



Chapter Five: Support for Military Families with Special Needs

In addition to the medical, financial, and educational benefits for military exceptional family members (EFMs) described in the previous chapters, the families of these children and adults also need the support of peers and professional service providers as they learn about and manage the care of their loved ones. An array of support services is available to them at the installation and in civilian communities throughout the country. Although each family's situation and need is unique, the sections in this chapter highlight some of the most common areas in which military special needs families will need support and suggest ways in which they can access it.

5.1 Special Needs Information and Assistance

More than anything else, parents of EFMs want good, reliable information and knowledgeable assistance in meeting their EFMs' needs and in becoming the strongest advocates that they can be. And they want to be directed to the right source of assistance without having their valuable time wasted pursuing dead-end leads. Military families today have more support than ever before for reliable information and professional programs that address special needs. In this section, they are organized into three categories.

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5.1.1 Family Support Services

Family centers have been one of the strongest strands in the network of community services available at military installations for active duty personnel and their families. For the past 25 years, they have been the primary resource for information, direct services, and support for families as they coped with the unique challenges of the military lifestyle. Today, there is a new source of assistance for service members and their families regardless of where they may be located around the world. Special needs families should know about both options.

Installation family centers: An Army Community Service Center, Fleet and Family Support Center, Air Force Family Center, or Marine and Family Services Center is found on almost all military installations in the United States and overseas where family travel is authorized. Family centers have well-established programs to provide at a minimum

- information and referral services
- relocation assistance
- deployment/mobilization support
- personal financial management services
- family member employment assistance
- family life education
- crisis response

Army and Marine Corps family centers also include exceptional family member programs to provide specialized information and support services to special needs families, but all family centers are capable of linking families with sources of special needs information and services in the military and civilian communities. Contact information for a DoD family center may be found by accessing the installation website or by using the Family Center Locator on the DoD MAPSite www.defenselink.mil/mapsite.

Military OneSource: Military OneSource is the newest component of the military family support network of services. It is accessed by telephone or the Internet and is available 24 hours a day, 365 days a year. Service and family members who call the toll free number will speak to a Master’s-level consultant who is trained to provide information, referral, and assistance with a range of support needs. They include

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| ■ relocation | ■ emotional well-being |
| ■ financial matters | ■ addiction and recovery |
| ■ legal issues | ■ health and wellness |
| ■ education | ■ family support |
| ■ consumer issues | |

Military OneSource has an extensive library of information materials on subjects relevant to military family life, including the area of special needs. It also offers translation services and will help a client with research needed to solve a problem. Military OneSource is an especially valuable resource for families who do not live near a DoD family center, including National Guardsmen and reservists who have been called to active duty. Special needs families should be encouraged to explore the



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5.1.2 Online Information Resources

There is currently no shortage of websites specifically designed to give service members and their families information and resources to help them negotiate the military lifestyle. Many have pages devoted to special needs information and issues. In addition to the sites listed below, most military installations have websites that will direct visitors to services at the installation with links to other local or Service-specific resources.

Military Homefront: www.militaryhomefront.dod.mil/ is DoD’s primary portal to information resources related to military quality of life. The Special Needs/EFMP site can be accessed by clicking on “Troops and Families.”

SITES: www.dmdc.osd.mil/appj/sites is the Web address for the Standard Installation Topic Exchange Service, a relocation assistance database that provides detailed, timely information about any installation. Schools, housing, recreation opportunities, child and youth services, and the cost of living are just a few of the topics covered to help families learn about their new location. Access to SITES is restricted to military ID card holders.

MAPSite: www.defenselink.mil/mapsite is a DoD site specifically designed to provide military family members with information and interactive resources for assistance with relocation, financial issues, and employment. It has a family center locator and links to many other useful websites.

Lifelines Services Network: www.lifelines.navy.mil/ serves the Navy and Marine Corps communities with a wide range of information on military lifestyle issues for service members and their families. Special needs information can be accessed by clicking the “Family Life” link.

Air Force Crossroads: www.afcrossroads.com is the official community website for the Air Force and offers information and resources on a wide range of topics pertaining to military family life, plus information about DoD installations. Some parts of the site are restricted to registered users.

Virtual ACS: www.armycommunityservice.org is the Army’s family support information website. It has an EFMP page, several directories including contact information for ACS centers, plus many other resources and links.

STOMP: www.stompproject.org is the Web address for Specialized Training of Military Parents, the only federally-funded parent training and information (PTI) center established to assist military families who have children with special education or health needs. This site offers publications on a range of military special needs issues and information on current topics of interest and upcoming events.

National Military Family Association: www.nmfa.org is the website that NMFA uses to inform military families about issues important to them and about its work in support of their interests. It has a number of links and information on topics not covered by the other military family websites.

Milspouse.org: www.milspouse.org/ is a website devoted primarily to information resources related to spouse employment, relocation, and education. Special needs resource information and links can be accessed by clicking on “Benefits and Services.”

Military Family Resource Center: www.mfrc-dodqol.org/ is MFRC’s site for policy makers and professionals who serve service members and their families. Directories listing contact information for family centers, family advocacy, child development, and youth services programs, plus links and FAQs can be accessed by clicking on “Family Resources.”

5.1.3 Advocacy

Military families can face enormous challenges in obtaining appropriate special education, treatment, and support services for their disabled children. Despite legal protections and benefits, parents must become advocates for their EFMs to ensure they have access to the services they are entitled to receive. Sometimes parents need the additional help of others with professional expertise or authority to advocate on their behalf. There are many sources of help for parents fighting



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for their children's rights and needs. The following resources can be of assistance to parents of EFMs when they need additional help advocating for their children.

Installation special needs coordinator/EFMP manager: For military families located near an installation, there will be a special needs point of contact whose primary duties include one-on-one assistance and advocacy on behalf of special needs families. The Army and Marine Corps have EFMP Managers located in their family centers. The Navy and Air Force have EFMP/Special Needs Coordinators in their medical treatment facilities.

School liaison officer: Many installations now have a school liaison officer whose role is to work with local schools in support of students from military families. They can be particularly helpful in advocating for parents of students transitioning from one school to another. The SLO should be knowledgeable about special education legal requirements and prepared to intervene on parents' behalf when they believe their child's special education needs are not being met.

Advocacy organizations: There are dozens of individuals and organizations that advocate for special needs children and adults, especially in the area of special education. These websites offer advocacy information for parents and links to advocacy organizations throughout the country.

- *Children's Disabilities Information* www.childrensdisabilities.info/advocacy/
- *Internet Special Education Resources* www.iser.com/CAadvocacy
- *Wrightslaw* www.wrightslaw.com/
- *Disability Information and Resources* www.makoa.org/legal
- *SNAP – Special Needs Advocate for Parents* www.snapinfo.org

5.2 Special Needs Child Care

Most military special needs families will rely on child care outside the home for their EFMs at some time during the early childhood years. Their use of child care providers may be occasional to allow the parent caregiver needed respite, or it may be daily to meet the needs of single parents or dual-income families. The Americans with Disabilities Act protects children with disabilities from being excluded from child care programs unless their presence would pose a direct threat to the health or safety of others or require a fundamental alteration of the program. Military and civilian child care programs must make reasonable accommodations to integrate children with disabilities, and they cannot just assume that a child's disability is too severe for successful integration. There must be an individualized assessment based on professional observations, past history, and standard assessment criteria. Programs use different methods for assessing a disabled child's needs and the necessary accommodations. Military child development programs use multidisciplinary teams that evaluate disabled children's needs individually and, with the parents, determine the most appropriate care options. A detailed description of special needs resource teams may be found in Chapter Six.



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5.2.1 Center-based Care

One option appropriate for many EFMs is care in a child care center. In a center, special needs children are “mainstreamed” with other non-disabled children in their age group. A center may be the recommended option for children who can benefit from socialization with others in a structured, classroom-like environment. By law, parents may not be charged higher rates for the care of a special needs child in a child care center.

Military child development centers: Centers on military installations normally offer full-day, part-day, hourly, and before-and-after-school care. Military centers coordinate with the installation EFMP on special needs care and exclude no child on the basis of disability. They have sliding fees based on family income, and waiting lists to get in are commonplace. DoD and the Military Services require child development centers to be inspected regularly and accredited by a professional accrediting organization.

Civilian centers: These facilities will vary in the types of services, ages served, cost, and in the degree of accommodation they are able to make. Service members with EFMs who do not have access to military child care programs should be encouraged to seek care only from accredited centers.

5.2.2 Family Child Care Homes

A family child care home is a home-based business that may offer full-day, part-day and hourly care, before and after school care, extended care, and specialized child care services for disabled or sick children. A family child care home may be the best option for EFMs who need the consistency of a single caregiver or who require complex procedures that must be learned by the caregiver. Family child care homes operated by military family members in government or private housing are certified by the military child development program, and the providers are screened and trained. DoD sets policy for these homes from the number of children allowed in care to the meals served and fees charged. In civilian communities, home-based child care businesses may or may not be licensed and inspected by the state, and regulations vary from state to state.

5.2.3 Respite Care

Respite care is temporary care for a disabled person for the purpose of giving the primary caregiver, usually a parent, relief from the routine of daily care giving. Respite care may be for a few hours so the primary caregiver can attend to personal needs or for a few days so the family can have a much-needed vacation. Occasional respite care helps to relieve the stress of caring for a disabled child and thus helps to prevent abuse and neglect and strengthen family stability. Services can be provided in the EFM's home, in the respite caregiver's home, or in a care facility. The TRICARE Extended Care Health Option (ECHO) program, covered in Chapter Four, has a respite care benefit. However, many parents who need respite care do not qualify under ECHO, but there are other respite care options and funding sources available from both military and civilian agencies.

5.2.4 Special Needs Child Care Information Resources

Depending on their location and individual needs, there are many sources of child care information that can be given to military parents with EFMs. The resources below will help special needs families find the care they need.

Installation resource and referral offices: Most installation Child Development Services programs have a resource and referral office to help parents find the right care for their child. It should be the first contact for parents looking for child care on or near a military installation. Contact information for military child development resource and referral offices can be found on the Military Family Resource Center's directories page, www.mfrc-dodqol.org/progDir/.

Civilian resource and referral programs: Military families without access to installation child development programs should be encouraged to seek assistance from a civilian child care resource and referral program before choosing a child care provider. The Child Care Aware website www.childcareaware.org/ can help them find the one that serves their area.

Respite care resources: Installation family centers, EFMP managers, and child development resource and referral programs will have information on respite care services offered on base and in the surrounding community. Some military special needs programs provide funds to offset the cost of care for families in need. Families who are not near a military installation may be referred to Arch National Respite Locator www.respitelocator.org.

5.3 Special Needs Housing

Housing is a significant issue for families with special needs that require modified living spaces. Because military families relocate often, those with housing accommodation requirements often deal with the same issues each time they move. Each Service has its own housing program that manages government-owned housing units and coordinates private, off-base housing through home-finding and referral services. The availability of quality military housing on base and affordable housing off base varies considerably from one location to another, making it difficult to give special needs families a blanket statement of how their housing needs will be met at a new duty station. They can be assured, however, that military housing programs are prohibited from discrimination on the basis of disability, and they are required to make reasonable accommodations for special needs. Each Service will make housing modifications to accommodate disabilities on a case-by-case basis or relocate families to suitable housing at no cost to the family. Military families that have special housing requirements such as handicapped accessibility or climate control/air quality monitoring should be advised to make contact with the housing office or EFMP coordinator at their new duty location as early as

possible. Medical documentation of special housing needs will normally be required before assignment to special needs housing or modification to a housing unit is approved.

5.3.1 Military Housing Privatization

A major initiative is currently underway to improve the availability, condition, and affordability of housing for military personnel through privatization.

The Military Housing Privatization Initiative

(MHPI) allows each Service to work with commercial enterprises to rehabilitate or rebuild substandard military family housing through a variety of financial mechanisms including loans,

loan guarantees, equity investments, conveyance or leasing of land, housing, or other facilities. Service members will be able to use their basic allowance for housing (BAH) to live in either private-sector housing or privatized military housing.

Privatized housing offers improved housing accommodations for special needs families who prefer living in military communities. As units are renovated or rebuilt, they will be brought up to modern housing standards, and a higher percentage of them will become handicapped accessible, particularly in areas of high EFM concentrations. The property managers will be required to make reasonable alterations and accommodations consistent with the Americans with Disabilities Act at no cost to the tenant. Common areas including playgrounds in privatized housing will all be handicapped accessible. For more information on privatization, special needs families may be referred to the MHPI website, www.acq.osd.mil/housing/.



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5.3.2 Private Sector Housing

For military special needs families who choose to rent in the private sector, own their home, or explore housing options for an adult EFM, local government housing programs should help them become familiar with issues and sources of support. In addition, HUD has a Disability Rights and Resources page that provides extensive fair-housing information for disabled persons, housing providers, and building professionals, including information on the Section 811 program for low-income adults with disabilities: www.hud.gov/offices/fheo/disabilities/.

5.3.3 Housing Discrimination

Even when they do not require housing modification, many special needs families are still subjected to housing discrimination. Military special needs families should report housing discrimination to their installation housing referral service, especially if it referred them to the housing provider. For service members in locations not served by a housing referral office, the HUD site shown above provides information on filing discrimination complaints, and the Bazelon Center for Mental Health Law has extensive information on fair housing laws and litigation with over a dozen information sheets on housing discrimination issues: www.bazelon.org/about (click on “Issues”).

5.3.4 Emergency Life Support and Evacuation

Whether they live in government or private housing, families with an EFM who is immobile and/or dependent on life-sustaining equipment must have plans and procedures in place for emergency evacuation or a back-up power source in the event of power outages. These families should be assisted in developing plans and, if they live on the installation, they should be included in housing disaster preparedness plans.

5.4 Financial Assistance

Most military families with EFMs struggle to make ends meet despite benefits they may receive to help with care. Financial assistance for purchasing special equipment or home health care services does not cover the many out-of-pocket expenses that are the norm for special needs families. These routine expenses include frequent trips for medical treatment, lost wages as a consequence of care, and purchases of supplies and equipment not covered by benefits. On average, special needs families have less earned income than other families because parents are less likely to both be working outside the home. This section provides some resources for special needs families who may be having temporary financial difficulties. For information on disability income benefits, see Chapter Four.



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5.4.1 Military Aid Societies

A private, nonprofit organization supports each of the Services by providing emergency financial assistance in the form of interest-free loans and grants to active and retired service members and their families. This assistance is there when military families have a valid financial need that they cannot meet. Active duty families usually know of or have used these organizations, but Reserve Component service members on active duty and their families may not be aware of all the ways they can help military families. More information about military aid societies can be found on their websites.

- Army Emergency Relief – www.aerhq.org/
- Air Force Aid Society – www.afas.org/
- Navy Marine Corps Relief Society – www.nmcrs.org/

5.4.2 Financial Management Information and Assistance

Most installation family centers have financial management assistance in the form of classes in managing personal finances, consumer spending and debt reduction. Some offer budget and debt counseling. All family centers will have information on credit counseling and consumer resources in their communities. Military families who do not have access to a family center should be referred to one of the national nonprofit credit counseling organizations which link customers to local services throughout the U.S. or offer services online.

- National Foundation for Credit Counseling – www.nfcc.org/
- Consumer Credit Counseling Services – www.cccsintl.org/
- Springboard – www.credit.org/

5.5 Special Needs Planning and Legal Assistance

A major issue for parents of EFMs with significant disability or mental illness is how they will be supported after the parents are no longer living or able to care for them. Planning for a disabled child's future care and quality of life may involve complex financial and legal arrangements to preserve assets for the child's care without jeopardizing eligibility for government benefits. Military legal services offices provide assistance for a wide range of legal needs including wills, power of attorney, and advice on issues such as divorce, consumer rights, estate planning, immigration, bankruptcy, and taxes (Army Legal Services' website www.jagcnet.army.mil/legal is an excellent resource for information about common legal problems and includes a military legal services locator). However, when it comes to complex, long-term planning for a disabled child, many parents will opt to secure the services of professionals who are experienced and knowledgeable about special needs trusts and appropriate funding vehicles.

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5.5.1 Financial Planning

Many financial planning, insurance, and investment companies now offer specialized services to help families prepare for the long-term care of a disabled member. Large firms such as MetLife, MassMutual, and Merrill Lynch have created special needs units and are training brokers and agents to help clients preserve government benefits, anticipate the long-term cost of special needs care, and incorporate special needs trusts in their plans. Special needs families that expect to contribute financially to the care of a child after they are gone should be cautioned to ensure they have a financial adviser who is knowledgeable about special needs issues. Christopher Oster, in his *Wall Street Journal* article, "Financial Firms Focus on Parents of Disabled," says that

One common mistake is placing money in a Uniform Gift to Minors Account, which some advisers suggest as a way to pass along assets to children without incurring big tax hits. But the money is held in the child's name and can disqualify her or him from government assistance at the age of 22, when benefits become harder to come by.

Parents need to know that there is no one-size-fits-all plan for a disabled child, but there are a few basics of special needs financial planning that a good adviser can help families cover.

5.5.2 Legal Planning Actions

Wills, guardianships, and trusts are legal actions that require the assistance of an attorney. All parents with EFMs should have an up-to-date will, but their need for a guardianship or trust will vary depending upon the child's unique needs and their family situation.

Wills: A will is the center piece of a special needs plan. After a person dies, it provides for property distribution, for naming a guardian (subject to state court confirmation), and for creating a trust or transferring assets into an existing trust. Wills may be changed to reflect new intentions up until the maker's death. Even when parents have few assets or liabilities that exceed assets, a will still allows them to indicate desires and intentions for their children. In special needs situations, the absence of a will could result in a distribution of assets which might be mismanaged or jeopardize government benefits, or it could leave guardianship choices to the court.

Trusts: A trust holds money or property for the benefit of another person and usually contains carefully written instructions on when and how the trust's assets can be used. Trusts have a person or institution designated to be the trustee to oversee distribution of assets. There are many different types of trusts including "special needs trusts" specifically designed so that funds supplement the beneficiary's care and do not pay for expenses covered by SSI, Medicaid, or other public funds that are tied to income and assets. Trusts may be funded through a combination of family assets, inheritance, gifts from family or friends, or life insurance.

Guardianship: A guardianship is a court-approved legal relationship between a competent adult and a minor child or an impaired adult. Guardians have a defined degree of authority over their wards. Therefore, appointments should be made only to the extent necessary for the protection and welfare of the individual and based on his or her needs and abilities. A guardianship may be for the person or for property. It may be full guardianship over all aspects of a person's care, limited guardianship that allows the ward to have autonomy in some areas, or temporary guardianship. Parents of significantly disabled children should be aware that when their child reaches the age of majority, they are no longer the legal guardians. The law regards disabled children over 18 (or 21 in some states) as adults unless someone has gone to court to become their guardian.

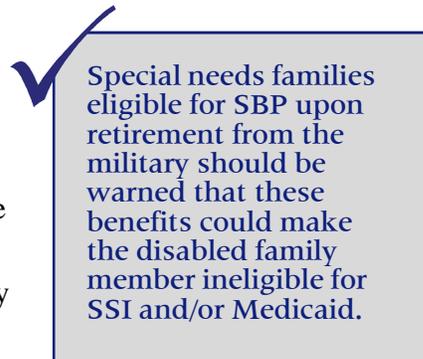


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Alternatives to Guardianship: Guardianship can be a very sensitive issue for families. When a person’s mental retardation or other disability is so severe that he or she cannot meet basic needs, there is no question about the need for a guardian. In other cases, families can be conflicted about a child’s ability to handle money, property, or personal care decisions. Parents may be well advised to explore alternatives to guardianship before pursuing legal action. Some common alternatives are appointing a representative payee for benefit checks, having joint property ownership and joint bank accounts, and establishing a durable power of attorney or health care proxy. Detailed information on guardianship may be found on the website of the National Guardianship Association, www.guardianship.org.

5.5.3 Survivor Benefit Plan

Military retirees rely on the Survivor Benefit Plan (SBP) to provide for their survivors upon their death. They are automatically enrolled at the time of retirement unless they take action to decline coverage or reduce the amount. They may also name their children up to age 18, or age 22 if still in school, as beneficiaries. Some disabled children may receive benefits for life if they became incapable of self support while they were eligible beneficiaries.



Special needs families eligible for SBP upon retirement from the military should be warned that these benefits could make the disabled family member ineligible for SSI and/or Medicaid.

Current laws prohibit SBP from being placed into any kind of trust. Special needs families eligible for SBP upon retirement from the military should be warned that these benefits could make the disabled family member ineligible for SSI and/or Medicaid.

5.5.4 Quality of Life Planning

In developing future plans for an EFM, parents must consider the quality of their child’s future as well as the financial support. Future planning should begin during the early teen years when the child, parents, and school begin developing a transition plan. Planning that focuses on the child’s goals for continuing education, job training, employment, and living arrangements should be augmented by discussions about money management plans, coping skills, and social/recreational opportunities. Continuing future planning into adulthood is important even if the child has mastered independent living but still relies on the parents for advice and emotional support. Parents should be encouraged to talk with their child often about the future and prepare him or her for a time when they will no longer be there.

Living Arrangements: Parents of disabled children who have reached the age of adulthood, but who remain at home unable to live independently, should have a plan for alternative living arrangements. There are many options, and parents will want to choose the one that best meets their child’s needs. Options may include group or supported living homes, public or private residential facilities, boarding homes, nursing homes, and mental hospitals. If parents and their child are considering a group home, they should be advised that some homes have waiting lists of many years, and they should look into this option as soon as possible.

Letter of Intent: A letter of intent is not a legal document, but it can be a useful tool for parents who want future caretakers to understand and support their child’s current quality of life. In it, parents can describe his or her likes and dislikes, diet, education, work, recreational needs, and health care issues. A letter of intent will also include information on doctors, therapists, and teachers as well as instructions for medications and therapeutic procedures. Some families put their letter in a three-ring binder with pictures of their child and photocopies of important documents such as the parents’ will and trust documents and the child’s social security card, birth certificate, medical records, Medicaid card, IEP, etc. Parents with a letter of intent should be reminded to keep it updated and make sure someone else knows where to find it.

5.5.5 Information Resources for Special Needs Planning

Installation legal services offices will have basic information about wills, trusts, and many other common legal matters. Military legal assistance attorneys can provide advice on a wide range of issues and refer clients for specialized services that they do not provide. There is a great deal of information on the Web about future planning for special needs children. At least two organizations publish special needs planning materials that may be downloaded from their websites.

- The ARC is a national organization that advocates for people with mental retardation, and its resources include “A Family Handbook on Future Planning,” www.thearc.org
- STOMP publications include a pamphlet specifically for military families entitled “Wills, Guardianship and Special Needs Trusts,” www.stompproject.org

Some insurance companies, investment firms, and financial planners will advertise special needs financial planning services. The companies mentioned in 5.5.1 above have special needs pages and information about services on their websites, while other companies address special needs planning only on a case-by-case basis. USAA,

which serves the unique insurance, banking, investment, and financial planning needs of the military community, offers advice on many topics of interest to military families, including special needs planning. The company also maintains a free Financial Advice Center to help military members and their families achieve financial security.

5.6 Emotional/Spiritual Support and Coping/Parenting Skills

When parents recognize their child is not going to have a typical course of development into adulthood, their lives are changed forever. At best, they experience a roller coaster of emotions that include the initial shock and sadness of learning their child has special needs to fear of the responsibility of caring for them to anger and frustration as they negotiate complex systems trying to get the special needs met. These painful emotions are, of course, intertwined with intense love and admiration for their child's unique qualities as a human being and pride in his or her accomplishments. At worst, parents of special needs children allow themselves to be defined by their children's circumstances. These parents may suffer significant depression or intense anger at their child, spouse, or others in their environment. Where a parent is on this emotional continuum is influenced by his or her personality style and coping skills, the family's strength and unity, and the support and encouragement available from others. Most special needs parents develop a sense of confidence, resiliency, and determination as a consequence of the demands of parenting a disabled child. Yet nearly every one of them, at certain times, will need help in developing the skills necessary to cope with parenting a special needs child and in managing the emotions that emerge. A few of them will need specific interventions to help them avoid the risk of abuse or neglect. This section offers options that may be suggested to parents who are in need of support as well as services for those at risk.

5.6.1 Counseling

Counseling is a way for people who are facing situations or emotions that they feel they can't handle or control to find help from a trained professional. A counselor will listen to the problem and ask probing questions to get at a deeper level of what is going on and then either explore with the client ways to change his or her thinking about an issue or teach skills that can be used to better manage feelings or situations. Counseling to help someone deal with a stressful or painful situation may require only a few sessions. By contrast, individuals who have serious emotional difficulties that are not in response to an immediate set of circumstances will need psychiatric care in

which counseling may be just one component. Parents of EFMs should be referred for counseling if they seem to be having difficulty accepting the child and coping with his/her needs or if they are feeling overwhelming emotions. Military parents have several options for cost-free counseling.

Military OneSource: One of the benefits of Military OneSource is short-term counseling up to six sessions. Military ID card holders can be referred to a counselor in their area who is part of Military OneSource’s extensive network of licensed and credentialed professionals. A call to the toll-free number, **1-800-655-4545**, is the first step in being connected with a counseling professional.

Chaplains/ministers: Many people are more comfortable seeking counseling that has a spiritual component. When parents of EFMs seem to be having difficulty coping, it is good to ask them about their religious ties before making a referral for counseling. Military chaplains and ministers in the civilian community often have professional counseling expertise over and above their ability to provide spiritual guidance and support.

Family Centers: Some military family centers offer short-term, solution-focused counseling within their programs. At the very least, family centers will provide consultation, assessment, and referral for counseling, plus help arrange respite care, if necessary, during counseling sessions.

Note: Anytime a person expresses the desire or intention to hurt his or her self or others, immediate action should be taken to ensure an emergency evaluation at a medical treatment facility. Counseling will be needed later after the person has stabilized emotionally.

5.6.2 Peer Support

Many people caring for a disabled family member have found emotional support through relationships with other parents in similar situations. Talking to others who share the same experiences, emotions, and concerns can be extremely reassuring as well as a source of new skills, knowledge, and insight.

Opportunities for peer support can be in person, through organized groups dealing with a particular issue or condition, and in cyberspace through online discussion groups, chat, and listservs.



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Support groups: Many installation family centers sponsor or have information on support groups for military special needs families. Local hospitals and schools often organize support groups around a particular disability, such as autism. Support groups may also be located by contacting the national association for a particular disability. When parents are interested in starting a group, they can be assisted by providing information and materials such as this online pamphlet provided by the Pennsylvania Parent to Parent organization: www.parenttoparent.org/Sup-run-t.htm.

Parent-to-parent programs: These programs are organized at the state and local levels to offer support and information to parents of children with disability, chronic illness, or special need. A typical parent-to-parent program will match a “support parent”—a trained volunteer who has developed effective coping skills and strategies for parenting a child with special needs—with a “referred parent” who has a child newly diagnosed, in crisis, in transition, or simply in need of support. Parents are matched as closely as possible based on the child’s diagnosis, family structure, and ethnic or religious similarities. The kind, frequency, and duration of contacts vary based on individual needs. The Beach Center on Disability at the University of Kansas (www.beachcenter.org) maintains an updated list of links to Parent-to-Parent groups by state.

Online chat, discussion boards, and listservs: Parents of special needs children are increasingly turning to the Internet to find support and encouragement. Many national associations for specific disabilities sponsor online discussion groups. STOMP has a listserv for military special needs families. (see Appendix D) And an online directory of support communities, www.supportpath.com/, lists message boards, chats, and information on hundreds of topics, including disabilities.

5.6.3 Services for At-Risk Special Needs Families

Caring for a disabled child can become so overwhelming for some parents that they are at risk for abuse or neglect. These parents can be stressed to the limits of their control when the child exhibits behaviors that are increasingly difficult to manage. Others overcome by sadness and depression may be in danger of neglecting the needs of all their children. And many parents, particularly very young ones, find themselves caring for a child with special needs when they lack even the most basic knowledge and skills necessary for successful parenting. When these young parents are military, they often do not have their own parents nearby to offer advice and support, and they may be separated as a family during critical periods in their child’s development if one parent is deployed. One of the most important things that professional services providers can do for special needs families is to recognize those at risk and ensure they are connected to services.

New parent support programs: Each of the Military Services has developed programs to support new parents beginning with the prenatal period through the first year of their baby's life. In Chapter Three, the role of new parent support programs (NPSP) in identifying infants with developmental delay and making referrals for early intervention services was discussed. But the primary goal of these programs is to support young military parents at risk for abuse or neglect by helping them develop the knowledge and skills needed to form healthy relationships and provide safe, nurturing environments for their babies. NPSP services are matched to the needs of individual families, and they include home visitations, education, counseling, and referrals to other resources. The installation family center can assist with referrals to NPSP. For military families that do not live near an installation, Healthy Families America is a resource for locating new parent support programs in civilian communities. Its website identifies contacts for state systems: www.healthyfamiliesamerica.org.

Parenting education programs: Military family centers, civilian family service agencies, community colleges, and adult education programs offer classes, workshops, and courses on parenting. They are designed to help parents develop skills such as effective discipline techniques or deal with specific situations such as divorce or blended families. Young parents who recognize their inexperience and express the desire to be more effective as parents are excellent candidates for parent training.

Family Advocacy Program: Each of the Services has a Family Advocacy Program (FAP) that addresses child and spouse abuse within military families. In addition to coordinating with commands and investigative agencies to ensure an appropriate response to incidents of abuse and neglect, FAP provides educational programs and resources to help parents and caregivers protect the children in their care. Anyone who suspects child abuse or neglect should report it to either the installation FAP office or to the local law enforcement agency.



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5.7 Other Support Services

The previous sections in this chapter do not in any way represent the full range of specialized programs and services available to families of children with special needs. This section covers a few other important areas of disability services in which families may have a need to be connected to resources in the military and civilian communities.

5.7.1 Adaptive Sports and Recreation Programs

Sport and recreation activities play just as important a role in the lives of many young people with disabilities as they do for non-disabled youth. Military and civilian youth programs in areas with a significant number of disabled children are likely to offer special needs sports and recreation opportunities. A number of large installations have special needs camps that are provided through collaboration among the EFMP, installation youth centers, and youth programs in the civilian community (see Model Installation Programs in Chapter 6). Parents should be encouraged to inquire about local adaptive sport and recreation programs with the EFMP or Youth Services program staff. Other resources for parents include

- Military Homefront – The DoD website has an exhaustive list of adaptive sports and recreation opportunities in the EFM pages, www.militaryhomefront.dod.mil/efm (click on Resources and scroll down to the Adaptive Sports and Recreation link)
- Special Olympics – the international organization that provides sports training and athletic competition in Olympic type sports for children and adults with intellectual disabilities has a local program locator on its website, www.specialolympics.org
- Adaptive Sports Association – a resource for adventure sports and outdoor recreational trips for people with physical and cognitive disabilities, www.asadurango.org

5.7.2 Support for Families with Seriously Ill or Hospitalized Members

When families have a seriously ill child or one who is hospitalized for an extended time, their burden can be financial as well as emotional. Organizations that provide assistance to families in these circumstances include

- **Fisher House** – a “home away from home” located at every major military hospital and several veterans’ hospitals to provide low cost lodging and support for families while their loved one is hospitalized, www.fisherhouse.org/
- **Make-a-Wish Foundation** – one of several “wish” organizations that grants wishes to children with life-threatening conditions, www.wish.org
- **National Patient Travel Helpline** – a source of information about all forms of charitable, long-distance medical air transportation and referrals to sources of help from a network of air transportation providers, www.patienttravel.org/

5.7.3 Assistive Technology

Assistive technology is any device which helps an individual with an impairment to perform tasks of daily living. There is a wide range of types of devices in assistive technology from low tech, homemade aids to computers and sophisticated electronic equipment. The Individuals with Disabilities Education Act says that students who need assistive technology are entitled to the aids and devices and the assistive technology services that are necessary for the student to benefit from a free, appropriate public education. For other disabled people and for non-educational purposes, assistive technology can be extremely expensive. However, the 1998 Assistive Technology Act, amended in 2004, provides federal funding for a nationwide program to increase access by disabled people to assistive technology devices and services. State assistive technology programs may use funding to provide information and referral services, demonstration centers, financial aid and loans of equipment, and training and technical assistance. The 2004 amendment requires state programs to use the bulk of their grants for direct aid to individuals through financing and loan programs. A listing of assistive technology projects by state can be found on the website of the Rehabilitation Engineering and Assistive Technology Society of North America’s Technical Assistance Project, www.resna.org/taproject.

