

Assistance to Parents of Children With Disabilities

► Help is Available

As the parent or guardian of a child with a disability, you may have many questions about support and assistance available to you. This chapter is designed to provide information and resources to assist you in making decisions for your child and family.

Section One will describe the resources available to you free of charge from the Missouri Developmental Disabilities Resource Center, which provides information on disabilities, emotional support through a parent matching network, and leadership development opportunities that can help you become a more knowledgeable advocate.

Section Two offers information to consider when a child with a disability is turning 18, such as guardianship, conservatorship and alternative safeguards.

Section Three provides information on educational rights and laws for children with disabilities.

Section Four describes financial assistance and services available in Missouri for children with disabilities.

► Section One — Resources

Missouri Developmental Disabilities Resource Center

The Missouri Developmental Disabilities Resource Center (MODDRC) provides a network of support options, including information, peer support, and leadership development opportunities. The MODDRC helps individuals with developmental disabilities and their families to be well informed, hopeful, connected within their communities, and know that they are not alone in their experience with disability. The MODDRC can help families in many ways:

Information on Specific Disabilities, Related Topics or Resources

- Receive information about specific types of disabilities or special health care needs.
- Learn about topics and best practices, such as therapies, interventions, planning for the future, legal issues, employment, inclusion, housing, microboards, assistive technology, and much more.
- Get help with identifying services and support in your community, as well as agencies that might be of assistance.

Peer Support through the Sharing Our Strengths Support Network

- Be connected with another parent or self-advocate who can discuss specific topic or concerns with you (Quick Match)
- Be matched with another parent or self-advocate to talk and share experiences, to help you feel less alone and more hopeful.
- Get help finding a support group in your area or for a specific disability type.
- Volunteer to become a trained mentor and help support others.

MODDRC Provides Leadership Development Opportunities

- Learn ways to volunteer in your local area or around the state
- Make a difference in your community
- Find opportunities to increase your knowledge and skill
- Connect to other advocates in the network

The MODDRC is a partnership of the UMKC-Institute for Human Development, a University Center for Excellence in Developmental Disabilities; the Missouri Planning Council for Developmental Disabilities; and the Missouri Department of Mental Health, Division of MR/DD. Connect to this FREE service at 800-444-0821 OR 800-773-8652

TTY 800-452-1185; www.moddr.com

▶ Section Two — Guardianship/Conservatorship/Alternatives

When a Child Becomes an Adult

Once your child reaches his 18th birthday, he becomes an “emancipated person,” an individual free to make choices for himself, regardless of his mental or physical capabilities. Often parents are encouraged by their school or service providers to seek guardianship of their child with a disability. However, there are many options available that can help parents protect their child and still provide them an appropriate level of independence.

The following are a list of questions that you should consider before your child with a disability reaches the age of 18:

- *What are my child’s strengths, abilities and limitations?*
- *What decisions is my child able to make without assistance?*
- *What decisions will my child need assistance with?*
- *Who are the people in my child’s life who will assist them in making decisions throughout their life?*
- *Will my child require “protection” from legal, financial or other contractual obligations?*

Planning for the Future

Decisions about guardianship or the other alternatives should not be considered based on your child’s diagnostic label, but rather on the individual strengths and

specific needs of your child. If your child only needs assistance with financial issues, then you should consider conservatorship. If your child does require guardianship, the least restrictive option should be considered first.

Person-centered planning is a great way to sort out your child's needs, identify their strengths, and make plans for their future. A group of people who know and care about the person, and especially the individual with a disability, should be involved in making the decisions about what kinds of safeguards should be implemented. This process allows for any decisions made to be reconsidered when needed and with the people who know and care about your child the most. For more information about person-centered planning, call the MODDRC at (800) 444-0821.

Alternate Protective Assignments

Parents should first consider alternatives to guardianship or conservatorship that are less restrictive. Alternatives could include **advance directives** that address only those areas where your child needs support. Some advance directives include:

- Durable power of attorney for health care
- Durable power of attorney for property
- Power of attorney for case/care management.

Advance directives could also be used to assist the individual in decision-making in education, health care surrogacy, representative or substitute payee, trusts, or joint checking accounts.

You might also consider community services or advocacy systems to provide the support your child might need to live as independently as possible.

Guardianship and Conservatorship

If alternatives are not an option, parents should consider guardianship or conservatorship. Guardianship is the legal process of determining a person's capacity to make their own decisions regarding personal affairs (such as where he lives or the care he requires.) Conservatorship is similar to guardianship, but differs in that it deals only with the financial affairs of an individual.

The law provides for **limited** guardianship and conservatorship, as well as **total** guardianship and conservatorship. Court orders for limited guardianship should restrict only those liberties necessary to protect the well-being of the individual while encouraging the development of maximum self-reliance and independence.

Guardianship

The Missouri Guardianship Code is designed to tailor guardianship and/or conservatorship to meet the individual needs of a person, taking care of only those needs a person is not capable of meeting himself. The law recognizes that people who have a disability or are otherwise incapacitated have abilities in different areas. For example, one person might forget to take medication and need a limited guardian to help with this task, while another person may have trouble with balancing his checkbook and need a conservator to help manage his money.

When a person has been deemed by a court (adjudicated) to be incapacitated (unable to make decisions affecting his personal affairs), a guardian is appointed to make decisions for him. When a person is adjudicated to need a guardian, that person loses certain legal rights, which could include the right to vote, enter into contracts, get married, etc.

Guardianship is the most restrictive and limiting choice and should only be used as a last resort. Alternative arrangements may be more fitting for the person, depending upon his or her ability to make decisions and to communicate these decisions.

Conservatorship

A conservator is appointed by the court after it is found that an individual doesn't have the capacity to manage his finances, such as balancing his checkbook. A conservator has *no* authority to make decisions regarding the individual's personal affairs. Only a guardian has such power.

Persons thinking about obtaining guardianship, conservatorship or implementing other alternative safeguards might contact an attorney or Missouri Protection and Advocacy at 800-392-8667 for more information and advice.

► Section Three — Special Education

A federal law called the Individuals with Disabilities Education Act (IDEA) requires that all children receive a free and appropriate education. IDEA requires individual evaluation, determination of eligibility, individual education planning, and individualized services for children with disabilities. Missouri law requires all public schools to provide education and related services in the least restrictive environment for all children determined to have a disability.

If your child has been diagnosed with a disability, they may be eligible for special education and related services. Evaluation of children suspected of having a disability may happen several ways. The parent may request an evaluation from the school by making that request in writing to the child's teacher, the school's special education team, and/or the school principal. Once an evaluation is requested in writing, schools must provide services to the child within 60 days of receiving the parent's written consent to evaluate.

The child's Individual Education Program (IEP) is developed by a team that consists of the parent, a regular education teacher, a special education teacher, a school representative, and an individual who can interpret the child's evaluation. The IEP will include individualized goals and describe specialized services, assessment accommodations, evaluation criteria, and procedures. The IEP will also include a statement describing the extent to which the child will participate in the general education program.

As a result of the IEP, the team will decide the setting where the services (or "placement") will be implemented. The school must reevaluate the child every three years, but if you are dissatisfied with the evaluation you can request a free Independent Education Evaluation.

If you are dissatisfied with the evaluation, placement or implementation of the IEP or related services, you are entitled to file for due process with the Division of Elementary and Secondary Education. Due process is a legal proceeding in which a final decision on the child’s eligibility, placement, or services being provided is decided.

For further information regarding Special Education in the state of Missouri, contact the Department of Elementary and Secondary Education, P.O. Box 480, Jefferson City, MO 65102, (573) 751-5739.

For a copy of Missouri state procedural safeguards, please visit:
http://dese.mo.gov/divspeced/Compliance/Proc_Safe/ProcSafe_Jul2005.pdf

MPACT (Missouri Parents Act), 8301 State Line Rd., Suite 204, Kansas City, MO 64114, www.ptimpact.com

Toll free 1-800-743-7634

Kansas City	(800) 743-7634	Joplin	(877) 466-6236
St. Louis	(800) 995-3160	Jefferson City	(877) 588-5644
Poplar Bluff	(877) 876-2831	Mexico	(877) 218-9973
St. Joseph	(877) 384-2839		

▶ Section Four — Financial Assistance and Services

Supplemental Security Income

Social Security Administration
(800) 772-1213.

The Supplemental Security Income (SSI) program provides cash benefits to needy individuals who are aged, blind or have a disability. There is no minimum age requirement for eligibility under SSI. However, unlike ordinary Social Security recipients, SSI recipients must meet certain income and financial resources tests to qualify for the program’s benefits. Your child under age 18 can qualify if he or she meets Social Security’s definition of disability for children, and if his or her income and resources fall within the eligibility limits.

You are not limited on the number of applications you may make for these benefits. If benefits are denied on the first application, that does not mean that benefits will be denied on the second application. Furthermore, if benefits are denied, reduced or terminated, you have a right to request reconsideration and, if necessary, a hearing before an administrative law judge.

Medicare

Social Security Administration at (800) 772-1213

Medicare is a federal health insurance program for people 65 or older, people of any age with permanent kidney failure, and people who have been entitled to Social Security disability benefits for 24 months. There are two parts under the Medicare system: Part A is commonly known as hospital insurance; and Part B is commonly called supplementary medical insurance and Part D is commonly called prescription drug benefit.

Part A is aimed at meeting the costs of inpatient hospital services, post-hospital extended care services, and post-hospital home health services. Part B is designed to help meet the costs of medical attention, such as physician services, physical therapy, prescribed medicines that cannot be self-administered, and rental or purchase of durable medical equipment (including wheelchairs, hospital beds and oxygen tents). If you disagree with the decision on your claim, you are entitled to ask for a review and then a formal hearing.

Medicaid

Medicaid assists the elderly and people with disabilities in meeting the costs of medical services. Benefits are distributed according to income and medical need. If Medicaid benefits are denied or terminated, you can request a hearing at the Division of Medical Services.

To apply for Medicaid, contact your local county office of the Family Support Division. The telephone number is listed in the white pages of your telephone directory.

Temporary Assistance for Needy Families (TANF)

In Missouri the program is referred to as “temporary assistance”. The purpose of the temporary assistance program is to provide assistance to needy families with children so they can be cared for in their own home and to reduce dependency by promoting job preparation, work and marriage. Temporary assistance offers two types of services to families. The services available are cash assistance and case management.

Children under the age of 18 years or 19 attending high school or equivalent and expected to graduate are eligible if they are:

- In need of assistance because there is insufficient income to meet basic needs are eligible for temporary assistance;
- Deprived of support because of the death, physical or mental incapacity or the continued absence from the home or unemployment;
- Living with one or both parents or a close relative who makes application for assistance and who meet certain criteria.

To apply for TANF, contact your local county office of the Family Support Division. The telephone number is listed in the white pages of your telephone directory.

► Additional Resources

Department of Health and Senior Services — Special Healthcare Needs

1-800-451-0669

The Department of Health and Senior Services – Special Healthcare Needs (formerly known as the Bureau of Special Healthcare Needs), provides diagnostic, preventive, and specialized medical care for eligible Missouri children.

- The Hope Program provides assistance for children birth to age 21 who meet financial and medical eligibility guidelines.
 - Limited coverage includes outpatient tests and evaluations and/or up to five days of inpatient diagnostic evaluations.
 - Extended coverage includes all of the above plus inpatient care, surgery, physical therapy, occupational therapy, speech and language therapy, prescription medicines, equipment, and supplies.
- The Healthy Children and Youth (HCY) Administrative Case Management Program assists families in meeting their child’s needs to function at an optimal level.

Governor’s Council on Disability

301 West High Street, Room 250-A,

P.O. Box 1668

Jefferson City, MO 65102

(800) 877-8249 (V/TTY)

(573) 751-2600 (V/TTY)

(573) 526-4109 (Fax)

This committee provides a Directory of Organization Resources for people with disabilities (including a list of articles providing services).

Missouri Commission on Human Rights

Jefferson City

P.O. Box 1129

Jefferson City, MO

65102

Kansas City

P.O. Box 01450

Kansas City, MO

64101

Sikeston

106 Authur Dr.

Sikeston, MO

63801

St. Louis

505 Washington

St. Louis, MO

6310

This commission processes complaints on discrimination in housing, employment and public accommodations based on race, color, sex, national origin, ancestry, religion, disability, age (employment only), and familial status-families with children under the age of 18 (in housing only).

Missouri Department of Mental Health, Division of Developmental Disabilities and Mental Retardation

The Department of Mental Health provides many diagnostic, treatment and support services to those with mental illness, mental retardation, or developmental disabilities, and those individuals who have substance abuse problems.

The Division of MRDD improves the lives of persons with developmental disabilities through programs and services to enable those persons to live independently, productively, safely, and in the most integrated living arrangements possible. The eleven regional centers serve as the entry point into the developmental disability service system. Those determined eligible are given a case manager who works with the person and or families/guardian to make appropriate community connections for supports needed.

Regional centers assist individuals with disabilities in meeting needs while maintaining people in their homes and communities, if possible. In general, the regional centers have access to early childhood intervention services, vocational services, residential services, specific therapies (i.e., speech therapy, occupational therapy, physical therapy, and counseling services), in-home supports, adaptive equipment, respite care, personal care attendant services, and crisis intervention services. There are so many services available that it would be difficult to list them all, but your regional center service coordinator will be knowledgeable about specific services in your area.

Missouri Planning Council for Developmental Disabilities

1706 E. Elm, P.O. Box 687
Jefferson City, MO 65102
(800) 500-7878

The Missouri Planning Council for Developmental Disabilities is a federally funded, 22-member, consumer-driven council appointed by the governor. Its mandate is to plan, advocate for, and give advice concerning programs and services for persons with developmental disabilities that will increase their opportunities for independence, productivity, and integration into communities.

Missouri Protection and Advocacy Services

925 S. Country Club Dr.,
Jefferson City, MO 65109;
(800) 392-8667.
Jefferson City (573) 893-3333
St. Louis (314) 725-1550
Kansas City (816) 756-1001

This organization is a private, non-profit corporation charged that implements portions of five separate federal laws designed to protect people with disabilities

from neglect or abuse: (1) Developmental Disabilities Act; (2) Vocational Rehabilitation Act; and (3) Protection and Advocacy for Mentally Ill Individuals Act; (4) Protection & Advocacy of Individual Rights; (5) Protection & Advocacy for Assistive Technology.

University of Missouri – Kansas City Institute for Human Development, UCEDD

2220 Holmes, 3rd Floor
Kansas City, MO 64108
(816) 235-1770
(800) 452-1185 (TTY)

The Institute for Human Development is located within the University of Missouri - Kansas City and houses one of more than 60 University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) across the country. Working with local, state, and national organizations, the UCEDD supports persons with developmental disabilities by building programs and activities designed to promote opportunities to exercise self-determination and independence, be productive, and be integrated and included in all facets of community life.