

### 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** 

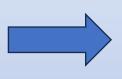
Government Regulators

Rights Advocates Disability Services

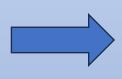
# **Perspectives**

Self-Family-Medical **Dental Advocates Advocates** State **Psychiatry** Nursing **Social Work** Government **Public** Hospital Missing\* Legal Guardian Administrator **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





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

#### March

Transition (Youth)

IEP Process - Schools

ISP Process - Disability Service Providers

Resources - Patients, Families, Providers

#### 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

#### 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

### **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

### **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

### **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

#### **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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