Missouri Medical Rights Workgroup

exploring decision-making options for patients with developmental disabilities

Basics of Medical Decision Making

demographics • ethics • law • process

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To better protect the rights of patients, while also respecting the duties of providers, it is important that stakeholders in the delivery of medical services agree on the basics of medical decision making by adults with developmental disabilities.

Stakeholders include patients, families, providers, disability rights advocates, disability services organizations, funding and regulatory agencies, professional and trade associations for health care providers, public administrators, and guardianship judges and attorneys.

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.

Overview

■ Any person eighteen years of age or older, if otherwise competent to contract, is authorized to consent to any medical treatment or procedure.

■ There is a legal presumption that all persons have the capacity to make their own health care decisions unless they are declared incompetent through a process authorized by law.

■ No patient is presumed to be incompetent, to forfeit any legal right, or to suffer any legal disability, unless otherwise prescribed by law, as a consequence of receiving evaluation, care, treatment, habilitation or rehabilitation for an intellectual or developmental disability.

■ Capacity to delegate medical decision-making to another person is presumed to exist unless proven otherwise. Patients have a right to a support person to assist them in making medical decisions. They may authorize access to medical records. They may also delegate authority to a representative to act as a surrogate decision-maker if they become incapacitated.

- The burden of proving lack of mental capacity rests upon the party making that allegation. Incapacity must be proven by clear and convincing evidence. Evidence is clear and convincing if it instantly tilts the scales in the affirmative when weighed against evidence in opposition, so that the evaluator is left with an abiding conviction that the evidence is true.

- Capacity to consent to medical procedures is not an all-or-nothing matter. It is situation specific and must be evaluated for each proposed procedure, unless the person is found to be totally incapacitated for all medical decisions.

- Since health care providers have an ethical and legal duty to obtain consent for medical procedures, they should first seek consent from a patient. If evidence suggests the patient lacks capacity to provide such consent, with or without support, the provider may obtain consent from the patient's authorized representative (designated medical proxy or authorized agent under a power of attorney). If there is no authorized representative, a more thorough evaluation of capacity should be performed by a qualified professional using best practices for such an assessment. If such an evaluation shows lack of capacity by clear and convincing evidence, and less restrictive alternatives for consent are unavailable, the provider may recommend a guardianship.

- Health care providers must obey laws and regulations governing medical decision-making and nondiscrimination when they provide services to adults with developmental disabilities.

- Providers may be required to offer practical accommodations or to make policy adjustments in order to ensure that such patients have meaningful access to the medical decision-making process. Failure to do so may result in complaints to the Missouri Department of Health, the Missouri Commission on Human Rights, or the Office of Civil Rights of the U.S. Department of Health and Human Services.

- Providers have a duty to be aware of the laws and regulations governing patient rights, respect those rights, advise patients of such rights, and have a grievance procedure for patients who allege their rights have been violated.

- More education is needed for patients, families, providers, and agencies, and more training is needed for medical professionals and administrators about the medical decision-making and nondiscrimination rights of adult patients with developmental disabilities.

Demographics

Approximately 4.7 million adults live in Missouri. Some 217,000 of these adults have a cognitive disability, with about 73,000 of them being developmental disabilities.

Only 14% of adults with mental or developmental disabilities in Missouri – approximately 30,000 – are living under an order of guardianship.

The vast majority (86%) of adults who have mental or developmental disabilities in Missouri make medical decisions without any court intervention. They may make such decisions independently, with the help of a chosen advisor, through a power of attorney or designated proxy, or with a formal supported decision-making agreement.

About 82,000 teenagers turn 18 each year in Missouri. About 1.58% of the population has an intellectual or developmental disability. Therefore, about 1,300 teens with intellectual or developmental disabilities become adults each year in Missouri. This is the "transitioning to adulthood" I/DD population who need immediate education, support, and assessment about medical capacity decision-making. Thousands of other teenagers with I/DD would benefit from long term education and counseling to prepare them for medical decision making well in advance of becoming adults.

Health care providers in Missouri are interacting on a regular basis with thousands of adult patients with mental or developmental disabilities who are not in guardianships and with hundreds of transitioning teenagers who have such disabilities.

Ethical Considerations

Medical ethics define the obligations of health care professionals to ensure the well-being of patients and to respect their basic human rights. Medical ethics apply to all health care providers.

Implementing the basic principles of medical ethics is an essential aspect of patient care. There are four main principles of medical ethics: (1) Autonomy: Allow an individual freedom to make their own decisions; (2) Justice: Treat all patients fairly and with equality; (3) Beneficence: Do good on behalf of the patients and society as a whole; and (4) Non-malfeasance: Do no harm or protect from harm.

There are limitations to each of these principles. For example, autonomy may not be feasible for a patient who lacks decision-making capacity due to a brain injury, severe dementia, or impairment from alcohol or drugs.

Inherent in these four principles is a requirement that consent be obtained for medical treatment. For adult patients who are not in a guardianship, consent is given by the patient or a representative designated by the patient.

When a procedure has benefits with little or no risk, only simple consent is required. Consent for a medical appointment is implied when the patient makes the appointment. Simple consent does not require a detailed explanation of benefits and risks for noninvasive and no risk procedures such as an eye exam, dental exam, teeth cleaning, blood pressure test, urine test, blood test, or a general physical exam.

When a procedure is beneficial but has significant potential side effects, a medical provider must obtain informed consent from a patient. After explaining the benefits and risks, the provider must feel a reasonable degree of confidence that the patient understands what has been said and the decision to proceed or not is voluntary. If there is a reasonable belief that the patient is unable to communicate a voluntary and informed choice, further steps are needed. The provider may ask the patient for permission to involve a trusted family member or friend to assist the patient in making an informed decision. If this does not resolve the situation, a formal evaluation of capacity to consent may be necessary.

Respect for patient autonomy is central to professional ethics., Physicians should involve patients in health care decisions commensurate with the patient's decision-making capacity. Even when a medical condition or disorder impairs a patient's decision-making capacity, the patient may still be able to participate in some aspects of decision making. Physicians should engage patients whose capacity is impaired in decisions involving their own care to the greatest extent possible, including when the patient has previously designated a surrogate to make decisions on his or her behalf. AMA Code of Ethics, Sec. 2.1.2.

When a patient lacks decision-making capacity, the physician has an ethical responsibility to identify an appropriate surrogate to make decisions on the patient's behalf. This may be the person designated by the patient as a surrogate through a durable power of attorney for health care or other mechanism. It may also be a family member or other intimate associate, in keeping with applicable law and policy if the patient has not previously designated a surrogate. AMA Code of Ethics, Sec. 2.1.2.

Legal Considerations

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.

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)). This provision shall be liberally interpreted. RSMo Section 431.061(2).

Capacity

In determining whether someone has capacity to contract, the question is whether on the day the decision is made, did they 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).

Capacity to consent to medical treatment must be evaluated in a specific and real life situation. Under hypothetical circumstances, neither the benefits nor the risks of treatment can be properly weighed or fully appreciated. *Cruzan, by Cruzan v. Harmon* (Mo. 1988) 760 S.W.2d 408, 416-17.

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

It is well-settled law that the burden of proving lack of mental capacity to contract rests upon the party making that allegation. *Christian Health Care v. Little,* 145 S.W.3d 44 (Mo. Ct. App. 2004).

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. RSMo Section 431.061(4).

Incapacity requires the existence of some physical or mental condition which puts the person at risk. Incapacity must be proven by clear and convincing evidence. It must be shown that the powers of reasoning and comprehension have been so far destroyed or reduced by mental weakness resulting from one cause or another that the person is incapable of knowing and appreciating the nature and consequences of his acts. In close cases, the dignity and personhood of the alleged incapacitated or disabled person should be respected, rather than taking a strict paternalistic approach of utmost security. *Matter of Nelson*, 891 S.W.2d 181 (Mo. Ct. App. 1995).

An incapacitated person is one who is "unable by reason of any physical or mental condition to receive and evaluate information or to communicate decisions" to such an extent that serious injury, illness or disease is likely to occur. Thus, an incapacity requires the existence of some physical or mental condition which puts the person at risk. Section 475.010(8) RSMo 1986.

Americans with Disabilities Act

The Americans with Disabilities Act (ADA) is a federal civil rights law that prohibits discrimination against people with disabilities. A person with a disability can be a person with a mobility or physical disability, sensory (vision or hearing), or *intellectual, psychiatric, or other mental disability*. Health care organizations that provide services to the public are covered by the ADA.

The ADA requires that health care entities provide full and equal access for people with disabilities. This can be done through:

- Reasonable Modifications of Policies, Practices, and Procedures. Adjusting policies, practices, and procedures, if needed, to provide goods, services, facilities, privileges, advantages, or accommodations.

- Effective Communication. Making communication, in all forms, easily understood.

Patients with mental or developmental disabilities must be provided with reasonable accommodations to assist them in participating in the medical decision-making process. To accomplish this objective, reasonable modifications to policies or procedures may be necessary.

Rehabilitation Act of 1973

Health care entities and professionals who receive federal funding must provide "meaningful access" to the services they offer. *Alexander v. Choate*, 469 U.S. 287, 301 (1985). Moreover, "to assure meaningful access, reasonable accommodations in the grantee's program or benefit may have to be made."

The failure to offer a reasonable accommodation or make a reasonable modification may constitute discrimination under the Rehabilitation Act and the ADA. See ADA Title III, 42 U.S.C. § 12182(b)(2)(A)(ii) (requiring places of public accommodation "to make reasonable modifications in policies, practices, or procedures"); Rehabilitation Act Reg. 28 C.F.R. § 41.53 ("A recipient shall make reasonable accommodation to the known physical or mental limitations of an otherwise qualified handicapped applicant or employee . . . .").

If a service provider receives federal funds for any of its programs, all of its programs or services must comply with the disability nondiscrimination provisions of the Rehabilitation Act . Nearly all hospitals and most health care providers receive federal funding. Such providers must take steps to ensure that patients with mental or developmental disabilities have meaningful access to the medical decision-making process.

Alternatives to Guardianship

Before appointing a guardian or conservator, the court shall consider whether an individual's needs may be met without the necessity of appointing a guardian or conservator through a less restrictive alternative. Such options may include, but are not limited to, the following: evidence an attorney-in-fact was appointed in a *durable power of attorney* executed by the individual before the petition was filed; a *supported decision-making agreement;* the provision of *protective or supportive services* or arrangements provided by individuals or public or private services or agencies; or the use of appropriate *services or assistive technology.* RSMo § 475.075(13).

Delegating Authority

A person may execute a power of attorney to delegate to another adult the authority to act in a fiduciary capacity on the person's behalf with respect to all lawful subjects and purposes. RSMo Section 404.810(1). This includes the authority to give consent to or prohibit any type of health care, medical care, treatment or procedure to the extent authorized by law. RSMo Section 404.810(1)(6)(10).

Unless the patient expressly authorizes otherwise in the power of attorney, the powers and duties of the attorney in fact to make health care decisions shall commence upon a certification by two licensed physicians based upon an examination of the patient that the patient is incapacitated and will continue to be incapacitated for the period of time during which treatment decisions will be required and the powers and duties shall cease upon certification that the patient is no longer incapacitated. RSMo Section 404.825.

In order to have capacity to execute a durable power of attorney for health care, at the time it is executed an adult must understand the significance of the document, namely, that the adult is authorizing another person to make medical decisions on their behalf. *Pazdernik v. Decker*, 652 S.W.2d 319 (Mo. Ct. App. 1983).

Supported Decision Making

Supported decision-making (SDM) was recognized by the Legislature in 2018 as a method of decision-making that may avoid the necessity of a guardianship. The statute, however, does not define SDM or specify procedures or requirements for such agreements. Under SDM, the patient makes medical decisions with the assistance of a chosen support person. The patient does not delegate decision-making authority to an agent. With SDM, the health care provider must obtained informed consent for medical procedures from the patient himself or herself. If the provider reasonably believes that the patient does not understand the matter or is unable to communicate effectively, informed consent would be lacking.

Decision-Making Process

Health care providers in Missouri who receive federal funding have a duty to: (1) train staff on the rights of patients; (2) obtain consent from a patient or their representative for medical procedures; (3) have policies on the use of medical directives; and refrain from engaging in disability discrimination in the delivery of medical services.

Refraining from disability discrimination requires providers to offer reasonable accommodations, if necessary, to assist patients in the decision-making process; respect the presumption of capacity absent clear and convincing evidence of incapacity; presume that a medical directive or power of attorney is valid unless there is clear and convincing evidence to the contrary; ensure that capacity assessments are performed by a qualified professional using protocols that conform to best practices; only recommend that a guardianship proceeding be initiated if less restrictive alternatives have been explored by the provider and family and that such options have been determined to be unfeasible.

Guardianship proceedings should not take away medical decision-making rights of an adult unless incapacity for health care decisions has been proven in court by clear and convincing evidence and, by the same evidentiary standard, there is proof that less restrictive alternatives have been seriously explored and have been determined to be unfeasible.

References and Resources

"Medical Decision-Making Rights: What You Should Know" (Helen Magazine - Sept. 2023)
https://alternativestoguardianship.com/helen-article.pdf

"Medical Decision-Making by Adults with Developmental Disabilities: Guidance for Patients, Families, Providers, State Agencies and Professional Associations" (Spectrum Institute - 2023) https://alternativestoguardianship.com/medical-guidance-mo.pdf

"Medical Decision Making Options for Adults with Developmental Disabilities: A Summary of Legal and Medical References for Health Care Providers, Patients and Families" (Spectrum Institute - 2023)
https://alternativestoguardianship.com/medical-decisions.pdf

"Report: HHS Publishes Proposed Federal Rule on Disability Discrimination by Federally Funded Health Care Providers" (Spectrum Institute - 2023)
https://alternativestoguardianship.com/hhs-rule-report.pdf

"Transitioning to Adulthood: Resources for Patients with Developmental Disabilities, Parents, and Health Care Providers" (Alternatives to Guardianship Project - 2023)
https://alternativestoguardianship.com/transitioning-resources.pdf

"Disability and Abuse: Administering Trauma-Informed Justice in Missouri Guardianship Proceedings – Annotated Bibliography" (Spectrum Institute - 2017)
https://alternativestoguardianship.com/annotated-bibliography-missouri.pdf

"Disability and Abuse: Administering Trauma-Informed Justice in Missouri Guardianship Proceedings – Facts, Findings, Recommendations" (Spectrum Institute - 2017)
https://alternativestoguardianship.com/recommendations-for-missouri.pdf