



2024 Annual Conference

***Best Practices for Alternatives to Guardianship
Including Medical Supported Decision-Making***

Results from a Working Group

Missouri Medical Rights Workgroup

exploring decision-making options for patients with developmental disabilities

----- Coordinators -----

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Participants

Patients

Supporters

Medical
Providers

Professional
Associations

Academics

Government
Regulators

Rights
Advocates

Disability
Services

Perspectives

Self-
Advocates

Family-
Advocates

Medical

Dental

Nursing

Social Work

Psychiatry

State
Government

Public
Guardian

Hospital
Administrator

Legal

Missing*
Judicial

Purpose



Identify ways to better **protect the medical rights** of adult patients with developmental disabilities while at the same time respecting the legal and ethical duties of health care providers.



Identify ways to **better prepare youth** with developmental disabilities to transition to adulthood when they have the authority to make medical decisions with the level of support they choose.

Reading Materials

Missouri Medical Rights Workgroup

exploring decision-making options for patients with developmental disabilities

Basics of Medical Decision Making

demographics • ethics • law • process

Basics include the demographics of this patient population; ethical requirements for medical professionals; legal considerations such as the right of medical self-determination, evidentiary presumptions, and the nondiscrimination duties of medical providers; potential alternatives to guardianship; and protocols for assessing a patient's functional capacity to make medical decisions with and without reasonable accommodations.

<https://alternativestoguardianship.com/consensus-basics.pdf>

Helen

MEDICAL

Decision-Making Rights

What You Should Know

<https://alternativestoguardianship.com/helen-article.pdf>

January

Substance (Who & What)

Demographics

data on patients, families, providers

Law

presumption, capacity, nondiscrimination, constitution, federal statutes, state statutes

Ethics

consent, do no harm, education & skills

February

Procedure (How)

Capacity Assessment

self-determination, support, delegation

Alternatives

designating agent, supported decision-making

Complaints

internal, to professional association,
to government agencies, to courts

March

Transition (Youth)

IEP Process - Schools

ISP Process - Disability Service Providers

Resources - Patients, Families, Providers

April

Education (Students & Professionals)

University Curricula

schools of medicine, nursing, psychology,
dentistry, social work, and law

Continuing Education

physicians, psychiatrists, dentists, nurses,
psychologists, social workers, and lawyers

Judicial Education

judges who preside in guardianship cases

What We Have Learned

Data on Patients

Best Practices:

Don't Prejudge

Diagnosis of Disability



Incapacity

86% of adults with cognitive or developmental disabilities in Missouri make medical decisions without a guardianship.

Data on Families

**Most People with
Developmental
Disabilities Have
Family Supporters**

Best Practices:

***With Patient's Consent,*
Allow Families to Assist with
Medical Decision-Making**

Data on Medical Professionals

Missouri has 15,000 medical, dental and nursing students and 45,000 doctors, dentists, and nurses.

Best Practices:

Students and Professionals Need Training on the Decision-Making Rights of Patients with Developmental Disabilities

Legal Considerations

Autonomy

Consent

Presumptions

Medical **autonomy** is a legal right for individuals 18 and older.

The law **presumes** every person to be of sound mind.

Mental or **developmental disabilities** do not necessarily deprive an adult of having the capacity to make medical decisions.

Best Practices:

***Presume Capacity
Unless Evidence
Shows the Contrary***

Legal Considerations

Criteria for Incapacity

The issue of capacity is **situation specific**. The question is whether the person has sufficient mental capacity to **understand the nature and effect of a particular transaction**.

Incapacity requires the existence of a condition which **puts the person at risk**.

Best Practices:

Assess Capacity for Specific Decisions, Not Globally

Capacity for Treatment Choices is Different than Capacity for a POA

Legal Considerations

Alternatives to Guardianship

POAs and supported decision-making are legal and should be used when feasible.

Federal laws **prohibit disability discrimination** and requires **reasonable accommodations** for adult patients with disabilities so they can make medical decisions **independently**, with **informal support**, or through a **power of attorney**.

Best Practices:

Recommend Guardianship as a Last Resort

Assess the Viability of Other Decision-Making Options

Legal Considerations

New HHS Rules

Section 1557 of the Affordable Care Act and Section 504 of the Rehabilitation Act Prohibit Disability Discrimination by Health Care Providers

HHS Issued **New and Detailed Rules** in 2024 on Patient Rights and Provider Duties

Best Practices:

Learn the New Federal Rules

Respect the Decision-Making Rights of Patients with Developmental Disabilities

Proactively Avoid Complaints by Patients and Families

More Information



<https://alternativestoguardianship.com/>

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