

---

# Introduction

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 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.



*Speak clearly, smile when you can, and remember that a pleasant attitude is much more productive than 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 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*

- |                          |                           |
|--------------------------|---------------------------|
| <input type="checkbox"/> | Two three-ring note books |
| <input type="checkbox"/> | Three-hole punch          |
| <input type="checkbox"/> | Highlighter               |
| <input type="checkbox"/> | Sticky notes              |
| <input type="checkbox"/> | #10 envelopes             |
| <input type="checkbox"/> | Stamps                    |
| <input type="checkbox"/> | Dividers for binders      |
| <input type="checkbox"/> | 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.

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.



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.

- 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.mil](http://www.tricare.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](http://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](http://www.stompproject.org), and see how other families have handled similar situations.

For help with TRICARE appeals, contact your regional contractor by going to [www.tricare.mil](http://www.tricare.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 see module two, *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](http://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](http://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](http://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](http://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](http://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 game-like 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*

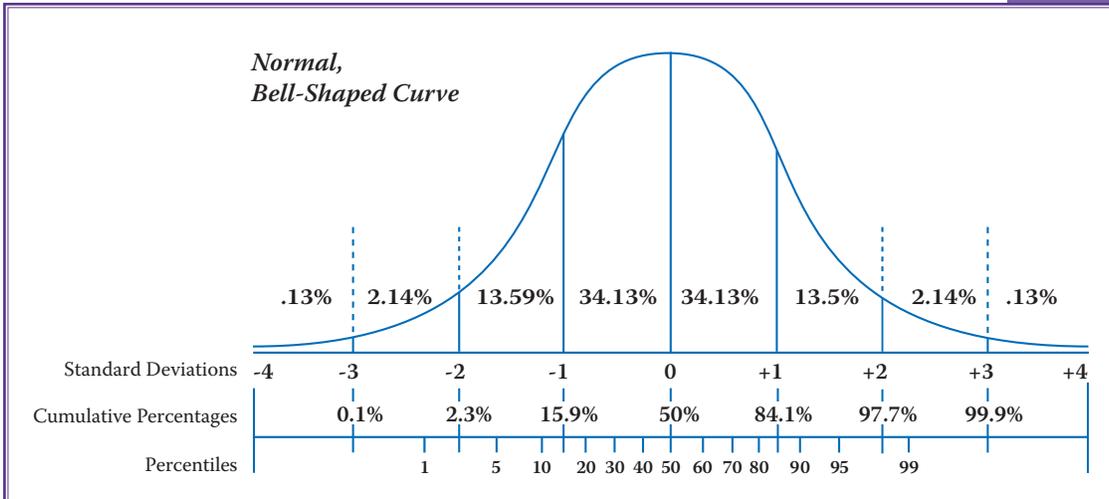
The bell curve is a visual way of organizing data, in this case test scores. The center of the bell, where it is the highest, shows the average test score or the fiftieth percentile. Those who did better than the average score will fall to the right of center and those who did less than the average score 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 84<sup>th</sup> 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.*

**did you know?**

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,

"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 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.



*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](http://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](http://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](http://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 through 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](http://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](http://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  
to 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.taalliance.org](http://www.taalliance.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](http://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.militaryinstallations.dod.mil](http://www.militaryinstallations.dod.mil)

Also available through Military Homefront is the Family Connections Forum at [www.militaryhomefront.dod.mil](http://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](http://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](http://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](http://www.eparent.com)