to hear about how it will affect the lives of his or her constituents.

You can share personal stories about what public education and other government services have done for your family. In addition, you can explain your child's need for additional services and funding.

For More Information

Read or download the other modules of this Parent Tool Kit at www.militaryhomefront.dod.mil/tf/efmp/toolbox:

- [Module 1, *Birth to Age Three*](#)
- [Module 2, *Special Education*](#)

- [Module 3, TRICARE® Health Benefits](#)
- [Module 4, Families in Transition](#)
- [Module 6, Resources and Support](#)

Seek Other Parents of Children with Disabilities

The installation Exceptional Family Member Program (EFMP) can help you find other families who have faced similar challenges. Knowing you are not alone can be a great comfort. Find contact information for your EFMP by visiting MilitaryINSTALLATIONS at www.militaryinstallations.dod.mil.

HOMEFRONTConnections

HOMEFRONTConnections, a DoD social networking site, provides a secure place where military family members with special needs can meet and interact online to share experiences, post pictures and videos, write blogs, and create discussion boards. Join an existing group or create your own. Visit HOMEFRONTConnections at <https://apps.mhf.dod.mil/homefrontconnections>.

Find Your State Parent Training and Information Center

Each state is home to at least one PTI Center. They serve families of children and young adults from birth to age twenty-two with all disabilities: physical, cognitive, emotional, and learning. They help families obtain appropriate education and services for their children; 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. For more information, visit www.militaryhomefront.dod.mil/tf/efmp/resources.

The National Center on Dispute Resolution in Special Education

The National Center on Dispute Resolution in Special Education uses mediation and other collaborative strategies to resolve disagreements about special education and early intervention programs. To contact CADRE, go to www.directionservice.org/cadre or call (541) 686-5060 or (541)284-4740 (TTY).

Books

Military OneSource offers a number of books on advocacy. These books are free and can be accessed through their resource library. For more information, visit Military OneSource at www.militaryonesource.com.

Many parents find discussion boards to be an invaluable resource for both sharing tips on how to get through the day and for becoming informed about public issues that may affect their child.

