DISABILITY & HEALTH INFORMATION CENTER

A PROGRAM OF MISSOURI FAMILY TO FAMILY RESOURCE CENTER | UMKC INSTITUTE FOR HUMAN DEVELOPMENT | UCEDD

A NEW WAY TO SUPPORT FAMILIES

Missouri Guardianship: Understanding Your Options & Alternatives

Welcome to the Missouri Developmental Disabilities Resource Center (MODDRC). You are receiving this letter with an enclosed packet of information because a request was made by you (or someone on your behalf) to the MODDRC.

We have compiled information from a number of sources and have included them in this packet, which is designed to provide:

- **Topical Information**
- **Personal Experiences and**
- **Resources**

The MODDRC, which has now expanded to include Missouri's Family-to-Family Health and Disability Information Center, seeks to inform and connect individuals with disabilities or special health care needs and/or their families to peer support. We provide opportunities for leadership development and volunteerism. We also seek to provide information and training to community agencies so that they can provide services to individuals with disabilities or special health care needs and/or their families. When contacting the MODDRC, you are connecting to staff with first-hand knowledge about disability related issues because they have the experience of living with the disability, either as an individual, parent or family member.

Thank you for using the MODDRC. This packet of information is one of the many ways that the MODDRC can support you in your journey with disability. We hope you will connect with us again.

MISSOURI FAMILY TO FAMILY RESOURCE CENTER
DISABILITY & HEALTH INFORMATION CENTER

Missouri Family to Family Disability & Health Information Center is housed within Missouri's University Center for Excellence in Developmental Disabilities Education, Research and Services (UCEDD) at the University of Missouri-Kansas City, Institute for Human Development.

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Overview

The purpose of this section is to help you gain a better understanding of a specific topic related to disability or special health care need. It is intended to provide a basic explanation of the topic and specific tips for success and may include:

- An overview of the topic
- Current practices
- Skills
- Tools

If you would like more information on this topic, please feel free to contact us again.

Overview: Missouri Guardianship: Understanding Your Options and Alternatives

Why are you thinking about Guardianship?

Someone may be telling you that you or someone you love needs to have a guardian. It might be school staff (schools routinely send out a letter about guardianship when a child who has an IEP turns 17), a medical professional, a service coordinator, or even another parent.

There is often a general assumption that just because someone has a disability (especially if it is a developmental disability) or special healthcare need, he or she will need a guardian as an adult. In reality, everyone is presumed competent to make choices about their own lives when they become an adult, unless a court says otherwise. With the right supports, many people with disabilities or special healthcare needs are able to remain "their own person," making their own decisions and being in charge of their own lives. The trick is to find a balance – giving the person enough support and protection so they can live a safe and healthy life without taking away their rights and freedom to make choices and decisions for themselves.

There are a lot of reasons why individuals with developmental disabilities, their families, and key supporters might be considering their guardianship options and alternatives for decision making support and/or protection. For example:

- You have a child with a developmental disability close to the age of 18.
- You have been told by an educator, service provider, or other professional that you need guardianship to maintain your rights to provide support and/or protection for someone you care about.
- Someone is pressuring you to file for guardianship.
- You or someone you know is, or is at risk for being, taken advantage of by others.
- You have fears and concerns in relation to your current guardianship status.
- You currently have a guardian, but don't think you need one, or you don't agree with the decisions they are making for you.
- The individual you are concerned about currently needs protection or assistance.
- You are seeking information about guardianship because someone you care for or someone you work with is experiencing a difficult time.

Before pursuing guardianship, it is important that you consider whether guardianship will achieve the outcome you desire. **Guardianship is not a quick fix,** it is a legal action that limits or denies a person the right to make their own decisions. It is important to consider the individual's needs for support and/or protection and then ask, "How will having a guardian address each specific need?"

Simply because a person has a developmental disability is not a reason to assume that he/she cannot make decisions or express preferences. Sometimes a person needs help making decisions and an advocate or guardian may be beneficial.

Why is Understanding Your Options and Alternatives Important?

When an individual is declared incapacitated for the purposes of guardianship he/she may lose many rights that are often taken for granted such as the right to vote, obtain a drivers license, consent or object to medical care, or enter into contracts like marriage or home ownership. Individuals with a guardian may not get to decide where they live, with whom they live, where they go in the community or how their money is spent. **The freedom to make these decisions plays an important part in defining all of us as human beings and determining our quality of life.**

Different individuals have different situations, needs, and available supports. Deciding what alternative(s) or guardianship option(s) will work best in your unique circumstance can be difficult. Each alternative to full guardianship has advantages and disadvantages, which must be considered. Understanding the options and alternatives will help you make informed decisions and find the least restrictive way(s) to provide an individual with the care, support, and protection he/she needs.

It is not uncommon for guardianship to be suggested for individuals who need help with regular activities of daily living such as paying bills, managing medications, or buying groceries and preparing meals. Prior to seeking guardianship it is important to understand the implications and long term effects of guardianship on an individual's life.

Since guardianship involves the loss of fundamental rights, it should only be considered when a person cannot make informed decisions on their own or when accommodated or supported in their decision-making. Guardianship can be very difficult to modify or terminate. Parents do not need to become guardians of their adult children in order to stay involved. Options and alternatives should not be based on a diagnostic label, but rather you should consider an individual's strengths and specific decision-making and protection needs.

Remember, there are ways other than guardianship to provide support and protection for an individual with a disability or special healthcare need and to establish decision-making supports in certain areas. Learning about alternatives may take effort on your part, but it may allow a person to keep more of their legal rights and stay involved in decisions about their own lives. Gather all of the facts so you can make an informed decision about whether guardianship is the best choice.

How do you know if you or someone you care about needs decision making support and/or protection?

The first step is to determine individual level of ability in key areas of life. You can use the checklist, "the tool," provided in ***MO Guardianship: Understanding Your Options and Alternatives***, developed by the UMKC Institute for Human Development (UCEDD), to help with this. It's best if several members of the individual's support team and the individual complete the form to determine what appropriate option or alternative meets the individual's need for support and/or protection.

The **tool** provides questions to help you **examine key areas** of an individual's life including:

- Employment
- Money management
- Health & nutrition
- Relationships
- Personal safety
- Community living
- Personal decision-making
- Determining & directing services and supports

What are the Options and Alternatives?

Alternatives to guardianship may allow individuals to hold on to some or all of their rights. They include:

- **General Supports** – natural, unpaid, and community resources and may include family, friends, and advocacy organizations.
- **Decision-Making Supports** – create legal documents (such as Power of Attorney) giving authority to someone on behalf of the individual in certain areas.
- **Money Management Supports** – help manage financial obligations and avoid exploitation. These supports include sucht things as joint bank accounts and trusts.
- **Personal Safety Supports** – are useful for individuals at risk for being abused/neglected by an intimate partner, spouse, family member, personal assistant or caregiver.

Full explanation of alternatives can be found in ***MO Guardianship: Understanding Your Options and Alternatives.***

Accessing your Guardianship Options & Alternatives

Once you've determined an individual's areas of need and identified appropriate options and alternatives to meet those needs, you'll need to access the alternatives you've selected and/or petition the court for a limited or full guardianship or a restoration of capacity to terminate or reduce a full guardianship.

How do I access the alternatives to guardianship?

- Build a support group
- Practice person-centered decision making
- Be aware that because guardianship is court-ordered you may need to seek appropriate legal counsel.
- Many of the alternatives are easily accessible at little or no cost.

What can you access **on your own** (*without an attorney*)?

- Friends/Family
- Advisors/Advocacy Organizations
- Community supports
- Representative Payee
- Limited and/or Joint Bank Accounts
- Direct Deposit and Automatic Bill Pay
- Protection Orders (TRO)
- Personal Contract/Agency Agreement

What might you **need an attorney to access**?

- Durable Power of Attorney
- Durable Power of Attorney for Health Care
- Living Will
- Living Trust
- Special Needs Trust
- Adult Protective Services
- Limited Guardianship
- Full/Plenary Guardianship

For help finding more information about this or other subjects, please contact us at the Missouri Family-to-Family Resource Center. We're here to help.

Works Cited

1-A Guide to Understanding Adult Guardianship and Guardianship Alternatives in Maine

2-Oklahoma Department of Human Services, Capacity Assessment. www.okdhs.org

MO Guardianship: Understanding Your Options & Alternatives. UMKC Institute for Human Development: A University Center for Excellence in Developmental Disabilities. www.ihd.umkc.edu

The Missouri Bar. http://www.mobar.org

Important Things to Remember

Autonomy

The word **"autonomy"** refers to the right of a person to make informed decisions about what happens to him or her such as the choice of whether to consent, refuse to consent, withdraw consent, or otherwise exercise freedom of choice in determining one's own actions and activities.

Self-determination

Self-determination refers to people making choices and decisions based on their own preferences and interests, to monitor and regulate their own actions, and to be goal-oriented and self-directing.

Self-determination provides individuals with the freedom and opportunity to make choices and decisions about all important aspects of one's life with freely chosen supports, as needed. It also gives the individual the ability to organize the support or assistance they need in ways that are unique to the individual. The individual is provided opportunities to practice responsibility and contribute to one's community and act as a citizen. It empowers individuals because the supports and protections focus on the desires and abilities of the individual. Self-determination actively involves the individual in the decisions being made about appropriate levels of support and protection for that individual's unique needs with a support group/team of family members, friends, and professionals. Finally, self-determination ensures that protections and supports are respectful of the individual.

What is person-centered decision making?

Person-centered decision making is the key component in helping a person maintain a sense of autonomy and self-determination by focusing on the desires and abilities of the individual. It involves a support team of family members, friends, professionals, and *most importantly* the individual. The individual chooses the members.

Person-centered decision making recognizes that individuals who have a disability may communicate choices, likes, and wishes in non-traditional ways which may include actions. The individual plays an important role in identifying areas in which assistance and support may be needed and how the team can meet those needs.

Family support Advocacy & Services

This section will provide you with a listing of agencies focused on areas such as educational, medical care or social services to individuals with developmental disabilities or special health care needs. This includes listings such as state or local agencies, hospitals, clinics or education systems.

Support for Families

Missouri Family-to-Family Resource Center
Housed at the UMKC-Institute for Human Development, UCEDD
215 W. Pershing
Kansas City, MO 64108
Phone: 816.235.1763
Toll Free: 800.444.0821
web: http://www.mofamilytofamily.org

Missouri Family-to-Family is a statewide network of parents, family members, and individuals with disabilities and/or special health care needs providing information and peer support through the MOF2F Disability & Health Information Center and Sharing Our Strengths (SOS). SOS is a statewide support network of parents, family members, individuals with developmental disabilities and/or special healthcare needs, and professionals who are matched with peer mentors to share experiences, offer emotional support, and to network with others. You can request an individual parent to parent or peer support match with another parent or individual who has experienced similar circumstances.

MO Guardianship: Understanding Your Options and Alternatives, developed by UMKC Institute for Human Development (UCEDD), is a manual that describes guardianship options and alternatives in detail to assist you in planning for your/your child's future. This manual and accompanying tool can be obtained from Missouri's Family-to-Family Health and Disability Resource Center by calling us at 800.444.0821 or by requesting it online.

People First of Missouri
1-800-558-8652
www.missouripeoplefirst.org

People First of Missouri is a self-advocacy, self-help organization that was formed by, is run by, and exists for people with developmental disabilities. PFMO members teach and empower people to understand their rights and responsibilities and to speak up for themselves (self-advocacy); stands up for one another to help people live the life they want with the supports they need (advocacy for one another); advocate for community services that allow people to have choices and control over their supports and lives (advocacy at the systems level); and work to create change in communities to ensure opportunity and full, meaningful participation for all people (advocacy within the community).

Missouri

Service Systems

The purpose of this section is to provide you with a listing of agencies focused on areas such as educational, medical care or social services to individuals with developmental disabilities or special health care needs. This includes listings such as state or local agencies, hospitals, clinics or education systems.

Missouri Service System Contacts

Finding an Attorney

- **The Missouri Bar Lawyer Referral Service** provides referrals for attorneys on a statewide basis, except for St. Louis and Springfield, and can be reached at 573-636-3635, Monday through Friday 9am until Noon and 1pm until 3pm.
- **St. Louis Metropolitan Bar Lawyer Referral Service** can be reached at 314-621-6681.
- **Springfield Metropolitan Bar** can be reached at 417-831-2783

If you cannot afford an attorney contact :

Missouri Protection and Advocacy Services
at 800-392-8667 or visit www.moadvocacy.org

- Jefferson City Office (Administration)
  925 S. Country Club Drive
  Jefferson City, MO 65109
  Tel: 573-893-3333 / 866-777-7199
  Fax: 573-893-4231
- Jefferson City Office (Application Unit)
  925 S. Country Club Drive
  Jefferson City, MO 65109
  Tel: 573-659-0678 / 800-392-8667
  Fax: 573-659-0677
- St. Louis Office
  1992 Innerbelt Business Center Drive
  Overland, MO 63114
  Tel: 314-785-1702 / 800-233-3958
- Kansas City Office
  3100 Main Street, Suite 207
  Kansas City, MO 64111
  Tel: 816-756-1001 / 800-233-3959
- Fulton Office
  P.O. Box 6187
  Fulton, MO 65251
  Tel: 573-592-2738 (JC office X-20)

Legal Aid of Western Missouri provides free/low cost legal services:

- Kansas City Central Office 816-474-6750
  - 1125 Grand Blvd. #1900
    Kansas City, MO 64106
- Kansas City West Office 816-474-9868
  - 920 Southwest Blvd.
    Kansas City, MO 64108
- Joplin 1-800-492-7095, 417-782-1650
  - 302 S. Joplin
    Joplin, MO 64801
- St. Joseph 1-800-892-2101, 816-364-2325
  - 106 S. 7th St., 4th Floor
    St. Joseph, MO 64502
- Warrensburg 1-800-892-2943, 660-747-7101
  - 305 N. Holden
    Warrensburg, MO 64093