

Missouri Medical Rights Workgroup

exploring decision-making options for patients with developmental disabilities

January 2024 Meetings WHO & WHAT

----- Coordinators -----

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<https://alternativestoguardianship.com/workgroup-jan24meeting.pdf>

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

* Read Essay

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 2024 Meetings

WHO & WHAT

Demographics

Data on patients, families, providers

Legal Considerations

Autonomy and consent, presumptions, criteria for capacity, burden of proof, nondiscrimination

Ethical Requirements

Autonomy, Justice, Beneficence, Non-maleficence

Demographics Data on Patients

4.7 Million Adults
live in Missouri

About 217,000
have a cognitive
disability

About 73,000
have a
developmental
disability

Only 30,500
adults with
cognitive or
developmental
disabilities
(14%) are living
under a
guardianship.



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

**DON'T
PREJUDGE!**

It is a factual
reality that most
adults with
cognitive or
developmental
disabilities have
the capacity to
make medical
decisions without
a guardian.

30,500 adults with cognitive or developmental disabilities are living under a guardianship.

11,000 of them have a public administrator as a guardian.

3,520 (32%) of these adults have intellectual or developmental disabilities.

Demographics Role of Public Administrators

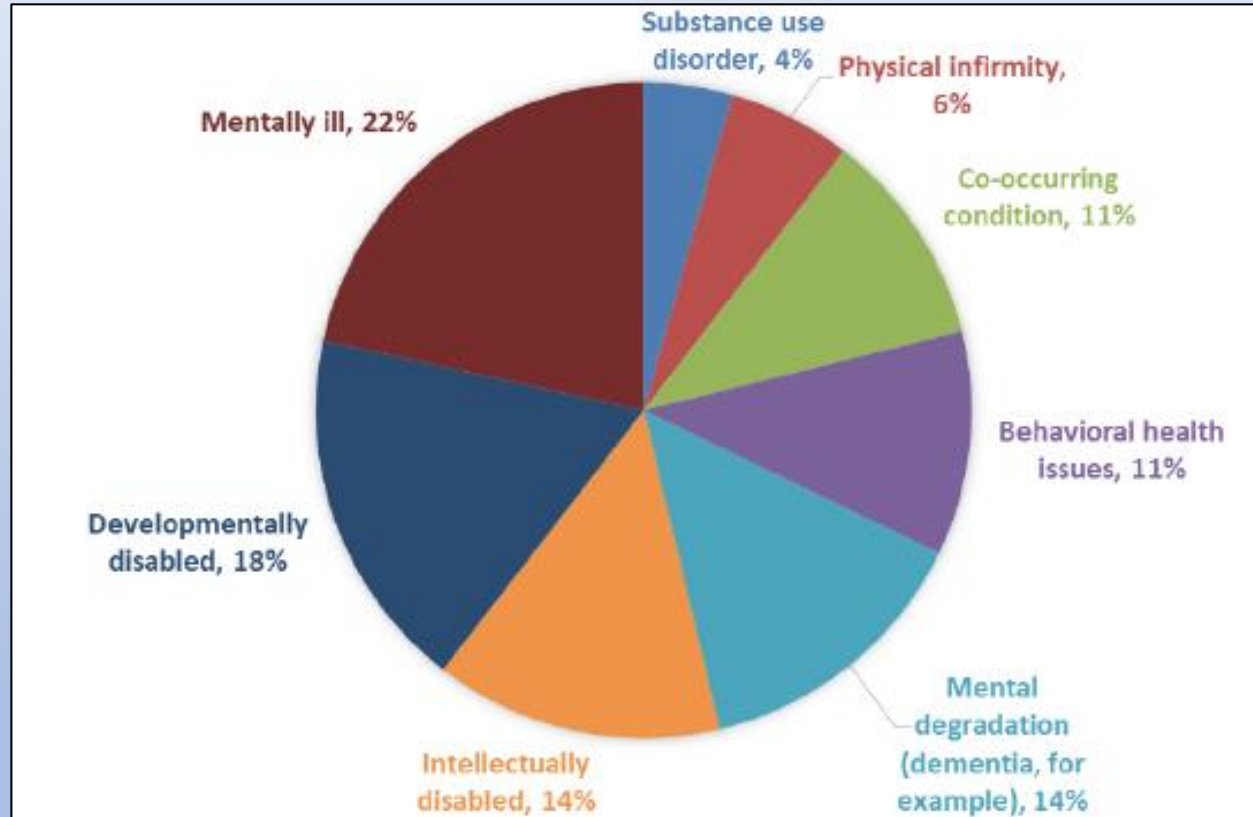


Chart is from the 2020 Missouri Public Guardianship Report

According to the report, public administrators generally **lack the resources** to:

Properly evaluate **less restrictive alternatives** (medical power of attorney or supported decision-making)

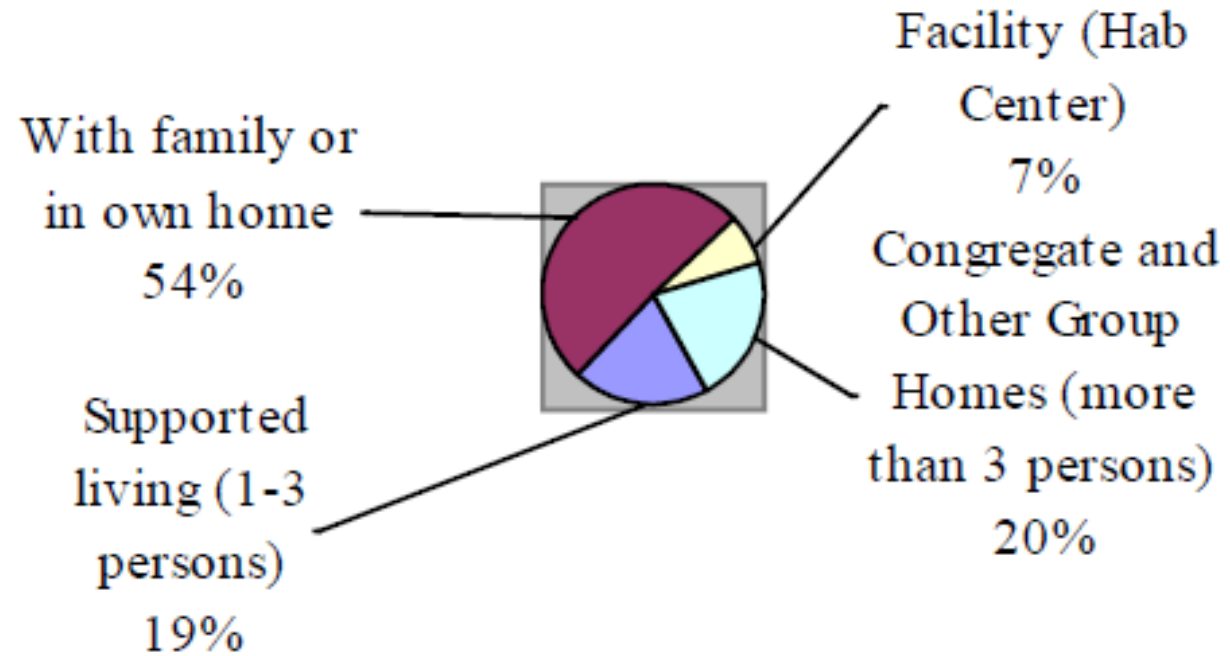
Petition to **terminate and restore rights**

Demographics:

Data on
Families

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

Place of Residence- Missouri, 2006⁵



5. *The State of the State for Missourians with Disabilities*
Roux, A. & Radicia, C., 2007

Demographics

Data on Medical Professionals

About 15,000 medical, dental and nursing students and about 45,000 doctors, dentists, and nurses in Missouri would benefit from receiving educational instruction about the medical rights of patients with cognitive or developmental disabilities.

5,412
Primary Care
Physicians

616
Psychiatrists

1,116
Pediatricians

35,735
Nurses

2,638
Dentists

4,369
MD or DO
Students

366
Dental
Students

10,224
Nursing
Students

Legal Considerations

Autonomy and Consent

The common law recognizes the right of individual autonomy over decisions relating to one's health and welfare.

Cruzan, by Cruzan v. Harmon (Mo. 1988) 760 S.W.2d 408, 416-17, affirmed 497 U.S. 261 (1990).

Any adult eighteen years of age or older is authorized by law to consent to a medical procedure if the person is competent to contract.

RSMo Section 431.061(1)).

Legal Considerations

Presumptions

The law **presumes** every person to be of sound mind until the contrary is shown.
State ex Rel. United Mut. Ins. Assn. v. Shain (Mo. 1942) 349 Mo. 460, 474

Mental or **developmental disabilities** do not necessarily deprive an adult of having the capacity to make medical decisions.
Ruckert v. Moore, 317 Mo. 228, 242 (Mo. 1927)

Legal Considerations

Burden of Proof

The burden of proving **lack of mental capacity** to contract is on the party making that allegation.

Christian Health Care v. Little, 145 S.W.3d 44 (Mo. Ct. App. 2004).

Incapacity must be proven by **clear and convincing evidence**.

Matter of Nelson, 891 S.W.2d 181 (Mo. Ct. App. 1995).

Evidence is clear and convincing when it establishes a **high probability** that a fact (e.g. incapacity) is true.

Rinehart v. Shelter (Mo. Ct. App. 2008) 261 S.W.3d 583, 597.

Legal Considerations

Criteria for Incapacity

The issue of capacity is **situation specific**. The question is whether on the day the decision is made, did the person have sufficient mental capacity to **understand the nature and effect of the particular transaction**.

McElroy v. Mathews, 263 S.W.2d 1, 10 (Mo. 1953)

Incapacity requires the existence of some physical or mental condition which **puts the person at risk**.

Matter of Nelson, 891 S.W.2d 181 (Mo. Ct. App. 1995).

Legal Considerations

Power of Attorney

An adult has capacity to execute a durable power of attorney for health care if, at the time it is executed, the patient understands the significance of the document, namely, that the adult is empowering another person to make medical decisions on their behalf.

Pazdernik v. Decker, 652 S.W.2d 319 (Mo. Ct. App. 1983).

A health care provider acting in good faith and not having been put on notice to the contrary, shall be justified in relying on the representations of a patient purporting to give consent (such as consent for a power of attorney).

RSMo Section 431.061(4).

Legal Considerations

Alternatives to Guardianship

Powers of attorney and supported decision-making arrangements have been recognized by the legislature as less restrictive alternatives to guardianship that should be used when feasible.

RSMo Section 475.075(13)

American with Disabilities Act: requires health care providers to refrain from disability discrimination and to offer **reasonable accommodations** to adult patients with disabilities so they can make medical decisions independently, with informal support, or through a power of attorney.

Section 504 of Rehabilitation Act: has similar nondiscrimination requirements for providers who receive federal funds. HHS is adopting new regulations.

Ethical Considerations

Autonomy – Justice – Beneficence – Non-maleficence

Autonomy: allow adult patients to make their own choices. Independently; with help from chosen support person(s); by chosen agent in a power of attorney.

Justice: treat all patients fairly and with equality. Avoid discrimination. No prejudice. Provide reasonable accommodations for decision-making.

Beneficence: do good to patients and for society. Learn how to better provide medical services to patients with developmental disabilities. Self education.

Non-maleficence: protect patients from harm. Take appropriate action if there are signs of abuse or undue influence.

Future Meetings

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)

To Self-Determination
from parents to patient decision-making*

To Guardianship
from parents to guardian

Restoration of Rights
from guardian back to patient*

* with or without supported decision-making

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

May Proposals

Consider recommendations for improved
policies and practices for:

patients
families
universities
professionals
administrators
regulators
judges

June Report

Discuss and vote on draft report containing:

findings
recommendations
implementation plan