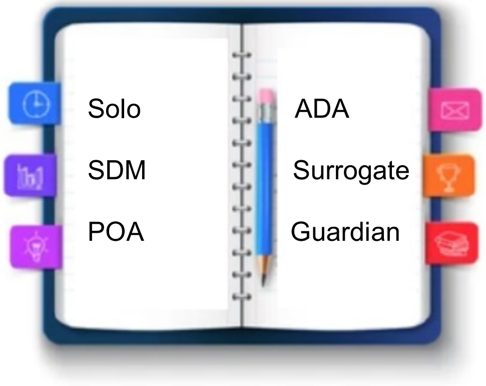
Medical Decision Making

OPTIONS

for adults with developmental disabilities



A Summary of Legal and Medical
References for Health Care
Providers, Patients
and Families

by Thomas F. Coleman
Spectrum Institute on behalf of
Alternatives to Guardianship Project

May 1, 2023

This report was produced by Spectrum Institute on behalf of the Alternatives to Guardianship Project. It is intended to provide information about medical decision-making options to health care providers, professional associations, disability rights and disability services organizations, and most importantly to people with disabilities and their families.

We hope this report will stimulate thought and conversations on how the decision-making rights of patients with developmental disabilities may be better protected and respected. At the same time, we hope that it will assist health care providers as they attempt to comply with ethical and legal standards involving consent to medical procedures.

The report is being sent to the following professional associations: Missouri Hospital Association, Missouri State Medical Association, Missouri Academy of Family Physicians, Missouri Association of Osteopathic Physicians and Surgeons, Missouri Nurses Association, Association of Missouri Nurse Practitioners, Missouri Primary Care Association, Missouri Academy of Physician Assistants, Missouri Dental Association, and the Missouri Pharmacy Association.

It is being sent to the following disability rights and disability services stakeholders: People First Missouri, Missouri Developmental Disabilities Council, Missouri Protection and Advocacy, Missouri Department of Health - Division of Developmental Disabilities, Missouri State University Disability Resource Center, MoWINGS, The Arc of Missouri, Missouri TASH, Missouri Association of County Developmental Disabilities Services, and UMKC Institute for Human Development.

It is also being sent to the Missouri Association of Public Administrators and the Missouri Association of Probate and Associate Circuit Judges.

We invite these organizations to contact us with their comments about this report and with suggestions on how, working together, we may improve the medical decision-making process for adults with developmental disabilities.

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Medical Decision Making

OPTIONS

for adults with developmental disabilities

Commentary

Thousands of patients with mental or developmental disabilities interact with health care providers each year in Missouri. Some are minors accompanied by parents. Others are adults who may or may not have a support person with them.

Mental disabilities include conditions such as anxiety, depression, PTSD, phobias, OCD, mood disorders, or dementia. Developmental disabilities include a range of conditions that result from cognitive and/or physical impairments. They are identified before the age of 22, and usually last for a person's lifetime. These disabilities include ADHD, intellectual disabilities, cerebral palsy, autism spectrum disorder, Down syndrome, language and learning disorders, vision impairment, and hearing loss. Some of these disabilities affect cognitive functioning while others affect communication or emotions or adaptive functioning.

Health care practitioners regularly provide medical services to patients with mental or developmental disabilities. Demographic data indicate that over 200,000 adults living in Missouri have a cognitive disability. Of these adults, about 73,000 have a developmental disability. Only 30,000 adults with cognitive or developmental disabilities are living under an order of guardianship – a situation in which a court-appointed guardian makes medical decisions for them. Therefore, the vast majority of adults in Missouri who have mental or developmental disabilities are making their own medical decisions, with or without informal assistance from others.

The services of health care providers are governed by a code of medical ethics as well as a variety of state and federal statutes and regulations. These ethical and legal standards prohibit health care practitioners from providing medical services without the consent of an authorized person. Failure to obtain the necessary consent may result in civil liability or loss of a professional license.

Federal law defers to state law on who is authorized to consent to medical procedures. Under Missouri law, a parent may consent to medical procedures for a minor. For adult patients, consent may be given by the patient, an agent designated by the patient in a power of attorney for health care, or by a court-appointed guardian. Independent patient consent is not valid if they lack the capacity to contract. A power of attorney is not valid if the patient did not understand the nature and effect of the document when it was executed.

The capacity to contract may vary according to the complexity of the transaction. An adult with limited mental capabilities may have the capacity to enter into a simple contract but not a complex one. For example, it does not take much ability to understand the significance of a verbal agreement that if one adult promises to give another adult an apple, the other adult with give the adult one dollar. In contrast, that same adult may not have the capacity to understand a 25-page single-spaced written agreement to purchase a house and place the house in a trust. Just because the adult lacks the capacity to enter into the house contract does not mean that they lack the capacity to enter into the contract to sell the apple.

Medical ethics make a distinction between simple consent and informed consent. Simple consent is sufficient to enable a medical practitioner to provide nonintrusive medical services with little or no risk. An adult with mental or developmental disabilities may very well have capacity to consent to simple procedures, such as taking their temperature, pulse, heartbeat, or blood pressure. Capacity to consent may exist for an eye exam or a dental cleaning. In contrast, capacity to consent may be lacking for intrusive procedures that carry a moderate or high risk of harm, such as a surgical procedure requiring general anesthesia, or taking medications that have potentially dangerous side effects.

For adults who are under an order of guardianship, medical providers can obtain informed consent from a guardian after they are given a full explanation of benefits and risks. Informed consent may also be obtained from an agent under a validly executed durable power of attorney for health care, again after a full explanation of benefits and risks.

However, if there is no properly authorized surrogate decision-maker, the provider must obtain simple or informed consent from the patient who has a mental or developmental disability. In doing so, the provider must comply with federal laws prohibiting discrimination on the basis of disability. Reasonable accommodations must be provided to such patients to enable them to have meaningful participation in the medical decision-making process and to effectively communicate with health care professionals in the process.

Reasonable accommodations for patients with mental or developmental disabilities may include: allowing the patient to have a support person present; allowing a support person to assist the patient in understanding procedures and communicating with medical staff; scheduling an interaction at a time of day most conducive to meaningful participation; giving oral or written information in simple terms; allowing for extra time for an appointment to enable more time for explaining to the patient and for the patient to process the information.

Parents of young people with developmental disabilities are often perplexed when their child becomes an adult. They have been accustomed to making medical decisions for their son or daughter during their childhood. Then comes the child's 18th birthday and things change. A medical practitioner may no longer legally rely on parental consent alone. Consent from the adult patient must be obtained, whether it is simple consent or informed consent. The practitioner may not be properly trained in legal and medical ethics on consent and may feel unskilled in making a forensic determination as to whether the patient has the legal capacity to consent. This may require them consulting with a psychiatric colleague or an ethics committee. Doing so takes time – a commodity that many medical practitioners find lacking. The default reaction may be for the practitioner to advise the parent to obtain a guardianship.

Advising the parent to seek a guardianship, when in fact such may not be necessary, may constitute disability discrimination in violation of federal law.

Patients with mental or developmental disabilities are presumed to have capacity to make medical decisions. Under the code of medical ethics, a health care provider must make a judgment call – based on evidence adduced during a proper mental examination – on whether a patient lacks the mental capacity to provide consent to a particular procedure or, in some cases, for medical care generally. Once a preliminary factual determination of incapacity is made, the provider should assess whether capacity to consent would exist if reasonable accommodations were made, such as the patient using a support person to help explain information to them and to help them communicate with medical staff.

If a provider determines, based on evidence elicited from a capacity evaluation, that the patient lacks capacity to consent even with supports or services, the provider should then inquire whether there is a legally-authorized surrogate available to make medical decisions. Is there a durable power of attorney for health care that was validly executed? Since there is a presumption of validity of such an agreement, in order to ignore it there must be reasonable grounds to believe that it was not validly executed.

If a provider determines the patient lacks capacity to consent to medical procedures and there is no legally-authorized surrogate to do so, then the issue of guardianship arises. In some states, there is a procedure for a patient to choose a surrogate even though the patient would lack capacity to execute a more complicated power of attorney. In California, there is a protocol adopted by the California Medical Association that allows a primary care physician to select a proxy for a specific procedure without the need to go to court. Missouri should consider this approach for patients who are not in a guardianship and who lack capacity to give informed consent for a medical procedure.

Missouri statutes declare that guardianship should be a last resort. It should be utilized only after all less restrictive methods have been explored and ruled out as not feasible.

Under Missouri law, the hierarchy of preference for medical decision making should be: solo or independent decisions *by the patient*; decisions *by the patient* with informal ADA support; decisions *by the patient* pursuant to formal supported decision-making agreement; decisions *by an agent* pursuant to a written durable power of attorney; decisions *by a court-appointed guardian*. Missouri law could be amended to allow a patient with limited capacity to delegate authority to a surrogate. The law could also be amended to allow a primary care physician to designate a surrogate, without a court proceeding, for a particular procedure.

Decision-Making Methods

in descending order of patient's capacity

✔ Solo*

patient makes decisions independently
limited capacity needed for simple consent
greater capacity needed for informed consent

✔ ADA*

patient makes decisions with informal support
limited capacity needed for simple consent
greater capacity needed for informed consent

✔ SDM*

patient makes decisions with
supported decision-making agreement
limited capacity needed for simple consent
greater capacity needed for informed consent

✔ POA*

patient delegates authority to agent
through written power of attorney
patient needs capacity to contract when POA is executed

✔ Surrogate**

patient delegates authority to surrogate orally or in writing
only limited capacity needed to select surrogate

✔ Surrogate**

primary care physician selects surrogate to make a specific decision
doctor finds patient to be incapacitated

✔ Guardian*

court appoints a guardian to make decisions
court finds patient to be incapacitated

* Authorized under existing law. ** Needs new legislation in Missouri

Medical Decision Making:
Legal and Medical Standards

Bibliography with Commentary

Authorization for Medical Consent in Missouri

RSMo Section 431.061: Who May Consent - Link

431.061. Consent to surgical or medical treatment, who may give, when. —

1. In addition to such other persons as may be so authorized and empowered, any one of the following persons *if otherwise competent to contract*, is authorized and empowered to *consent*, either orally or otherwise, to any surgical, medical, or other treatment or procedures, including immunizations, not prohibited by law: (Emphasis Added)

(1) Any adult eighteen years of age or older for himself;
(2) Any parent for his minor child in his legal custody;
(3) Any minor who has been lawfully married and any minor parent or legal custodian of a child for himself, his child and any child in his legal custody;
(4) Any minor for himself in case of:
  (a) Pregnancy, but excluding abortions;
  (b) Venereal disease;
  (c) Drug or substance abuse including those referred to in chapter 195;
(5) Any adult standing in loco parentis, whether serving formally or not, for his minor charge in case of emergency as defined in section 431.063;
(6) Any guardian of the person for his ward;
(7) Any relative caregiver of a minor child as provided for under section 431.058.

2. The provisions of sections 431.061 and 431.063 shall be liberally construed, and all relationships set forth in subsection 1 of this section shall include the adoptive and step-relationship as well as the natural relationship and the relationship by the half blood as well as by the whole blood.

3. A consent by one person so authorized and empowered shall be sufficient notwithstanding that there are other persons so authorized and empowered or that such other persons shall refuse or decline to consent or shall protest against the proposed surgical, medical or other treatment or procedures.

4. Any person acting in good faith and not having been put on notice to the contrary shall

be justified in relying on the representations of any person purporting to give such consent, including, but not limited to, his identity, his age, his marital status, and his relationship to any other person for whom the consent is purportedly given.

***McElroy v. Mathews*, 263 S.W.2d 1, 10 (Mo. 1953): Capacity to Contract -** Link

In determining whether someone had capacity to contract, the question is whether on the day the transaction occurred, did they have sufficient mental capacity to understand the nature and effect of the particular transaction. *Vining v. Ramage*, 319 Mo. 65, 86, 3 S.W.2d 712, 721 [5,6]; 17 C.J.S., Contracts, § 133, page 482. Greater mental capacity is required to make a contract which embraces matters requiring mature consideration and reflection, than is required to make a will or gift conveyance.

Comment: Applying this standard to a medical setting, a patient has capacity to consent to a procedure if they understand the nature and effect of the procedure. Many adults with developmental disabilities may have capacity to consent to simple medical procedures with little or no risk. The more invasive and the greater the risk, some adults with developmental disabilities may lack the ability to give mature consideration and reflection to the matter and thus could lack the capacity to consent.

***Ruckert v. Moore*, 317 Mo. 228, 242 (Mo. 1927): Mental Disability -** Link

If a person understands the nature of the business in which he is engaged and the effect of what he is doing, his acts are valid, and this is true though the mind of such person may be impaired by age or disease.

Comment: Mental or developmental disabilities, in and of themselves, do not automatically deprive an adult of having the capacity to make medical decisions.

***State v. Gomez* (Mo. Ct. App. 2003) 92 S.W.3d 253, 258 – Definition of Consent -** Link

Consent or lack of consent may be *expressed or implied*. Assent does not constitute consent if: (a) It is given by a person who lacks the mental capacity to authorize the conduct charged to constitute the offense and such mental incapacity is manifest or known to the actor; or (b) It is given by a person who by reason of youth, mental disease or defect, or intoxication, is manifestly unable or known by the actor to be unable to make a reasonable judgment as to the nature or harmfulness of the conduct charged to constitute the offense; or (c) It is induced by force, duress, or deception.

Comment: Mere assent (passively going along with something) is not considered consent if an individual lacks mental capacity to consent because they cannot make a reasoned judgment in the matter.

Missouri Requirements for Informed Consent

Missouri Supreme Court: Informed Consent

Cruzan, by Cruzan v. Harmon **(Mo. 1988) 760 S.W.2d 408, 416-17 - Link**

The common law recognizes the right of individual autonomy over decisions relating to one's health and welfare. From this root of autonomy, the common law developed the principle that a battery occurs when a physician performs a medical procedure without valid consent. *Hershley v. Brown*,655 S.W.2d 671, 676 (Mo.App. 1983). The doctrine of informed consent arose in recognition of the value society places on a person's autonomy and as the primary vehicle by which a person can protect the integrity of his body. If one can consent to treatment, one can also refuse it. Thus, as a necessary corollary to informed consent, the right to refuse treatment arose. "The patient's ability to control his bodily integrity ... is significant only when one recognizes that this right also encompasses a right to informed refusal."

A decision as to medical treatment must be informed. There are three basic prerequisites for informed consent: the patient must have the capacity to reason and make judgments, the decision must be made voluntarily and without coercion, and the patient must have a clear understanding of the risks and benefits of the proposed treatment alternatives or nontreatment, along with a full understanding of the nature of the disease and the prognosis. Wanzer, Adelstein, Cranford, Federman, Hook, Moertel, Safar, Stone, Taussig Van Eys, "The Physician's Responsibility Toward Hopelessly Ill Patients," 310 New Eng. J. Med., 955, 957 (1984). In the absence of these three elements, neither consent nor refusal can be informed. Thus, it is definitionally impossible for a person to make an informed decision — either to consent or to refuse — under hypothetical circumstances; under such circumstances, neither the benefits nor the risks of treatment can be properly weighed or fully appreciated.

Comment: Informed consent requires the presence of three elements: (1) capacity to reason and make judgments; (2) it must be voluntary; and (3) clear understanding of (a) the nature of the disease and prognosis; and (b) the risks and benefits of treatment versus nontreatment.

United States Supreme Court: Informed Consent

Cruzan v. Director, Missouri Dept. of Health **(1990) 497 U.S. 261, 269 - Link**

At common law, even the touching of one person by another without consent and without legal justification was a battery. See W. Keeton, D. Dobbs, R. Keeton, D. Owen, Prosser and Keeton on Law of Torts § 9, pp. 39-42 (5th ed. 1984). Before the turn of the century, this Court observed that "[n]o right is held more sacred, or is more carefully guarded by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law." *Union Pacific R. Co. v. Botsford*, 141 U.S. 250, 251 (1891). This notion of bodily integrity has been embodied in the requirement that informed consent is generally required for medical treatment. Justice Cardozo, while on the Court of Appeals of New York, aptly described this doctrine: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body, and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages." *Schloendorff v. Society of New York Hospital*, 211 N.Y. 125, 129-30, 105 N.E. 92, 93 (1914). The informed consent doctrine is firmly entrenched in American tort law.

The logical corollary of the doctrine of informed consent is that the patient generally possesses the right not to consent, that is, to refuse treatment.

The Fourteenth Amendment provides that no State shall "deprive any person of life, liberty, or property, without due process of law." The principle that a *competent* person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions. *Cruzan, supra* at p. 278. (Emphasis Added)

[A]n *incompetent* person is not able to make an informed and voluntary choice to exercise a hypothetical right to refuse treatment or any other right. Such a "right" must be exercised for her, if at all, by some sort of surrogate.” Cruzan supra. at p. 280.

Not all *incompetent* patients will have loved ones available to serve as surrogate decisionmakers. And even where family members are present, "[t]here will, of course, be some unfortunate situations in which family members will not act to protect a patient." *In re Jobes*, 108 N.J. 394, 419, 529 A.2d 434, 477 (1987). A State is entitled to guard against potential abuses in such situations. Similarly, a State is entitled to consider that a judicial proceeding to make a determination regarding an incompetent's wishes may very well not be an adversarial one, with the added guarantee of accurate fact-finding that the adversary process brings with it. Cruzan supra. at p. 281.

Comment. In the case of a patient who is not competent to make his or her own medical decisions, a family member does not have a constitutional right to make medical decisions for the patient. States have the authority to establish legal procedures for substituted decision making. In the absence of a document validly executed by an adult delegating such authority to another, the state may require a judicial proceeding, such as a guardianship, authorizing someone other than the patient to make medical decisions.

Missouri Court of Appeals: Informed Consent and Health Care Providers

Robinson v. Health Midwest Development, No. WD 58290 (2001) - Link

[A] physician in this state owes a duty to a patient to inform or warn the patient about the risks and dangers associated with the taking of a prescribed drug, including not engaging in certain activities because of the related side effects. Our courts recognize a cause of action by a patient against a physician for the lack of informed consent to medical treatment.

[A] pharmacist, who like a physician is a "health care provider" by definition, § 538.205(4), has a duty to warn a patron of the risks associated with the taking of a drug prescribed by a physician.

Comment: The requirement of informed consent applied to all licensed health care providers as defined by statute [Now Section 538.205(6)]. "Health care provider", is defined as "any physician, hospital, health maintenance organization, ambulatory surgical center, long-term care facility including those licensed under chapter 198, dentist, registered or licensed practical nurse, optometrist, podiatrist, pharmacist, chiropractor, professional physical therapist, psychologist, physician-in-training, and any other person or entity that provides health care services under the authority of a license or certificate."

Missouri Court of Appeals: Informed Consent and Malpractice

J.K.M. v. Dempsey, 317 S.W.3d 621, 627 (Mo. Ct. App. 2010) - Link

"'The basic philosophy in malpractice cases is that the doctor is negligent by reason of the fact that he has failed to adhere to a standard of reasonable medical care and that consequently the service rendered was substandard and negligent.'" *Wuerz v. Huffaker*, 42 S.W.3d 652, 656 (Mo.App. E.D. 2001) (quoting Aiken v. Clary, 396 S.W.2d 668, 673 (Mo. banc 1965)). "This applies whether the alleged malpractice consists of improper care or treatment or a failure to sufficiently inform a patient to enable the patient to give informed consent to the treatment." *Wuerz*, supra, at p. 656.

Comment: A cause of action for malpractice exists if informed consent is lacking because a doctor negligently failed to give a patient sufficient information to make a reasoned choice.

Wuerz v. Huffaker, 42 S.W.3d 652 (Mo. Ct. App. 2001) – Consent - Link

"Informed consent" is defined as: 1. A person's agreement to allow something to happen, made with full knowledge of the risks involved and the alternatives. 2. A patient's knowing choice about treatment or a procedure, made after a physician or other healthcare provider discloses whatever information a reasonably prudent provider in the medical community would provide to a patient regarding the risks involved in the proposed treatment. Black's Law Dictionary, 300 (7th ed. 1999).

In contrast, in the absence of any consent, a physician is subject to liability for battery. *Baltzell*, 752 S.W.2d at 906; Louisell Williams, Sections 22.03, 8.06 (1998). To establish battery based on lack of consent, a plaintiff is only required to prove the occurrence of unconsented touching. Louisell Williams, Section 22.03. The sole question in such a case is whether the patient was informed of the nature of the procedure and consented to it. Id.

Missouri Statute: Discipline of Health Care Providers

RSMo Section 334.100: Revocation or Suspension of License - Link

2. The board may cause a complaint to be filed with the administrative hearing commission against any holder of any certificate of registration or authority, permit or license required by this chapter for any of the following causes . . . (4) Misconduct, fraud, misrepresentation, dishonesty, *unethical conduct or unprofessional conduct* in the performance of the functions or duties of any profession licensed regulated by this chapter. (Emphasis Added)

Comment: Performing medical services without first obtaining lawful consent would be unethical or unprofessional conduct. A health care provider rendering medical services to an individual who lacks capacity to give informed consent places their license in jeopardy.

Federal Requirements for Informed Consent

Title 42 of the Code of Federal Regulations: Requirements for Hospitals Participating in Medicare or Medicaid - Link

§ 482.24(c)(4). Records. All records must document the following, as appropriate: (v) Properly executed informed consent forms for procedures and treatments specified by the medical staff, or by Federal or State law if applicable, to require written patient consent.

§ 482.51(b)(2) Surgical Services. A properly executed informed consent form for the operation must be in the patient's chart before surgery, except in emergencies.

Comment: All hospitals participate in Medicare and Medicaid programs. Therefore, all hospitals must maintain records on patient consent to medical services.

CMS Guidance: Informed Consent - Link

Requirements related to informed consent for hospitals are found in the Patients' Rights Condition of Participation (CoP) at 42 CFR 482.13(b)(2); the Medical Records CoP at 482.24(c)(2)(v); and the Surgical Services CoP at 482.51(b)(2).

Regulation §482.13(b)(2). The patient or his or her representative (as allowed under State law) has the right to make informed decisions regarding his or her care. The patient's rights include being informed of his or her health status, being involved in care planning and treatment, and being able to request or refuse treatment.

Interpretive Guidelines §482.13(b)(2). The right to make informed decisions means that the patient or patient's representative is given the information needed in order to make "informed" decisions regarding his/her care.

A patient may wish to delegate his/her right to make informed decisions to another person. *To the degree permitted by State law*, and to the maximum extent practicable, the hospital must respect the patient's wishes and follow that process. In some cases, the patient may be unconscious or *otherwise incapacitated*. If the patient is unable to make a decision, the hospital must consult the patient's advance directives, medical power of attorney or patient representative, if any of these are available. In the advance directive or the medical power of attorney, the patient may provide guidance as to his/her wishes in certain situations, or may delegate decision-making to another individual *as permitted by State law*. If such an individual has been selected by the patient, or if a person willing and able under applicable State law is available to make treatment decisions, relevant information should be provided to the representative so that informed health care decisions can be made for the patient. However, as soon as the patient is able to be informed of his/her rights, the hospital should provide that information to the patient.

Hospitals must utilize an informed consent process that assures patients or their representatives are given the information and disclosures needed to make an informed decision about whether to consent to a procedure or type of care that requires consent.

Comment: Federal regulations require informed consent for procedures provided through Medicare or Medicaid. The hospital must respect the patient's wishes to the extent permitted by state law. State law governs the details of a health care provider assessing the patient's capacity to give informed consent. If capacity is lacking, state law determines whether a health care proxy or power of attorney is valid. Hospitals should have a process to determine whether a patient with a developmental disability can give informed consent and, if not, what legal alternatives are available to secure such consent (valid proxy or power of attorney).

Medical Authorities on Informed Consent

American Society for Health Care Risk Management: Types of Consent - Link

The two types of consent are simple and informed. A simple consent applies to common treatments or procedures with minimal risks, such as withdrawing blood, treating the flu or getting an MRI. Informed consent applies to more invasive procedures that carry more risk, such as surgery, complicated medical plans or research treatments.

Comment: An adult with a developmental disability may have sufficient capacity to give *simple* consent for procedures with no risk (nonintrusive exam of blood pressure, heartbeat, eyes, nose, ears, throat) or minimal risk (dental cleaning, blood draw, x-ray, etc) but may lack capacity to give *informed* consent for a high-risk intrusive procedure (surgery requiring general anesthesia, etc.)

American Medical Association Code of Medical Ethics: Informed Consent - Link

Section 2.1.1. Informed consent to medical treatment is fundamental in both ethics and law. . . The process of informed consent occurs when communication between a patient and physician results in the patient's authorization or agreement to undergo a specific medical intervention. In seeking a patient's informed consent (or the consent of the patient's surrogate if the patient lacks *decision-making capacity* or declines to participate in making decisions), physicians should: (Emphasis Added)

(a) *Assess the patient's ability to understand relevant medical information and the implications of treatment alternatives and to make an independent, voluntary decision.* (Emphasis Added)

(b) Present relevant information accurately and sensitively, in keeping with the patient's preferences for receiving medical information. The physician should include information about: (I) the diagnosis (when known); (ii) the nature and purpose of recommended interventions; (iii) the burdens, risks, and expected benefits of all options, including forgoing treatment.

(c) Document the informed consent conversation and the patient's (or surrogate's) decision in the medical record in some manner. When the patient/surrogate has provided specific written consent, the consent form should be included in the record.

University of Missouri School of Medicine: Informed Consent - Link

Health care providers treating patients need to obtain patient consent before proceeding. . . [P]roviders and healthcare institutions are legally required to obtain informed consent from patients before administering tests, procedures, and other therapeutic interventions, and before allowing participation in research studies. This legal requirement is commonly considered satisfied if: the patient has *decision-making capacity* (decisional capacity) and the patient signs a consent form or document. (Emphasis Added)

Various interpretations exist of the necessary conditions for a patient to possess decision-making capacity:

Sufficient age, commonly eighteen; Ability to understand the nature, possible risks, and anticipated benefits of the proposed intervention; Ability to use the information provided to come to a freely chosen decision; Not mentally impaired so as to prevent understanding; Judgment not compromised by illness, medication, or alcohol.

The determination of whether a patient possesses decisional capacity is sometimes difficult to make and open to question. When a patient's awareness is compromised by sedation or the nature of the illness or injury, the determination of whether the "consenting" patient really possesses decision-making capacity may affect the decision to proceed with treatment.

Federal Requirements for Advance Directives

Title 42 of the Code of Federal Regulations: Advance Directives - Link

9.100 Definition. For purposes of this part, advance directive means a written instruction, such as a living will or durable power of attorney for health care, recognized under State law (whether statutory or as recognized by the courts of the State), relating to the provision of health care when the individual is incapacitated.

Comment: If an individual is incapacitated and therefore cannot make their own medical decisions, health care providers offering services funded through Medicare or Medicaid may recognize advance directives for purposes of obtaining informed consent, but only to the extent the instrument is valid under state law.

§ 489.102 Requirements for providers. (a) Hospitals, critical access hospitals, skilled nursing facilities, nursing facilities, home health agencies, providers of home health care (and for Medicaid purposes, providers of personal care services), hospices, and religious nonmedical health care institutions must maintain written policies and procedures concerning advance directives with respect to all adult individuals receiving medical care, or patient care in the case of a patient in a religious nonmedical health care institution, by or through the provider and are required to:

(1) Provide written information to such individuals concerning— I) An individual's rights under State law (whether statutory or recognized by the courts of the State) to make decisions concerning such medical care, including the right to accept or refuse medical or surgical treatment and the right to formulate, at the individual's option, advance directives. Providers are permitted to contract with other entities to furnish this information but are still legally responsible for ensuring that the requirements of this section are met. Providers are to update and disseminate amended information as soon as possible, but no later than 90 days from the effective date of the changes to State law;

(4) Ensure compliance with requirements of State law (whether statutory or recognized by the courts of the State) regarding advance directives. The provider must inform individuals that complaints concerning the advance directive requirements may be filed with the State survey and certification agency;

(5) Provide for education of staff concerning its policies and procedures on advance directives; and

(6) Provide for community education regarding issues concerning advance directives that

may include material required in paragraph (a)(1) of this section, either directly or in concert with other providers and organizations.

(e) If an adult individual is incapacitated at the time of admission or at the start of care and is unable to receive information (due to the incapacitating conditions or a mental disorder) or articulate whether or not he or she has executed an advance directive, then the provider may give advance directive information to the individual's family or surrogate in the same manner that it issues other materials about policies and procedures to the family of the incapacitated individual or to a surrogate or other concerned persons in accordance with State law. The provider is not relieved of its obligation to provide this information to the individual once he or she is no longer incapacitated or unable to receive such information. Follow-up procedures must be in place to provide the information to the individual directly at the appropriate time.

Comment: Hospitals and other health care facilities providing medical services funded by Medicare or Medicaid have obligations to develop and publish procedures for advance directives that comply with state law. They must also provide education to staff and offer community education programs regarding advance directives. Hospital intake procedures and general educational materials and programs should be developed to address the issue of medical decision making by adult patients who have developmental disabilities.

Missouri Requirements for Advance Directives

RSMo Section 404.810: Durable Power of Attorney for Health Care

404.710. Power of attorney with general powers. — Link

1. A principal may delegate to an attorney in fact in a power of attorney general powers to act in a fiduciary capacity on the principal's behalf with respect to all lawful subjects and purposes or with respect to one or more express subjects or purposes. A power of attorney with general powers may be durable or not durable.

6. Any power of attorney, whether durable or not durable, and whether or not it grants general powers for all subjects and purposes or with respect to express subjects or purposes, shall be construed to grant power or authority to an attorney in fact to carry out any of the actions described in this subsection if the actions are expressly enumerated and authorized in the power of attorney. Any power of attorney may grant power of authority to an attorney in fact to carry out any of the following actions if the actions are expressly authorized in the power of attorney: (7) To give or withhold consent to an autopsy or postmortem examination; (8) To make an anatomical gift of, or prohibit an anatomical gift of, all or part of the principal's body under the Revised Uniform Anatomical Gift Act or to exercise the right of sepulcher over the principal's body under section 194.119; (9) To nominate a

guardian or conservator for the principal; and if so stated in the power of attorney, the attorney in fact may nominate himself as such; *(10) To give consent to or prohibit any type of health care, medical care, treatment or procedure to the extent authorized by sections 404.800 to 404.865;* (Emphasis Added)

404.825. Examination of patient required, content. — 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. One of the certifying physicians may be the patient's attending physician. The certification shall be made according to accepted medical standards.

Comment: An adult may delegate to a health care agent the authority to make medical decisions in the event the adult is declared to be incapacitated subsequent to the execution of the durable power of attorney. The statutes do not state what level of capacity an adult must have at the time a durable power of attorney is executed, but there is some case law that addresses this issue.

***Pazdernik v. Decker*, 652 S.W.2d 319 (Mo. Ct. App. 1983): Capacity to Execute - Link**

If at the time a power of attorney is executed, an adult lacks the mental capacity to understand the nature of their acts or the significance of the document which they signed, the document is void.

A power of attorney is void if there is clear and convincing evidence that on the date the document was executed an adult did not understand the significance of the document. Testimony regarding the adult’s activities and that of providers of care can justify an inference that the adult was incapacitated at the time of the execution of a durable power of attorney, even where there is no direct evidence as to lack of capacity on the date that the power of attorney was executed. *Couch v. Couch*, 824 S.W.2d 65, 71 (Mo.App. 1991)

Comment: 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.

***Ivie v. Smith* (Mo. Ct. App., Nov. 20, 2013, No. SD32222) - Link**

It is true that in the case of attempted agreements by incompetents, some cases make a distinction between void and voidable agreements, stating that a contract entered into by a person who has not been adjudicated incompetent is merely voidable upon proof of mental incapacity. See, e.g., *Cohen v. Crumpacker*, 586 S.W.2d 370, 374-75 (Mo. App. W.D. 1979) (upholding the trial court's order of specific performance of a contract where the party seeking to avoid the contract failed to introduce evidence of the seller's mental condition). However, even in cases where there was no adjudication of incompetence, once the agreement was challenged and lack of mental capacity was proven, the agreement has been declared void. E.g., *Pazdernik v. Decker*, 652 S.W.2d 319, 320 (Mo. App. E.D. 1983) (holding that a power of attorney signed by a person who was mentally incompetent was void).

Comment: While a power of attorney for health care signed by an adult with a mental or developmental disability who has not been declared incompetent by a court may be presumptively valid, it may later be challenged. If evidence is later produced in court that the adult lacked capacity to understand the nature and effect of the document at the time it was executed, the document can be declared void. A medical practitioner who had no reason to suspect its invalidity might have a defense that he or she reasonably believed the document was valid. However, an inquiry could be made into the practitioner's history with the patient and his or her knowledge of the patient's mental capacity on the date the document was executed.

Medical Ethics and Advance Directives

AMA Code of Medical Ethics: Recognition of Surrogates - Link

Respect for patient autonomy is central to professional ethics and 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.

When a patient lacks decision-making capacity, the physician has an ethical responsibility to:

(a) Identify an appropriate surrogate to make decisions on the patient's behalf: (I) the person the patient designated as surrogate through a durable power of attorney for health care or other mechanism; (ii) a family member or other intimate associate, in keeping with applicable law and policy if the patient has not previously designated a surrogate.

(b) Recognize that the patient's surrogate is entitled to the same respect as the patient.

(c) Provide advice, guidance, and support to the surrogate.

(d) Assist the surrogate to make decisions in keeping with the standard of substituted judgment, basing decisions on: (I) the patient's preferences (if any) as expressed in an advance directive or as documented in the medical record; (ii) the patient's views about life and how it should be lived; (iii) how the patient constructed his or her life story; (iv) the patient's attitudes toward sickness, suffering, and certain medical procedures.

(e) Assist the surrogate to make decisions in keeping with the best interest standard when the patient's preferences and values are not known and cannot reasonably be inferred, such as when the patient has not previously expressed preferences or has never had decision-making capacity. Best interest decisions should be based on: (I) the pain and suffering associated with the intervention; (ii) the degree of and potential for benefit; (iii) impairments that may result from the intervention; (iv) quality of life as experienced by the patient.

(f) Consult an ethics committee or other institutional resource when: (I) no surrogate is available or there is ongoing disagreement about who is the appropriate surrogate; (ii) ongoing disagreement about a treatment decision cannot be resolved; or (iii) the physician judges that the surrogate's decision: a. is clearly not what the patient would have decided when the patient's preferences are known or can be inferred; b. could not reasonably be judged to be in the patient's best interest; c. primarily serves the interests of the surrogate or other third party rather than the patient.

California Hospital Association – Model Policy on Health Care Surrogates - Link

This policy guides California medical professionals through a procedure for selecting a surrogate decision maker when patients lose decision-making capacity and lack a written advance directive for health care or a court-appointed conservator. This document illustrates best practices and clarifies the process commonly and currently used by health care professionals.

The California Medical Association, the California Hospital Association and the California Coalition for Compassionate Care have considered the ethical, medical, and legal issues in this process. We believe that patients, physicians and health care institutions benefit when a uniform process is agreed upon by which such designations will be made. We have written these procedures in the form of a policy.

Comment: Missouri law does not specify a procedure for selecting a health care surrogate when an incapacitated patient does not have an advance directive and is not in a guardianship. The Missouri Medical Association and Hospital Association should collaborate with the Alternatives to Guardianship Project and other stakeholders to formulate a policy similar this and/or develop proposed legislation, perhaps similar to SB 493 which was introduced in 2017 to designate who shall make medical decision for an incapacitated patient who lacks an advance directive and is not in a guardianship.

Alternatives to Guardianship Project – Health Care Proxies - Link

Capacity to make medical decisions requires the ability of a person to give informed consent to various medical procedures. Depending on the complexity of the medical procedure, and the risks involved, such capacity may require a degree of understanding and rational thought processes that an adult with a mental or developmental disability may not possess. However, the individual may have sufficient capacity to know who they want making such decisions for them.

There is a difference between capacity to give informed consent to medical procedures and capacity to name a health care proxy (HCP) to make such decisions on one's behalf. Just because capacity for the former is lacking does not mean that capacity for the latter is absent.

Some adults may have capacity to make their own medical decisions, even complex ones, pursuant to a supported decision-making (SDM) arrangement. But those who can't make their own medical decisions, even with SDM assistance, should have the option of designating a medical decision-maker through a health care proxy.

Comment: Building on experiences in Utah and Vermont, medical professionals in Missouri, working with disability rights organizations and disability service providers, should develop a legislative proposal recognizing a lower threshold of capacity to designate a healthcare proxy than to make one's own medical decisions. An individual may not have capacity to give specific instructions to the proxy on what decisions to make under various circumstances, but he or she may have the capacity to know who they want to make such choices. Courts and capacity assessment professionals in Missouri would benefit from such statutory guidance.

Federal Disability Laws and Health Care

ADA National Network: Health Care and the ADA - Link

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), *intellectual, psychiatric, or other mental disability*. (Emphasis Added)

Health care organizations that provide services to the public are covered by the ADA. Covered health care facilities include, but are not limited to: hospitals, doctors' offices, pharmacies, dentists' offices, acupuncturists' offices, etc.

Health care agencies run by state and local governments are covered under Title II of the ADA. Health care organizations run by private businesses or nonprofit organizations are covered under Title III of 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.

Comment: Health care providers, whether public or private, must take reasonable steps to ensure that patients with mental or developmental disabilities have meaningful access to health care services and have effective communication with doctors, nurses, and other staff. This may require modifications in normal procedures, such as scheduling at a time when the patient is at their best, scheduling longer appointments to allow for more time to explain and answer questions, using simple words, avoid complicated terminology, allow or even encourage the presence of a support person of the patient's choice at the appointment, giving written instructions in simple terms, etc. Under federal law, patients with mental or developmental disabilities have a right to reasonable accommodations to assist them in participating in the medical decision-making process.

Rehabilitation Act of 1973 – Federally-Funded Medical Service Providers

Service providers must provide "meaningful access to the benefit that the grantee offers." *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." Id. The failure to accommodate or make a reasonable modification constitutes 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 regulation, 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 . . . .").

Comment: 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 of 1973. Virtually all hospitals and most health care providers receive federal funding for some of their services. Such providers must take steps to ensure that patients with mental or developmental or other disabilities have meaningful access to the medical decision-making process. This may require accommodations to such patients or modifications of normal procedures as explained in the previous comment.

Affordable Care Act – 45 CFR Part 92 – Nondiscrimination - Link

The purpose of this part is to provide for the enforcement of section 1557 of the Patient Protection and Affordable Care Act, 42 U.S.C. 18116, prohibiting discrimination under any health program or activity receiving Federal financial assistance.

§ 92.2 Nondiscrimination requirements. (a) Except as provided in Title I of the Patient Protection and Affordable Care Act (or any amendment thereto), an individual shall not, on any of the grounds set forth in paragraph (b) of this section, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any health program or activity, any part of which is receiving Federal financial assistance.

(b) The grounds are the grounds prohibited under the following statutes: . . . (4) Section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794) (disability).

§ 92.102 Effective communication for individuals with disabilities. (a) Any entity operating or administering a program or activity under this part shall take appropriate steps to ensure that communications with individuals with disabilities are as effective as communications with others in such programs or activities,

§ 92.105 Requirement to make reasonable modifications. Any entity to which section 1557 applies (as defined in § 92.3 of this part) shall make reasonable modifications to its policies, practices, or procedures when such modifications are necessary to avoid discrimination on the basis of disability, unless the covered entity can demonstrate that making the modifications would fundamentally alter the nature of the health program or activity. For the purposes of this section, the term "reasonable modifications" shall be interpreted in a manner consistent with the term as set forth in the regulation promulgated under Title II of the Americans with Disabilities Act, at 28 CFR 35.130(b)(7).

Comment: The nondiscrimination provisions of the Affordable Care Act require health care providers receiving federal funds to ensure effective communication, to the extent reasonably possible, between a patient with a developmental disability and health care staff in the medical decision-making process.

Supported Decision-Making

MO Rev Stat § 475.075 - Less Restrictive Alternatives to Guardianship - Link

13. Before appointing a guardian or conservator, the court shall consider whether the respondent's needs may be met without the necessity of the appointment of a guardian or conservator, or both, by a less restrictive alternative including, but not limited to, the following: (1) Evidence that the respondent has appointed an attorney-in-fact in a *durable power of attorney* executed by the respondent before the petition was filed; . . . (4) *Supported decision-making agreements* or the provision of protective or supportive services or arrangements provided by individuals or public or private services or agencies; . . . (5) The use of appropriate *services or assistive technology.* (Emphasis Added)

Comment: 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.

Alternatives to Guardianship Project – SDM Options for Missouri - Link

The first supported decision-making law (SDM) was enacted in Texas in 2015. In the following years, 20 more states have passed such laws. Some focus exclusively on reforms to the guardianship process. Others recognize SDM agreements, establishing the process for adults to enter into such contracts, the required contents, and the legal consequences to SDM participants, including adults who create them as well as designated supporters who provide assistance and third parties who rely on them.

With the assistance of Spectrum Institute, the Alternatives to Guardianship Project has reviewed SDM laws in 21 states and the District of Columbia. We have identified the key elements in the SDM statutory scheme in each of them. The purpose of this review has been to create a menu of options to be considered for inclusion in new SDM legislation in Missouri.

The report provides a framework to stimulate conversations among stakeholders and strategic planning by advocates for new legislation in Missouri to make SDM and other less restrictive alternatives to guardianship for people with mental and developmental disabilities a viable and practical reality rather than a theoretical possibility.

Comment: The Missouri Legislature specifically recognized a role for supported decision-making agreements in th lives of adults with mental or developmental disabilities. It recognized that through an SDM agreement, a guardianship proceeding may not be necessary for such adults. Associations representing health care providers should work with disability rights organizations and other stakeholders to develop policies and procedures for using SDM agreements in medical settings.