

FAMILY

CHILDREN WITH SPECIAL NEEDS





OUR MISSION

The mission of The USAA
Educational Foundation is
to help consumers make
informed decisions by providing
information on financial
management, safety concerns
and significant life events.



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2 WHAT YOU SHOULD KNOW

Understanding Special Needs

The American Academy of Pediatrics (AAP) defines children with special needs as "those who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally." The term "special needs" can describe numerous conditions ranging from mild to severe, including sensory impairment.

Parenting any child brings rewards and opportunities. When your child has special needs, the rewards are precious and the opportunities may be challenging. Your child is a child first. Spend time enjoying your child, focusing on his unique personality and interest, not on the limitations. Try to notice things your child has in common with all children and enjoy your child's strengths. This publication provides information and resources to help with some of the practical issues you will face.

TYPES OF SPECIAL NEEDS		
TYPE	DEFINITION	EXAMPLES
Physical	 Conditions that substantially limit basic activities such as walking, climbing stairs, reaching, lifting or carrying. May require devices such as wheelchairs, crutches or artificial limbs. 	 Medical issues such as muscular dystrophy, multiple sclerosis, cystic fibrosis, cancer or heart defects. Chronic conditions such as asthma, diabetes or epilepsy. Congenital conditions such as cerebral palsy or spina bifida.
Developmental	 Conditions that substantially limit the capacity for self-care, communica- tion, learning, mobility, self-direction or independent living. 	 Genetic disorders such as Down syndrome or autism. Learning disabilities such as dyslexia and central auditory processing disorder.
Behavioral/ Emotional	 Conditions that adversely affect educational performance and interpersonal relationships and cannot be explained by intellectual, sensory or health factors. Conditions marked by general unhappiness or depression, inappropriate behaviors, anxiety or fear. 	Bipolar disorder.Oppositional defiant disorder.Attention deficit disorder.
Sensory Impairment	 Conditions that affect vision and/or hearing. May require special equipment and modifications to communicate. 	Blind or visually impaired.Deaf or limited hearing.
For information and advice about specific conditions, visit The National Dissemination Center for Children with Disabilities at www.nichcy.org and click "Disabilities."		

Act Now

It is important to take action as soon as you think your child may have special needs. Use the "My Observations Work Sheet" to record your observations and questions about your child's progress. Take note of symptoms that concern you, but also pay attention to your child's strengths.

WIT UDS	MY OBSERVATIONS WORK SHEET		
DATE	OBSERVATION/OCCURRENCE	QUESTIONS/NOTES	

Importance Of Early Intervention

Early intervention is a system of services for children from birth to 3 years of age. Children at risk of a developmental delay or disorder are routinely referred to early intervention by their physicians. If a child qualifies, she may receive a range of services at no (or low) cost to the family. Early intervention is designed to improve outcomes for children with disabilities by providing early, appropriate and intensive interventions.

Make appointments to have your child evaluated — the sooner, the better. Research shows that early intervention can improve your child's developmental potential.

WHO EVALUATES MY CHILD? Your Child's Can assess your child's development. Pediatrician Can provide referrals to medical specialists as needed. May direct you to early intervention providers in your location. Your State's Early • Provides specialized health, educational and therapeutic services for infants and toddlers having developmental delays or disabilities. Intervention Program (EIP) Services vary by state. (for infants and Your child must meet certain eligibility requirements to qualify for services. toddlers) Visit www.nectac.org/contact/ptccoord.asp to locate your state's provider. Your Local Public Required by federal law to evaluate children as young as 3 years of age if School (for children a parent suspects a disability. over 3 years of age) Call your neighborhood school or local school district office for information.

Whenever you meet with a physician, therapist, teacher or other professional, remember:

- Take a list of your observations and questions.
- Take detailed notes during these appointments.

These records will help you track your child's progress over time.

6 BEING YOUR CHILD'S ADVOCATE

You are a very important part of advocacy for your child. Keep in mind a few things that will allow this to be a smooth partnership between you, the school and the medical team.

- You know your child better than a physician, therapist, teacher or other professional.
- When meeting with specialists, share your observations and ask questions.
- Do not hesitate to request further explanation, especially if something does not seem right to you.
- Stay organized. You will need detailed records to coordinate your child's ongoing care.

IMPORTANT FIRST STEPS	
When your child is diagnosed with special needs:	
Consider A Second Opinion	 Definitive tests can identify some, but not all, disabilities. Making an accurate diagnosis can be complex, requiring multiple tests and assessments of your child's physical symptoms or behaviors. A second opinion can help confirm and clarify a diagnosis.
Accept The Diagnosis	For your child's sake do not delay getting help.Understand that multiple diagnoses may exist and surface at a later date.
Schedule Care As Soon As Possible	 Research shows early intervention improves your child's ability to develop and learn. The earlier your child receives care, the better your child's chance of benefiting from available services.
Accept Your Feelings	 It is normal to feel disappointment, sadness and even grief upon learning your child has a disability. Give yourself time to develop new expectations and dreams for your child. Recognize that family members and close friends may experience similar feelings.
Become An Expert	 Learn as much as you can about your child's condition. Read articles, books and online information. Ask your physician to direct you to reputable resources. Learn about programs available to help your child. Keep a daily log of your child's progress.
Join Support Groups	 Seek the advice and support of other parents of children with special needs. Ask your physician, local community center or place of worship for help finding a support group that is right for you.
Be Patient	 Your child has a lifetime to grow and develop. Avoid negatively comparing your child to other children, even those with similar disabilities.

Choosing A Program

Many program options are available to children with special needs. It can be difficult to determine the right approach for your child, especially if you receive different or even conflicting recommendations. Whatever course you choose, remember the following:

- No one program works for every child.
- Obtain copies of reports from each medical visit.
- Your child's care will need to adjust as your child grows and develops.
- Your participation is essential. Your child will benefit most when you work closely with physicians, teachers and other experts and follow through with a program at home.
- Early intervention improves your child's ability to develop and learn.

Paying For Care

Your child may be eligible for the following state and federal government assistance programs.

FINANCIAL	ASSISTANCE PROGRAMS
Medicaid	 May pay for physician services, hospital, home health, nursing and transportation. Most programs have income eligibility requirements.
Institutional Medicaid	Available for hospital stays beyond 30 days.No income eligibility requirement.
Medicaid Waiver Programs	 Provided through state Medicaid agencies. May fund services including home health care, respite, transportation, supported employment and adult day support. Eligibility is based on the disabled individual's income and the level of care required, not on a parent's income and resources.
Medicare	 Provides publicly funded health insurance for certain adults with disabilities. Provides publicly funded health insurance for dependent adult children of parents who receive Medicare if the child developed a permanent and severe disability before 22 years of age.

FINANCIAL ASSISTANCE PROGRAMS (CONTINUED) Social The Supplemental Security Income (SSI) program pays benefits to children Security who are disabled and have low family income and resources. In most cases, children who receive SSI payments also receive Medicaid. Compassionate allowances provide financial assistance quickly to children whose medical conditions are so serious that they obviously meet disability standards. For details, visit www.ssa.gov. Children's • A federally funded health insurance program for children whose parents are Health ineligible for Medicaid but cannot afford private insurance. Insurance Provides insurance for prescription drugs and for vision, hearing and mental **Program** health services in all 50 states and the District of Columbia. (CHIP) A child having personal assets of more than \$2,000 becomes ineligible for some federal government benefits. Ask an attorney specializing in special needs law about establishing a special trust for funds above this amount.

Doing Research

Begin your research using the "For More Information" section of this publication. Then, ask your child's physician, local Early Intervention Program (EIP) office or local school district for additional sources of information.

The Internet is useful for finding medical facts, advocacy tips, parenting advice, coping strategies and support groups, but information may be outdated or inaccurate. Verify information by checking it against multiple sources. Always consult an expert you trust before following advice found online.

Planning your child's special education can be complex and time consuming. Before you begin, visit the National Dissemination Center for Children with Disabilities Web site, at www.nichcy.org. It provides detailed information to help you understand and manage the special education process.

Evaluate Needs

Whether your child's disability is diagnosed during infancy or later, an evaluation is necessary for receiving special education services.

- The school system must ensure that your child's evaluation is focused on your child's needs and that it assesses all areas related to a suspected disability.
- If you do not feel that the evaluation has addressed all of your child's educational needs, you have the right to take your child for an independent evaluation. You may ask the school system to pay for this evaluation.
- You and a group of qualified professionals will review the evaluation results and decide
 if your child has a disability as defined by the Individuals with Disabilities Education Act
 (IDEA). If not, your child may still qualify for services under Section 504, as described in
 the chart on federal laws for children with special needs.
- If your child is eligible for special education, you, your child's teacher and other professionals as appropriate will meet to create an Individual Education Program (IEP) for your child.
- Special education services begin after the IEP is written and you have agreed to the outline of educational services.

Parents of children with special needs should be familiar with acronyms used by educators and medical professionals. For a listing visit www.nectac.org/chouse/acronyms.asp.

Know Your Child's Rights

Every child in the United States is legally entitled to a free and appropriate education in the least restrictive environment. The following federal laws apply specifically to children with special needs:

FEDERAL LAWS FOR CHILDREN WITH SPECIAL NEEDS

The Individuals With Disabilities Education Act (IDEA)

- Governs how states and public agencies provide early intervention, special education and related services to children with disabilities.
- Applies to children from preschool through 21 years of age having serious emotional disturbance, learning disabilities, mental retardation, traumatic brain injury, autism, vision and hearing impairments, physical disabilities or other health impairments.
- Requires that students with these disabilities be prepared for further education, employment and independent living.

Section 504 Of The Rehabilitation Act

- Prohibits schools from discriminating against children with disabilities.
- Requires schools to provide reasonable accommodations (including untimed tests, modified homework and other provisions) for these children.
- Applies to children whose disabilities are less severe than those covered under IDEA, or do not fit within the IDEA eligibility categories. Any child with an impairment that substantially limits a major life activity (including learning and social development) is considered disabled.

The Americans With Disabilities Act (ADA)

- Requires all educational institutions, other than those operated by religious organizations, to accommodate the needs of children with psychiatric problems.
- Prohibits the denial of educational services, programs or activities to students with disabilities and prohibits discrimination against all such students.

No Child Left Behind Act

- Requires states to uphold achievement standards for all students in certain grades in order to receive federal funding.
- Has improved expectations and results for students with disabilities.
- For a full description, visit www.ed.gov/nclb.
- Eligibility criteria and available services vary by state. Consult your state's Department of Education for details.

Preserve Your Child's Rights

In some cases, you may need to take the following steps to ensure your child receives appropriate services:

- Request a copy of your school district's Section 504 plan in order to be fully aware of the services available to your child.
- The nearest Civil Rights Regional Office of the U.S. Department of Education can provide assistance in obtaining additional information on the specific types of disabilities covered under Section 504.
- If you do not feel the school district is addressing the educational needs of your child, you may request a facilitated Individualized Education Program (IEP) meeting with a neutral facilitator. If the outcome is not satisfactory a "due process" hearing can be requested through the local department of education. A mediator will provide neutral conversation between you and the school district so that the best plan can be developed for your child.

Remember, you are a partner in your child's education.

For more information, visit the U.S. Department of Education Office for Civil Rights at www.ed.gov.

12 BALANCING LIFE

When you have a child with special needs, most normal activities of family life take on added complexity. You and your family will have to approach everyday issues with creativity and flexibility.

Giving Your Child Confidence

For all children, achievement depends on self-confidence and self-worth. The most important thing you can give your child with special needs is the feeling that she is valuable.

- Avoid focusing too much on your child's progress with therapy or learning new skills.
- Provide opportunities for social interaction with other children and adults, through play groups, places of worship and other support systems.
- Consider camps, school programs and community activities for children with special needs, where your child can gain independence and confidence.

Special Olympics provides opportunities for children with special needs to develop physical fitness, skills, courage and friendships. For more information visit www.specialolympics.org.

Coping With Teasing and Bullying

Most children face teasing during childhood. As a parent you can help ward off bullying and protect your child by encouraging the following:

- Help your child develop a strong sense of self. Recognize that you cannot isolate your child from disrespectful individuals.
- Teach your child appropriate ways to respond to bullying without fighting.
 - Ignore the situation.
 - Request help from an adult.
 - Support other children who are being bullied.
- Help teachers understand your child's disability and what your child needs. Work with the school system to prevent and respond to bullying problems.

Words Matter

Like any individual, your child has unique interests, abilities, hopes and needs. Use language to help your child — and others — recognize this fact.

SAY:	INSTEAD OF:
He has a disability.	He is handicapped.
 She rides a power chair. 	She cannot walk.
 He walks with crutches. 	He is crippled.
She has a congenital disability.	• She has a birth defect.

Managing Change

Many children with special needs depend on a highly structured schedule. When you know your child's schedule will be interrupted by a major change, such as a family relocation, change of schools, military parent's deployment or even a family vacation, it is important to plan ahead.

- Begin talking about the change ahead of time.
- Keep a calendar that you and your child use to track the days and weeks until the change comes.
- Show your child photographs of the new location.

Relocation

When a major change occurs, such as moving to a new state, you will need to take the following extra steps to ensure your child's transition is a smooth one:

V	MOVING CHECKLIST
	 Tell your child's teachers, physicians, therapists and other professionals that you are moving, as soon as possible.
	 Request copies of all evaluations, assessments, reports, Individual Education Programs (IEPs) and related documents in your child's school files.
	 Ask for school records, such as IEPs or transition plans, to be updated if needed.
	 Send copies of all records to your child's new school. Make appointments for meetings soon after your move.
	Request copies of all medical records.
	 Ask for referrals to physicians in your new location.
	 Make sure you have at least a 1-month supply of all prescriptions.
	Learn about disability benefits in your new state.
	 Ask your new state's department of special education about policies and eligibility requirements. For a listing, visit www.MilitaryChild.org, click the tab Military Parent Information.
	Keep all records with you throughout the move. Do not allow them to be packed.

Traveling Safely

Ask your pediatrician for advice on traveling safely with your child.

- Find out if your child has special positioning or transportation needs.
- Your child may require a special medical child safety seat or restraint when riding in a vehicle.
- Never try to alter a child safety seat to fit your child with special needs.

For more information, visit the American Academy of Pediatrics (AAP) Web site at www.aap.org/family/SpecialCarSeatsChart.pdf.

Balancing Family Needs

When your child with special needs requires constant time and care, it can be difficult to give other children the attention they need. Consider these suggestions:

- Set aside one-on-one, uninterrupted time each day or week for other children. Ask your spouse, a grandparent or close friend to care for your child with special needs during this time.
- Keep sibling rivalry in perspective, remembering that some amount of sibling competition is normal in any family.
- Include other children in their sibling's care as appropriate. Answer other children's questions about their brother or sister.
- Communicate and be honest. Admit that you give more time to your child with special needs. Explain that more time does not equal more love.
- Find creative ways to tell each of your children how much you love them.

Caring for a child with special needs is very rewarding. However, from time to time, a caregiver might feel frustrated or like no one understands their struggles. Making time for yourself and allowing others to help you will be a very rewarding way to provide the utmost care for your child with special needs as well as the rest of the family.

Take Care Of Yourself

The responsibility, emotion and stress of caring for a child with special needs can put you at risk of exhaustion and illness. Occasional feelings of loneliness, jealousy, self-pity and frustration are normal. Some days will be better than others and you should not be concerned by temporary feelings of sadness or fatigue.

However, if you experience more extreme symptoms — such as overwhelming sadness, selfcriticism, apathy or hopelessness — you may be suffering from depression. If these symptoms persist, schedule an appointment with your physician.

To maintain energy and emotional strength:

- Exercise regularly.
- Maintain a healthy diet.
- Try to sleep 7 to 9 hours every night.
- Ask for help so you can take longer breaks periodically.
- Take one day at a time and try not to worry about the future.
- Maintain your sense of humor and focus on the positive aspects of your situation.

Important Adjustments

As a caregiver of a child with special needs, you will find meaning and balance in giving them the best care possible. The following page includes tips for when you feel your relationships, career and personal activities begin to undergo stressful situations. Creating balance for yourself and family is crucial to promoting a stable and healthy lifestyle.

RELATIONSHIPS

HOW THEY ARE AFFECTED

- You may have less time with your spouse, other children, extended family members and friends.
- The pressure of added responsibilities may affect your behavior toward your loved ones.
- Making decisions about your child's care can be difficult and stressful, especially if parents disagree on the best choice.

WHAT YOU CAN DO

- Avoid isolation. Make time for family and friends who provide needed support.
- Remember disputes will occur and are normal. Handle problems openly and honestly.
 Do not ignore them.
- Consider asking a trusted friend, clergy member, physician, social worker or professional counselor for help if you cannot resolve important issues.

CAREER

HOW IT IS AFFECTED

- You may have to use vacation time or paid time off for medical appointments, school meetings and other responsibilities.
- You may need to limit hours of work, take a leave of absence, change positions, forego promotions or training opportunities or take early retirement.

WHAT YOU CAN DO

- Demonstrate respect for your employer's schedule by giving as much advance notice as possible when you need time off to care for your child.
- Learn your employer's caregiving policies and provisions. Talk with your manager or supervisor about possible options for your situation.

PERSONAL ACTIVITIES

HOW THEY ARE AFFECTED

- · You will have less leisure time.
- You may need to postpone or give up hobbies and goals important to you.
- Caring for your child may infringe on social engagements and time with friends.

WHAT YOU CAN DO

- Allow time for breaks from caregiving responsibilities.
- Think about which activities you are willing to eliminate if necessary.
- Avoid isolation. Make time for friends who provide needed support.

Involve Others

It is important to share caregiving responsibilities with your spouse, older siblings, a grandparent or close friend. If you cannot turn to family members or friends, ask the following individuals, organizations and agencies for help:

- Your family physician.
- Your company's Employee Assistance Program or benefits specialists.
- Caregiver support groups.
- Respite care providers.
- Community resources, such as social service agencies.
- Clergy members, social workers, psychologists and nurses trained to provide counseling.
- Local place of worship and private organizations.
- Local government agencies.

Stay Organized

- Create a master list of all physicians, agencies and other providers having information about your child. Include mailing addresses, phone numbers and e-mail addresses.
- Ask each provider to send you complete copies of your child's records.
- Keep copies of your child's educational records evaluations, written correspondence with teachers and other documents.
- Take detailed notes of conversations with physicians, insurance providers, service agencies, government offices or community organizations. Record the name of the individual, date of the conversation, contact information and content of the discussion.
- Keep all information in a master file, sorted by year and date. Make sure your spouse and at least one other trusted individual knows where this information is located.

18 RESOURCES FOR MILITARY FAMILIES

Navigating the military health care system is often a maze of obstacles for parents of children with special needs. However, there are resources available for military families.

Exceptional Family Member Program (EFMP) is to help servicemembers find the appropriate resources for their child. The EFMP has two components: personnel and family support. Your military installation can help you complete the appropriate documents to enroll in the EFMP program.

TRICARE is the military health insurance plan for eligible family members of active duty service-members; military retirees and their eligible family members; surviving eligible family members of deceased active duty or retired servicemembers; and some former spouses of active duty or retired servicemembers. In addition to standard TRICARE benefits there is an additional benefit program for the dependents of active duty servicemembers who have a disability.

The TRICARE Extended Care Health Option (ECHO) provides services that enhance the TRICARE plan selected by the servicemember. Depending on the diagnosis, ECHO may provide the following services:

- Medical and rehabilitative services.
- Training to use assistive technology devices.
- Institutional care when a residential environment is required.
- Transportation under certain circumstances.
- Assistive services, such as those from a qualified interpreter or translator, for beneficiaries whose visual or hearing impairment qualifies them for ECHO benefits.
- Durable equipment, including adaptation and maintenance.
- In-home medical services through TRICARE ECHO Extended Home Health Care (EHHC).
- In-home respite care services.

For more information on TRICARE visit www.tricare.mil/.

Specialized Training Of Military Parents (STOMP) is a National Parent Training and Information Center for military families providing support and advice to military parents regardless of the child's medical condition. For more information on STOMP visit www.stompproject.org/.

The time you spend caring for your child's immediate needs can detract from planning for the future. At a minimum, you should take these basic steps to provide for your child's future care.

Prepare A Letter Of Intent

A letter of intent is not a legal document. However, it is an important way to communicate your child's needs to future caregivers. It should contain every detail of your child's medical needs, schedule and care, and should be updated regularly.

Draft A Will

Without a will, a court makes decisions about your property according to state law — which does not consider how those decisions might jeopardize your child's access to care. A will is necessary for you to name a guardian who can provide for your child's care. You should consider naming a successor in the event that the guardian you choose is unable to take on the responsibility. Even with a will, you will need to make special provisions to ensure your child with special needs does not become ineligible for needed government benefits upon your death.

Consider A Special Needs Trust

A special needs trust or supplemental needs trust, can allow you to leave money or other assets to your disabled child without losing eligibility for necessary government benefits. A special needs trust can ensure that your child receives money for education, counseling, medical attention or other expenses not covered by public assistance. The trust may be funded through a life insurance policy or assets such as bank accounts or real estate.

Consult A Professional

Do not leave your child's care to chance. As you make provisions for the future, it is important to seek professional advice from financial planning professionals and attorneys who specialize in special needs law.

Staying Positive

Caring for a child with special needs requires patience, flexibility and commitment. As a parent of a child with special needs, you want the best possible life for your child. When the challenge becomes overwhelming, rest and reflect on the significance of providing for your child's health and happiness, as well as the joy your child brings to your daily life.

Your Journey

Learning that your child has special needs is the beginning of a long, but rewarding journey. Those who have traveled it often say that the satisfaction they experienced — and the special opportunities they received — brought them more love and joy than they ever expected as a parent.

20 FOR MORE INFORMATION

American Academy of Child and Adolescent Psychiatry

3615 Wisconsin Avenue, N.W. Washington, DC 20016-3007 (202) 966-7300 www.aacap.org

American Academy of Pediatrics

141 Northwest Point Boulevard Elk Grove Village, IL 60007 (847) 434-4000 www.aap.org

Center for the Improvement of Child Caring

6260 Laurel Canyon Boulevard, Suite 304 North Hollywood, CA 91606 (800) 325-CICC (2422) www.ciccparenting.org

First Signs, Inc.

P.O. Box 358 Merrimac, MA 01860 (978) 346-4380 www.firstsigns.org

Military Child Education Coalition

909 Mountain Lion Circle P. O. Box 2519 Harker Heights, TX 76548-2519 (254) 953-1923 www.militarychild.org

My Child Without Limits

www.mychildwithoutlimits.org

National Dissemination Center for Children with Disabilities

1825 Connecticut Avenue, N.W., Suite 700 Washington, DC 20009 (800) 695-0285 www.nichcy.org

National Early Childhood Technical Assistance Center

Campus Box 8040, UNC-CH Chapel Hill, NC 27599-8040 (919) 962-2001 www.nectac.org

National Institute of Child Health and Human Development

P.O. Box 3006 Rockville, MD 20847 (800) 370-2943 www.nichd.nih.gov

Social Security Administration

Windsor Park Building 6401 Security Boulevard Baltimore, MD 21235 (800) 772-1213 www.ssa.gov

U.S. Department of Education Office of Special Education and Rehabilitative Services

www.ed.gov/about/offices/list/osers/index.html

United Way

www.liveunited.org

RESOURCES







The USAA Educational Foundation offers the following publications on a variety of topics:

KEEPING YOUR CHILD SAFE (#549)

HELPING CHILDREN DEVELOP HEALTHY HABITS (#547)

BALANCING FAMILY AND CAREER (#529)

FAMILY VALUES: BUILDING A LEGACY (#562)

PARENTING A TEEN (#515)

SUICIDE PREVENTION (#581)

ESTATE PLANNING (#518)

INSTALLING CHILD SAFETY SEATS (#544)

CHILD SAFETY IN AND AROUND VEHICLES (#555)

BICYCLE SAFETY (#542)

INTERNET SAFETY FOR TEENS (#573)

PREPARING YOUR CHILD FOR COLLEGE (#514)

FAMILIES DEALING WITH DEPLOYMENT (#538)

To order a free copy of any of these and other publications, visit www.usaaedfoundation.org or call (800) 531-6196.

Information in this publication was current at the time it was printed. However, the Foundation cannot guarantee that Web sites, physical addresses and phone numbers listed in this publication have not changed since then.

If a Web site address, physical address or phone number has changed since you received this publication, log onto a search engine and type in keywords of the subject matter or organization you are researching to locate such updated information.

THE USAA EDUCATIONAL FOUNDATION®

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