



## Module Four | Special Needs Families in Transition

### I. Introduction

PowerPoint Slide:  Handout: 

This workshop is designed for Service members and their families who have children with exceptional health care or educational needs. Information regarding relocation, deployment, disaster preparation, and the transition of special needs children to adulthood will be discussed.

### II. Learning Objectives

Upon completion of the unit, the participants will be familiar with the following:

- Role of installation family centers in relocation
- Planning for travel with a special needs child
- Safety in a new home
- Resources offering counseling
- Items to bring in case of an evacuation
- Financial and planning aspects of parenting an adult child with special needs

### III. Preparation and Procedures

*Target Audience:* The target audience for this workshop is military personnel and their spouses who have children with special needs and who may be involved in Exceptional Family Member Program (EFMP) or special education. Marketing should be through installation family centers, EFMP coordinators, military treatment facilities (MTFs) and DoD schools. Remember that childcare may be an issue for participants. Consider this when scheduling a time and, if possible, have suggestions available for childcare arrangements.

*Module length:* Approximately 1.5 hours. Time may vary depending on the needs of the particular group and the amount of participant interaction.

*Registration:* Registration is recommended. All participants should receive a reminder phone call or email about three days prior to the workshop. During the reminder call, ask if the participant has a particular interest. If possible, gather information concerning local support groups that may be of particular interest to participants.

*Training Considerations/Options:*

- This can be a stand alone workshop offered to military parents of children with special needs who are anticipating a move, dealing with a deployment, or whose special needs children are in high school; it can also be part of a series of workshops concerning parenting children with special needs while in the military.
- A casual, interactive group discussion is favored since one benefit of the workshop is to help parents make personal connections.

## IV. Training Materials and Tools

*Equipment and Materials:*

- Tables and chairs to accommodate all participants
- Separate table for resource materials
- Brochures from resources list
- Name tags and markers
- Projector and screen (PowerPoint capable)
- PowerPoint capable computer
- PowerPoint slides
- Microphone
- Sign-in sheet
- Extra pens

*Handouts:*

- A copy of the PowerPoint presentation, with room for notes (To do this open the PowerPoint file. Click on “File” from your menu. Choose “print.” Under “print what,” choose “handouts” and then choose three per page.)
- Childcare Questions
- Document List
- Resource List (Be sure to include local contact information for TRICARE Regional Contractors.)

Handouts should be given to participants on arrival or as they sign in.

*Resource Materials:*

- Local area support group fliers
- Extended Care Health Option (ECHO) brochures
- Child Find brochure
- STOMP brochure
- NICHCY brochure (call 1-800-695-0285)
- EFMP Brochures
- Have available CD's of the DoD Special Needs Family Tool Kit (This can be found at <http://www.militaryhomefront.dod.mil>. Type “DoD Special Needs Parent Toolkit” in the search box. Go to the “Service Provider Exceptional Family Member” area and create copies for workshop attendees.)

Materials may include extra copies of handouts or single copies of bookstore videos for participants to look at. Consider asking the local library to set up a display of relevant books that could be checked out at a later date.

**Take Note:**

You may choose to expand or condense the content. It is strongly recommended that you supplement this material with any pertinent local resources and contact information.

## V. Curriculum Outline for Special Needs Families in Transition

### 1. Introduction

- a. Introduce yourself
- b. Icebreaker (if group is very small, introductions may be sufficient)
- c. Define purpose of the workshop

### 2. Relocating

- a. Resources
- b. Talking to children about a move
- c. Planning a move
- d. Moving day

### 3. Traveling with Special Needs Children

- a. Airlines
- b. Train
- c. Temporary lodging

### 4. New Home

- a. Schools
- b. Childcare
- c. Safety
- d. Child information sheet
- e. Spouse employment

### 5. Deployment

- a. Helping children understand
- b. Mental health care
- c. Coming home

### 6. Disaster Preparation

- a. Needed supplies
- b. Service animals
- c. Power loss

## 7. Transition to Adulthood

- a. Self-advocacy
- b. Life skills
- c. Questions to consider
- d. Available services
- e. Financial matters

## 8. Summary

# VI. Curriculum Detail

## *Introduction*

Welcome participants to the workshop.

Introduce yourself, sharing any pertinent information, and begin your group discussion or ice breaker.

*Say:* For military families, change is certain. Families whose children have special needs must work harder than most to help their children manage the stress that comes with relocating and deployments. This workshop will focus on several areas of transition, change, and growth that military families whose children have special needs may face. Advice on coping with these challenges and resources to fall back on when help is needed will be discussed. We will also discuss relocation, deployment, disaster preparation, and your child's transition to adulthood. All of the contact information for the organizations and websites discussed today is included in your handouts.

## *Relocating*

*Say:* Moving is part of life in the military, and it can be exhausting emotionally and physically. As a family whose child has special needs, you have the further challenge of helping your child cope with the changes and keeping him or her cared for and safe during the transition. There are a number of resources to assist you. Your first stop for relocation assistance should be your installation family center(s). Ask to speak with the relocation specialist. The Relocation Assistance Program is available to provide you with information about your specific moving allowances and moving in general. Ask about resources to help you meet the needs of your exceptional child.



Your installation family center(s) can also connect you with the Exceptional Family Member Program (EFMP) and, through EFMP, respite care programs or specialized daycare programs, if available. Remember, while information is available at all installation family centers, only the Army and Marine Corps family centers have designated EFMP personnel.

**Take Note:**

If possible, offer the participants the name of the relocation specialist they should ask for in the installation family center(s) and include contact information with the handouts.

The purpose of EFMP is to ensure your family member's medical and/or educational needs will be considered during the assignment coordination process. However, Service members do have the option of accepting duty stations where services do not exist for exceptional family members. This usually means that the Service member must live apart from the family so that the child's needs can be met.

*Plan My Move* is a website designed for relocating military families. Here you will find up-to-date information about your new duty station as well as the surrounding area. There is a feature that will estimate your moving expenses and has information about travel allowances and advice on planning your move.



Before military families can be stationed overseas or to a remote assignment they are screened for overseas suitability. This screening is required of all military families and civilian personnel traveling overseas at government expense and will determine if members of the family have special needs that require specific medical and/or educational attention. The presence of a special need does not mean a family will be ineligible to relocate overseas; however, it does mean extra care will be taken to ensure the family will be living in an area that has the necessary medical and/or educational services available.

Service members may not be denied an essential overseas duty assignment solely because they have children who are, or who may be, eligible for educational intervention, such as Early Intervention services (EIS) or special education services. TRICARE policy does require Service members with overseas orders to verify command sponsorship for accompanying family members for enrollment in TRICARE Overseas Program Prime, including TRICARE Global Remote Overseas.

If a family is considering a non-command sponsored move overseas there are some important issues to consider. Because command sponsorship is necessary for TRICARE Overseas Program Prime and TRICARE Global Remote Overseas, families without command sponsorship who need healthcare services from the military system must use TRICARE Standard.

When TRICARE Standard beneficiaries seek care overseas, they may have to pay the entire bill at the time of service and then file a claim for reimbursement. Under TRICARE Standard, family members must pay an annual deductible and cost shares each time they get care outside of the MTF. Also, TRICARE Standard and Plus beneficiaries are only eligible for space-available care at an MTF overseas. Going non-command sponsored to an overseas location is a bad idea.

*Say:* Before you talk to your kids about the move, think about the best way to present such information. If you think the reaction is likely to be a positive one, you may want to speak with all the children together in a family meeting. If you think a child might be upset by the news that you are moving, you may want to consider telling your children one-on-one before the family meets to discuss the news. This way each child can react individually and it may avoid a situation where one upset child sets a tone that negatively influences the other children.

Before you tell your children that you are moving, gather information that will be of interest to your children about the new location. Are you moving closer to family or friends? Will you be near a beach or an amusement park?

Moving away from familiar surrounding can be scary and children will be better able to cope with their concerns if they can speak freely to their parents about them. Happy and excited feelings are easier to accept, but anger and sorrow are just as valid. If your child gets the message that only happy feelings should be expressed, the negative feelings will just go underground and may well surface as negative behaviors. This does not mean that one child should be allowed to set a negative tone for the whole family or that poor behavior should be ignored, but honest talk might diffuse some of the power of sad feelings.

Saying goodbye can be the hardest part of moving, and some children are very emotional about this time. Discuss with your children ways they can keep in touch with their friends. Stay positive yourself. This is not to say that you should deny your own mixed feelings about relocation, but do keep the tenor of your conversations upbeat as children look to their parents for cues on how to behave.

Consider your child's developmental level. What will help him or her to better understand what is happening?

Your child may benefit from a visual schedule of events to be prepared for the upheaval that comes with moving. Maybe you could make a large calendar and have pictures of boxes on packing day, a truck on moving day, and pictures of your family driving to the new location. Reassure your child that the movers will deliver your families possessions to your new home.

Show your children a map or a globe that has both your old location and your new location. Discuss with them the route you will take to your new home.



Find time in the normal family rituals to ask each child how they feel about the move: whether they are excited, angry, or worried. Reassure your children that all these feelings are normal and remind them that the current home was once new and now feels like home. This will happen again.

If your child would be interested, it might be a good idea to give him or her materials and extra photos to assemble their own scrapbook. You could provide a disposable camera so the child can take pictures of special places and people for a scrapbook.

If you have small children, read stories about moving to your child. This will help give the child the vocabulary needed to express feelings as well as help see that moving is something lots of families do.

MTOM, Military Teens on the Move, is a website designed for children ages six to eighteen years old. It uses testimonials and humor to provide children with information and to address the challenges facing children in the military as they cope with the strains of moving.



*Say:* Before moving day there are number of things you may do to make the experience easier. Ask your child's teacher to write a letter introducing your child to the new teacher. A personal report of your child's strengths and weaknesses, as well as a description of what works well with your child, may help the new teacher to get to know your child a little faster. Contact your new state's Parent Training and Information Center for information on schools in your new area. There is a link included with your handouts that can help you find Parent Training Centers across the country.

Before you move, check to see what medical care is available at the new duty station. The provider directory, available on the TRICARE website, can help you locate specialty services. Use the phone numbers provided to ask if the doctor is still a network provider and accepting new patients.

There are a number of important papers that you should have copies of. Carry with you copies of your child's Individual Education Program or Individual Family Service Plan. If you are a Navy or Marine Corps family assigned as an EFMP category four or higher, bring proof of your category assignment with you to your next duty station so that you can prove you are eligible for priority housing. Also carry with you birth certificates, social security cards, adoption papers, and passports.

If your family member has been assigned a new case manager ask your current case manager for the new contact information. This will help prevent problems that arise when families can't get appointments right away and will prevent unnecessary trips to the emergency room as the case manager will advocate for your family.

*Say:* Before the movers arrive, designate a specific area or room in which to save items you do not want the movers to pack. Mark the area clearly with a sign asking the movers to stay out.



Be sure to put the important documents we just mentioned in this room, along with your child's favorite comfort items: toys, favorite pillow or blanket, or favorite music or DVDs. Put special feeding equipment, medicine, and all medical equipment needed by family members in this room. This may include a bedrail if your child will need one while traveling. Your Installation Transportation Office has special procedures to follow for the transportation of medical equipment necessary for medical treatment required by the sponsor or family member. Some types of medical equipment may be shipped in the same manner as professional books, papers, and equipment.

Moving day can be hectic and children seem to absorb the excitement and nervousness that comes with it. Some children benefit from seeing what is happening with their belongings. Seeing the packers boxing things up and stacking them in a truck helps them to understand what is happening. For other children, any change is disturbing and seeing their home dismantled is upsetting. If your child is likely to be bored, upset, or require extra attention, you may want to arrange for childcare either in or away from your home that day.

### *Traveling with Special Needs Children*

*Say:* Whether traveling by train, plane, or automobile, traveling with children takes some planning. Families who are traveling with children who have special needs may need to spend extra time organizing the trip as well as allowing themselves a little extra time in their schedule. Almost all children are troubled by rushing. If you can build in a little flexibility to your travel schedule, a small upset has less chance of becoming a big problem. There are several things you can do to help your trip go smoothly:



- Tell the Traffic Management Office (TMO) that your child has special needs so that these can be taken into consideration as travel plans are made
- Be proactive about contacting airlines or train companies to alert them to any special services your family may require, such as the use of oxygen
- Keep light snacks and security items within reach
- Bring trash bags to keep your area neat
- Bring an inexpensive umbrella stroller since it can be helpful in large airports and train stations
- Consider taping emergency contact information into your child's clothes
- Bring hand wipes for frequent hand cleaning after rest stops and before eating

Car travel gives you the flexibility to stop when you'd like to rest or explore. You may want to give your child a map so your family's progress can be charted.



*Say:* The Air Carrier Access Act prohibits airlines from refusing passengers on the basis of a disability, and it actually requires U.S. Air carriers to accommodate the needs of passengers with disabilities. However, to avoid confusion or delay, communication with your airline is very important. Keep the following tips in mind when flying:

- You should contact the airlines at least forty-eight hours before the flight if special services such as oxygen, which the airline will provide for an additional fee, or the use of a wheelchair are needed
- Ask about the accessibility of the bathrooms, especially if you will be flying on older or small aircraft
- Assistive devices, wheelchairs for example, do not count as carry on luggage and have priority for in-cabin storage as long as you take advantage of pre-boarding
- If a family member suffers from seizures you should consult with your family member's physician prior to the receipt of PCS orders. If a family member is unable to fly this should be documented by the physician in the DD2792 medical summary
- Consider carrying a backpack rather than a diaper bag, as it will leave your hands free
- Think about whether your family should take advantage of pre-boarding (The air conditioning is generally not turned on until just before take off, and a squirmy child will have to sit longer than necessary in an overheated plane. If there are two adults traveling, you may want to send one ahead with the baggage and have the other board later with the children.)
- If you are bringing your car seat, check the airlines website for compatibility with airline seats



*Say:* If you travel by train, Amtrak will assist those with 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 can be stowed. If your child requires oxygen, you must make reservations in advance and give notice of your need to bring oxygen at least twelve hours before you board. Contact information for Amtrak is included with your handouts. You may call for more information about bringing oxygen on trains and station accessibility.

*Say:* For information on temporary lodging, go to <http://www.militarytravel.com>; the website address is included with your handouts. Make your reservations as far in advance as possible. Mention your family's EFMP status as some bases have special accommodations. If your family has special requirements, such as wheelchair accessibility or a room with TTY for the hearing impaired, make sure to mention this.



Some families use the time in temporary housing, as they wait for their belongings to catch up with them, as a break from usual household responsibilities. Take this time to explore your new surroundings and find fun in your new location.

### *New Home*

*Say:* The search for housing is on. Many families put the search for the right school system ahead of the search for a new home, since the location of the home will affect school choice. Investigate schools both on and off base. Contact these schools before your arrival and ask about how your child's unique needs will be met. Meet with administrators and show them your child's IEP. Ask about available services or special programs. Your child's IEP should be honored until your child is reevaluated for eligibility for special education, and if appropriate, a new IEP is written. Remember that services may vary, as may the school's approach to special education. If you choose to live on base and your child has profound challenges, your child may need to attend a public school off base if it is determined that the civilian school can better meet your child's needs.



Five percent of base housing is wheelchair accessible, a feature that can be hard to find off base. Life on base also offers easier access to a supportive community. The wait for on base housing varies, but be sure to mention your family's EFMP status, as some Services offer priority housing to eligible families.

For parents who work outside the home, quality childcare is a high priority. This can be difficult for military families whose hours are long and variable, especially when your child has special needs. Most military installations have resource teams to help parents of special needs children find appropriate childcare. The Army calls this service the Special Needs Accommodations Process (SNAP), and the Navy and Marines call it the Special Needs Evaluation Review Team (SNERT). The Air Force does not have this service. 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. This team will identify childcare options and activities that will best meet your child's needs as well as consider if any technical support, staffing, or special services are necessary.



For more information about childcare, check with your installation's Resource and Referral Office. A resource specialist can guide you through the registration process and explain accreditation and fee structures. You will also find information about childcare options both

on and off base. If you are new to a base and can't find the resource office, your installation's Child Development Center is a good place to bring your questions. Contact information for all military Child Development centers can be found on MilitaryHOMEFRONT's MilitaryINSTALLATIONS site.

Take Note:

Have the contact information for the special needs resource team and base childcare center in your area included with the handouts. Also include contact information for the base Resource and Referral Office.

Included with your handouts is a list of questions to consider when choosing a childcare provider.



*Say:* Move in day is exciting. Everyone is relieved to have familiar objects back, and the new house starts to look like home. Pay special attention to children who may wander away or find danger in unfamiliar surroundings. Look over your new home with an eye for hazards, such as busy roads or creeks nearby. Hold a family meeting to discuss these hazards and establish firm boundaries.

If you are concerned that your child might slip out of the house despite your vigilance, 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 your request to base housing or to your landlord to ask permission to install the extra security devices.

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

If you have oxygen tanks in your home, the local fire department needs to know about them. Also, if your child is likely to hide during an emergency, tell the fire department.



*Say:* If you are concerned about your child slipping away from the house, talk to the local police or MP's about this. Provide them with a current photo and description of your child. Explain how your child is different and how he or she might react if confronted. Be sure to include all contact information. In this example of an ID sheet for a child, the parents have included information about the child's autism, as well as his asthma and peanut allergy. You may want to make several copies of this information to have on hand in case of an emergency and when you travel.

*Say:* Military spouses raising a special needs child face significant hurdles regarding careers and employment. Fortunately, there are resources available to assist you.

The Military Spouse Career Center is the result of a partnership between the Department of Defense and Monster.com. This is a virtual resource, and it can provide assistance to you regardless of your location. You will find information on spouse friendly employers, education and scholarships, licensing, and certification. The contact information is with your handouts.

MilitaryHOMEFRONT has information on spouse employment in the Troops and Families section.

Many installations have installation family centers that offer professional family members employment readiness training and support services. This is a resource for local job fairs and job search databases. You will find assistance with resume writing, career counseling, and job search skills.

### *Deployment*

#### Take Note:

Change or add to the following text to include installation specific information about spouse employment through the local installation family center(s).

*Say:* We are going to change topics now and discuss the challenges that come with the deployment of a military parent. 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. Use your words to help your children find theirs. For example, you might say, “I don’t want Daddy to leave and waiting for him to leave makes me feel sad and worried. Do you ever feel that way?”

Help your child to see that although some things will be different with a parent gone, many things will remain the same. Reinforce that someone will always be there to keep the child safe.

Consider your child’s developmental level. Will visual aids, like maps and calendars, help your child to understand where the parent is going and when he or she will return? Before the deployment, make a collage of pictures of the deploying parent with your child as well as with the whole family and hang it near your child’s bed.



The deploying parent might want to schedule a trip to the child's school to meet with teachers. The point of this trip is to be sure the teacher knows about the change in your child's life, and to let your child show you around his or her classroom and perhaps hear you tell teachers how proud you are of him or her. Once you are gone you will be better able to ask questions about your child's school life if you are familiar with it.

Have a family meeting about ways to keep in touch: letters, pictures, and tapes are all good ways to remain connected.

While away, the deployed parent should write letters to each child, as children enjoy few things more than getting their own mail. A letter to the family pet will also be sure to bring a smile to your child's face.

Remember that just because your child is not expressing his or her feelings, it does not mean he or she is not troubled. If your child is acting out, it may be because of unexpressed emotions. Help your child to name these feelings. It is okay for your child to see that you have sad feeling too, but if you are about to fall apart, try to do this away from your kids. Strong emotions from a parent can be scary for children.

Your child may grieve a lot during the deployment. To a child it may feel like the parent is gone forever. Grief without understanding is difficult to work through.



*Say:* If you or your child are having difficulty adjusting to the deployment, do not hesitate to seek help. Counseling is available through several resources.

You can contact Military OneSource, where help is available twenty-four hours a day.

Through TRICARE Prime, Standard or Extra, you are entitled to eight sessions of counseling without a referral from your primary care manager. This means you can contact a counselor yourself and ask if TRICARE is accepted. If more than eight sessions are needed, authorization can be obtained. Another source of support may be your chaplain. It is important to ask if the chaplain is licensed to provide marriage or family therapy.

During deployments both parents have difficult jobs to do. Taking care of yourself has never been more important. Asking for help is a sign of strength.

Ask about respite care. Army families have the option of going to their family center and speaking to their EFMP Coordinator to access ECHO respite care if they are already receiving another benefit under ECHO. Families from other branches should go to their TRICARE Service Center or speak with their Regional Managed Care Support Contractor about ECHO and the respite care benefit. The whole family will benefit if the parent at home has a chance to recharge his or her batteries.

*Say:* For many children, any change is unsettling, even good change. When the deployed parent returns, children may feel happy and excited or worried and stressed. Depending on the child's developmental level, he or she may feel uncomfortable around the returned parent, almost as if he or she were a stranger. Remind your spouse that the child's behavior is a reaction to change, not to the returning parent.



Reunion time can be exciting, and children tend to take center stage; however, once the excitement has subsided, schedule time to reconnect with your spouse, as maintaining a strong marriage is one of the best things parents can do for their children.

### ***Disaster Preparation***

*Say:* We are going to change direction again, and talk about disaster preparation because, as with so many things, families whose member's have special needs must plan ahead so that when something unexpected occurs, evacuation or other plans can be put into effect with a minimum of delay.



Careful preparation will reduce the stress and hardship that follow an unexpected calamity. Remember that your family may need more time than others to evacuate.

Here are some ideas about what to pack should your family need to evacuate an unsafe area:

- At least thirty days of medication (Consider not only prescription medicine, but pain medicine and any lotions or creams that your child needs to be comfortable.)
- Breathing aids, such as nebulizers, inhalers, or oxygen tanks, should be close at hand at all times as many respiratory illnesses can be aggravated by stress
- Important documents, such as copies of medical records, insurance papers, or birth certificates
- Enough diapers and clothing for a week
- A bed rail, if necessary
- Any special food or eating utensils
- Entertainment for the children, such as cards, games, or favorite DVDs
- Comfort or security items (Sometimes a familiar pillow can make a huge difference in the quality of sleep a child has.)

- A battery operated flashlight and radio
- A current photo, along with a physical and medical description of your child (Include a list of necessary medication and contact information for your child's physician.)

Be sure to carry with you contact information for your doctor and let your extended family know where you will be. Remember that cellular phone service may be interrupted during a large scale evacuation.



*Say:* Federal laws allow guide dogs into emergency shelters. If you will be evacuating with a guide dog, be sure to bring any important vaccination papers and your dog's rabies and license tags. Remember that in a disaster a guide dog may become confused and need more attention than usual.

Here is a list of needed supplies if you will be evacuating with a guide dog:

- Food for a week
- Water for the time you will be traveling
- Bowls
- Records of shots and licensures
- Disposable bags for cleaning up after your dog



*Say:* 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 your EFMP coordinator or housing manager and inform them of your need for a constant source of electricity. If generators are not available, contact your Primary Care Manager to discuss if or when your child should be moved to a hospital or other facility where power is available.

### ***Transition to Adulthood***



*Say:* Our final topic for today is your child's transition from being a student to becoming an adult. Parents teach their children self-help skills very early in life. Self-advocacy is one of those skills. Whenever possible, let your child speak for him or herself. This might mean encouraging your child to order his or her own food in a restaurant, or explaining to a new teacher the desire to sit in the front of a classroom.

Between the ages of fourteen and sixteen, a child's Individual Education Program (IEP) will begin to address the transition process. The transition process must begin by the time your

child is sixteen. During this time the focus of your child's education turns from identifying and minimizing your child's challenges to looking toward your child's future. Transition includes a coordinated set of activities that will aid your child in acquiring life skills, such as filling out job applications, managing money, or learning to navigate mass transit.

Once a child graduates from high school, it is important to be aware that there is no guaranteed program to pick up where IDEA leaves off.

*Say:* Parents of healthy children can usually plan on their children living independently and becoming financially independent. However, if your child has a lifelong disability, you will need to think about your child's adult life and plan accordingly.



As you plan for your child's adult life, consider the following questions:

- Will your child need continuous care?
- What is your child's future earning potential?
- Will your child be able to make his or her own decisions about finances or health care?
- Will family members be available and willing to provide assistance after you are gone?

*Say:* One of the most important adult services, vocational rehabilitation, is available in most states. Vocational rehabilitation services can help your child with the support and training necessary to find and keep a job. Contact your state's Parent Training Center and ask about programs that help with transition. Unlike the special education system, a person with disabilities does not automatically get free services. A person must meet certain qualifications and may have to pay for some services.



As your child enters the teen years, you may want to contact the state developmental disability authority in the state you would like to retire to and ask about housing and group homes. The time to begin thinking about assisted living facilities is when your child is still young, as waiting lists can be years long.

Another question to consider is who will provide assistance to your child after you are gone? It is a good idea for you to write a Letter of Intent. This letter, which is not a legally binding document, provides parents with the opportunity to speak to whomever will be caring for and making decisions for the child after the parents have died. You may want to write out your child's story, including a medical and educational overview. Describe your child's favorite activities, foods, and people. This tool will help whoever is caring for your child to better know you and your child, and it will provide additional information for them to consider as they make decisions for the child.

Guardianship and the Declaration of Incapacitation is also an issue to consider as your child grows. Usually, when a child reaches the age of majority, which is usually eighteen, it is assumed that he or she is capable of making decisions about health, finances, and the future. Once your child reaches the age of majority, you can no longer assume you will be able to talk to your child's physician about his or her health. You will have no control over financial decisions or contracts your child might sign. If you are concerned about your child's ability to make these decisions responsibly, consider asking the courts for guardianship.

Guardianship is a court approved relationship between a legal guardian and a person with some level of incapacitation. The court will define the degree of authority the guardian will have to act on behalf of the disabled individual. The documentation for this process varies from state to state. Generally, a physician's statement will be needed to show that your child is not capable of becoming independent. The complexity of the guardianship process varies from state to state, and should you move from one state to another you will need to go through the process again because there is no reciprocal process concerning guardianship between states. It is important to begin this process before your child reaches the age of majority. It is much more difficult to obtain guardianship after your child has reached this age.



*Say:* There are some public programs that will help. Supplemental Security Income (SSI) is a minimum monthly cash payment for categorically aged, blind, or disabled individuals. Eligibility is based on the limitation of assets and should not be confused with other Social Security benefits. Medicaid, a program to pay for health care for certain low income individuals, is frequently tied to SSI approval.

Medicaid does not pay money to you, but instead sends it directly to health care providers. Sometimes a co-pay is necessary. Many states have special Medicaid programs for people with disabilities and not all are income based.

It is very important to remember that an adult who has more than \$2,000 in assets cannot qualify for Supplemental Security Income or Medicaid. So, how can you insure a child's well-being and financial security?

One crucial aspect of financial security is the Special Needs Trust. These are discretionary trusts that are created for people with disabilities to supplement, but not replace public benefits. This type of trust will allow a disabled person to continue to receive SSI, Medicaid, Section Eight Housing, and other public benefits while still benefiting from trust fund money.

The money from the trust can be used for many things: a special wheelchair, a handicapped accessible van, a vacation, a personal attendant, or other recreational or cultural events. SSI is designed to pay for food, clothing, and shelter, while Medicaid pays for medical bills. The money in the trust can be used for all other needs that are identified in the trust.

Contact a lawyer with experience in Special Needs Trusts. Don't delay because of the initial expense. Make several calls and explain your circumstances. Many lawyers will consider

reducing their fees or letting you pay over time. You may think you do not have enough assets to need a trust, but remember that life insurance is an asset, as is any equity you may have in your home.

It is important to share this information about trusts with family members who may wish to leave money to disabled children in their wills. Any money given directly to the child will interfere with the child's ability to access public funds until the inheritance is gone.

Finally, military ID cards are authorized for unmarried children of military sponsors who are age twenty-one or over and are severely disabled due to a condition that existed prior to the child's twenty-first birthday. These individuals may also be entitled to TRICARE benefits.

A wonderful resource for more information about wills, Special Needs trusts, and Guardianships is STOMP.

Again, contact information is with your handouts.

### *Summary*

*Say:* We have discussed many aspects of military life with a special needs child, with the emphasis on relocation, deployment, disaster preparation, and the transition to adulthood. What is your next step? It might be to prepare a child ID page or to make a list of important documents you want to have copies of. Explore the resources provided to you and talk to others who have similar challenges. Contact STOMP or visit your installation family center(s) to find out what services are available.

Please stop by the resource table for more information before you leave, and thank you for coming.

#### Take Note:

Alert participants to other workshops that are available, such as the following:

- *Birth to Age Three*, which has an emphasis on Early Intervention
- *Special Education*, which has information about the special education system
- *Health Care for Children with Special Needs*, which has information about TRICARE programs for families with special needs
- *Advocacy*, which has an emphasis on effective advocating for your special needs child while serving in the military
- *Resources and Support*, which is an extensive look at the resources available to military families with special needs children



# 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?

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 Individualized Family Service Plan (IFSP) or Individualized Education Plan (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 three and four 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? Do you have a nurse on staff?

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

Do you provide Emergency Respite Care?

## *Document List*

### Documents you may want to hand carry:

- Birth certificates, Adoption papers
- Passports
- Insurance papers
- Your Individualized Family Support Plan (IFSP)
- Your child's Individualized Education Program (IEP)
- Important pages of medical records
- Confirmation of your child's Exceptional Family Member Program (EFMP) status

# *Additional Resources*

## Families in Transition

### **Section 504 of the Civil Rights Act**

Section 504 of the Rehabilitation Act is a civil rights law that also applies to public schools and prohibits discrimination on the basis of a disability. Section 504 has a broader definition of disability than does IDEA, so some children who do not qualify for special education under IDEA, can qualify under 504. For more information about Section 504 of the Rehabilitation Act, go to <http://www.ed.gov/about/offices/list/ocr/index.html>.

### **The Individuals with Disabilities Act (IDEA)**

The Individuals with Disabilities Act, which is known as IDEA, is the legislation that guides these school systems. IDEA establishes educational requirements for children with disabilities between the ages of three to twenty-one. For more information about IDEA, go to <http://idea.ed.gov>.

### **Installation Family Centers**

Your family center has information and referral specialists who can provide information about EFMP, as well as local organizations with interests in certain disabilities. The Army and Marine Corps have dedicated EFMP personnel in their family centers. The following link can help you find an installation family center(s) near you: <http://www.militaryinstallations.dod.mil>

### **NICHCY**

The National Dissemination Center for Children with Disabilities (NICHCY) offers a wealth of information in both English and Spanish on a variety of special needs related topics, such as Early Intervention, Special Education, Section 504, Housing Options, Transitioning, Special Needs Trusts, and more. Go to [www.nichcy.org](http://www.nichcy.org)

### **STOMP**

STOMP (Specialized Training of Military Parents) is a federally funded Parent Training and Information (PTI) Center established to assist military families who have children with special education or health needs. STOMP is funded through a grant from the U.S. Department of Education. The staff of the STOMP Project is made up of parents of children who have disabilities and have experience in raising their children in military communities.

STOMP serves families by providing information and training about laws, regulations, and resources for military families of children with disabilities. STOMP assists parents and professionals in developing their own community support groups and providing a forum where families can connect and discuss issues faced by military families whose children have disabilities. Go to <http://www.stompproject.org> or call 1-800-5-parent.

### **SCOR**

TRICARE has a Special Care Organizational Record (SCOR) that you will find helpful when organizing your child's medical records. It can be found at <http://www.tricare.osd.mil/OCMO/download/SCOR.doc>.

### **State Parent Training and Information (PTI) Center**

Each state is home to at least one parent center. Parent centers serve families of children and young adults from birth to age twenty-two with various disabilities: physical, cognitive, emotional, and learning. They educate families about how to obtain an appropriate education and services for their children with disabilities, work to improve educational results for all children, train and inform parents and professionals on a variety of topics, and connect children with disabilities to community resources that address their needs. Go to <http://www.taalliance.org/centers>.

### **Books:**

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

*Writing Measurable IEP Goals and Objectives* by Bateman and Herr

*The Complete IEP Guide, 4th Edition; How to Advocate for your Special Ed Child*  
by Lawrence Siegel