

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 resources 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 topics or concerns with you (Quick Match).
- Be matched with another parent or self-advocate to talk and share experiences, and 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 1-800-444-0821.

Contact MODDRC

Institute for Human Development, UCE
215 W. Pershing
Kansas City, MO 64108
816-235-1763 (Kansas City)
1-800-444-0821 (toll free)
www.moddrc.org

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?*
- *With what decisions will my child need assistance?*
- *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 1-800-444-0821.

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 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 1-800-392-8667 for more information and advice.

SECTION THREE – SPECIAL EDUCATION

Individuals with Disabilities Education Act (IDEA)

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 (including charter 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 test the child to see if a disability exists or explain, in writing, why the school won't test the child. School districts are required to provide

parents with a copy of Missouri’s procedural safeguards as well as a copy of the Parents’ Bill of Rights in the special education process.

If the child qualifies for special education services, an Individual Education Program (IEP) will be developed for the child. An 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 part of the IEP, the team will decide the setting where the services will be implemented; children must be educated in the “least restrictive environment” (i.e., the environment where the child can be educated, to the maximum extent possible, with non-disabled students). 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/index.html.

For a copy of Missouri’s Parents’ Bill of Rights, please visit: <http://dese.mo.gov/divspeced/Compliance/parentbillofrights.html>.

For a parent’s guide to special education in Missouri, please visit: <http://dese.mo.gov/divspeced/Compliance/documents/ParentGuide.pdf>.

Section 504 of the Rehabilitation Act of 1973

Section 504 is an anti-discrimination law that protects disabled children from discrimination in public school programming (including extracurricular activities and field trips). Section 504 eligibility is determined by examining the child’s disability and determining whether it impacts a “major life activity” (or a “major bodily function”), which

includes things such as walking, breathing, learning, thinking and reading. Similar to eligibility for special education services, eligibility for Section 504 is determined by a team (including the parent) with knowledge about the child, the child's suspected disability and available placement options. At the beginning of the process, you should receive from the school a copy of their procedural safeguards outlining your rights during the process.

If the child is determined to be eligible for protection under Section 504, a Section 504 plan should be written for the child. A Section 504 plan sets forth modifications and accommodations that will be provided to the child due to the disability. Should a child have a disability that requires the administration of medication at school, it is advisable that a medication plan be created for the child.

Should you be dissatisfied with evaluation, placement or implementation of the Section 504 plan, you are entitled to file a due process complaint with the school district (as outlined in the procedural safeguards you received). A due process hearing is a legal proceeding in which a final decision on the child's eligibility, placement, or services being provided is decided. Another option available to parents dissatisfied with Section 504 evaluation, placement or implementation is to file a complaint with the U.S. Department of Education's Office for Civil Rights in Kansas City.

For information on Section 504, please visit:
<http://www2.ed.gov/about/offices/list/ocr/504faq.html#evaluation>.

Missouri's OCR office is located in Kansas City:

Kansas City Office
Office for Civil Rights
U.S. Department of Education
8930 Ward Parkway, Suite 2037
Kansas City, MO 64114-3302
Telephone: 816-268-0550
Fax: 816-823-1404; TDD: 877-521-2172
Email: OCR.KansasCity@ed.gov

MPACT (Missouri Parents Act), 205 Jefferson St. 6, Jefferson City, MO 65101, www.ptimpact.org

Toll free 1-800-743-7634 (MPACT is a statewide parent training and information center)

Kansas City 1-800-743-7645

St. Louis 1-800-995-3160

Poplar Bluff 1-877-876-2831

St. Joseph 1-877-384-2839

Joplin 1-877-466-6236

Jefferson City 1-877-588-5644

Mexico 1-877-218-9973

SECTION FOUR – FINANCIAL ASSISTANCE AND SUPPORT RESOURCES

Supplemental Security Income

Social Security Administration

1-800-772-1213

Helpful websites: <http://www.ssa.gov/pgm/ssi.htm> *and* www.ssa.gov/locator/

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, applicants for SSI benefits 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. You may apply for benefits at your local Social Security office, and you may contact Social Security to schedule an appointment to file an application. 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

Helpful website: <http://www.medicare.gov>

Social Security Administration

1-800-772-1213

Medicare is a federal health insurance program for people 65 years of age or older, people of any age with permanent kidney failure or Lou Gehrig's disease, and people who have been entitled to Social Security disability benefits for 24 months. There are different forms of coverage under the Medicare program and this coverage is designated as a specific part. Part A is commonly known as hospital insurance. Part B is commonly called supplementary medical insurance (SMI). Part C is known as "Medicare Advantage." Part D provides prescription drug benefits.

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). Part C (Medicare Advantage) is like a health maintenance organization (HMO) or preferred provider organization (PPO). Part D provides Medicare prescription drug coverage. Prescription drug coverage is run by an insurance company or other private company approved by Medicare.

If you disagree with the decision on your Medicare claim, you are entitled to ask for a review and then a formal hearing. For each part of the Medicare program, there is a specific appeals process.

Medicaid (MO HealthNet)

Helpful website: <http://www.dss.mo.gov/fsd/msmed.htm>

MO HealthNet (Medicaid) provides access to health care benefits for eligible low-income individuals. The Missouri Family Support Division determines eligibility for the MO HealthNet Program and the MO HealthNet Division (formerly the Division of Medical Services) is responsible for the financial administration of the program.

MO HealthNet benefits are available to individuals with disabilities, pregnant women, children and families, and there are specific MO HealthNet programs designed to serve each of these groups.

MO HealthNet for Kids (MHK) and MO HealthNet for Families (MHF) provide access to health care for children with family incomes up to 300 percent of the federal poverty limit and to parents with limited income. Pregnant women may also qualify for MO HealthNet benefits. MO HealthNet for the Elderly, Disabled and Blind (MHABD) assists the elderly and people with disabilities (may include disabled children) in meeting the costs of medical services. Benefits for many families and children are provided through managed care plans. Eligibility for MO HealthNet benefits is based on income and medical need. Some MO HealthNet programs also have asset (resources) limits. If MO HealthNet benefits are denied or terminated, you can request a hearing through the Missouri Family Support Division.

To apply for MO HealthNet benefits, contact your local county office of the Missouri Family Support Division (FSD). The telephone number is listed in the White Pages of your telephone directory. You may apply for some MO HealthNet programs online. Application forms for many programs administered by Missouri FSD are also available at the agency's website.

Temporary Assistance for Needy Families (TANF)

Helpful website: <http://www.dss.mo.gov/fsd/tempa.htm>

The Temporary Assistance program provides assistance to needy families with children so they can be cared for in their own home. The program also works at reducing dependency by promoting job preparation, work, and marriage. Funds may also be used to prevent non-marital pregnancies and encourage the formation and maintenance of two-parent families. Temporary assistance offers two types of services to families: cash assistance and case management. Recipients must meet financial and program eligibility guidelines. Recipients of Temporary Assistance are subject to a five-year lifetime limit for receiving cash assistance benefits unless they meet an exemption, exclusion or extension criteria.

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

Other Self-Sufficiency and Income Maintenance Programs Administered by the Family Support Division

Helpful websites: <http://www.dss.mo.gov/fsd/pap.htm> and <http://www.dss.mo.gov/fsd/rsb>

In addition to the MO HealthNet programs and Temporary Assistance, the Missouri Family Support Division (FSD) is the agency of state government responsible for the administration of other benefit programs such as the Food Stamp, Child Care Services and Rehabilitation Services for the Blind programs. To learn more about these programs, please visit the above-listed websites.

Additional Resources

Department of Health and Senior Services – Special Healthcare Needs

<http://health.mo.gov/living/families/shcn>

Telephone: 573-751-6246

(toll-free) 1-800-451-0669

PO Box 570, Jefferson City, MO 65102-0570

The Department of Health and Senior Services – Special Healthcare Needs (SCHN, formerly known as the Bureau of Special Healthcare Needs) provides diagnostic, preventive, and specialized medical care for eligible Missouri children. SCHN operates programs designed to offer support to families with children who have special health care needs:

- The Children and Youth with Special Health Care Needs Program provides assistance for children birth to age 21 who meet financial and medical eligibility guidelines.
- 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

<http://www.disabilityinfo.mo.gov/>

Governor's Council on Disability

Truman State Office Building

301 West High Street, Room 250-A

P.O. Box 1668

Jefferson City, MO 65102

1-800-877-8249 (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

<http://www.labor.mo.gov/mohumanrights/>

Jefferson City: 573-751-3325

St. Louis: 314-340-7590

Toll Free Complaint Hotline: 877-781-4236

Relay Missouri: 711

Relay Missouri: 1-800-735-2966 (TDD) 1-800-735-2466 (Voice)

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

<http://dmh.mo.gov/>

Kansas City Regional Office

821 East Admiral Blvd.

P.O. Box 412557

Kansas City, MO 64106

Phone: 816-889-3400

Toll Free: 1-800-454-2331

Sikeston Regional Office

112 Plaza Drive, PO Box 966

Sikeston, MO 63801

Phone: 573-472-5300

Toll Free: 1-800-497-4647

St. Louis County Regional Office

9900 Page, Suite 106

St. Louis, MO 63132

Phone: 314-877-2711

Toll Free: 1-800-374-6458

St. Louis Regional Tri-County Office

111 N. 7th Street, 6th Floor Wainwright Bldg

St. Louis, MO 63101

Phone: 314-244-8800

Toll Free: 1-800-358-7665

Springfield Regional Office

1515 East Pythian, PO Box 5030

Springfield, MO 65801-5030

Phone: 417-895-7400

Toll Free: 1-888-549-6635

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 11 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 support 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 support, 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

1716 Four Seasons Drive, Suite 103

Jefferson City, MO 65101

Phone: 573-751-8611

Toll free: 1-800-500-7878

The Missouri Planning Council for Developmental Disabilities is a federally-funded, 23-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

<http://www.moadvocacy.org>

925 South Country Club Dr., Jefferson City MO 65109

Administration:

573-893-3333 / 1-866-777-7199 / Fax 573-893-4231

Application Unit:

573-659-0678 / 1-800-392-8667 / Fax 573-659-0677

MO Relay (TDD) 1-800-735-2966

This organization is a private, non-profit corporation charged with implementing portions of five separate federal laws designed to protect people with disabilities from neglect or abuse: (1) Developmental Disabilities Act; (2) Vocational Rehabilitation Act; (3) Protection and Advocacy for Mentally Ill Individuals Act; (4) Protection & Advocacy of Individual Rights; and (5) Protection & Advocacy for Assistive Technology.

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

<http://www.ihd.umkc.edu/?catid=85>

UMKC Institute for Human Development

215 W. Pershing Road, 6th Floor

Kansas City, MO 64108

(816) 235-1770

1-800-452-1185 (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.

Legal Services of Missouri

<http://www.lsmo.org>

Legal Services of Missouri's website provides self-help resources and general legal information as well as a way to locate your regional Legal Services office if you are in need of civil legal assistance.

Missouri 2-1-1

<http://www.211helps.org/gethelp>

The United Way operates a directory of 2-1-1 lines across the country that provides free information and referral information for health, human and community services. 2-1-1 provides information and referral on topics such as emergency food pantries, rental assistance, public health clinics, child care resources, support groups, legal aid, and a variety of non-profit and governmental agencies.