

Health Care and Developmental Disabilities

A Message to Providers

Continuing education is the key to compliance by providers with their legal and ethical duties to ensure that the medical decision-making process is accessible to patients with developmental disabilities.

The following suggestions are intended to assist hospitals, doctors, nurses, dentists, and other health care providers to respect the medical decision-making rights of adult patients with developmental disabilities while also complying with their ethical and legal duties as medical professionals. More details on this topic are contained in a [memo](https://alternativestoguardianship.com/how-to-references.pdf) titled *References for Patients, Families, and Providers*. <https://alternativestoguardianship.com/how-to-references.pdf>

1. How to Comply with the Americans with Disabilities Act



The Americans with Disabilities Act (ADA) is a federal law that prohibits disability discrimination. It applies to health care providers and protects patients with mental or developmental disabilities. Title II of the ADA regulates health care services offered by state and local government entities. Title III of the ADA regulates medical and dental offices and hospital facilities that are operated by private businesses. Section 504 of the Rehabilitation Act of 1973 imposes ADA duties on health care providers who receive federal funds for any part of their operations or services.

A. ADA Duties. Medical providers have three types of duties to patients under the ADA and Section 504: (1) nondiscrimination; (2) effective communication; and (3) reasonable accommodation.

✓ **Nondiscrimination.** Health care providers may not discriminate against patients on the basis of a disability. To comply with this mandate, providers must provide services to such patients that are equal to services provided to patients without disabilities.

✓ **Effective Communication.** Health care providers must take reasonable steps to ensure that communications with patients who have disabilities are as effective as communications with patients who do not have disabilities.

✓ **Reasonable Accommodation.** Health care providers must offer reasonable accommodations to patients with developmental disabilities or make modifications to policies and practices to ensure nondiscrimination and effective communication with such patients *unless* doing so would *fundamentally alter* the nature of the service or impose an *undue hardship* on the provider.

B. Medical Decision-Making. The process of making decisions regarding medical treatment is an integral part of health care services. Therefore, providers must avoid discriminating against patients with developmental disabilities in the decision-making process. Steps must be taken to ensure that communications with such patients about decision-making are effective. Accommodations must be offered to ensure nondiscrimination and effective communications in the decision-making process unless doing so would fundamentally alter the nature of the treatment or impose an undue hardship on the provider. The burden of proof to establish these exceptions is on the provider, not the patient.



✓ **Nondiscrimination.** Because adult patients have a legal right to self-determination, health care providers must respect the decisions of patients to consent to or refuse medical treatment. The same is true for adult patients with developmental disabilities. They are presumed to be competent to make medical decisions. The presumption prevails unless is rebutted with contrary *evidence*.

✓ **Effective Communication.** Providers engage in a communication process with patients when they obtain consent for treatment. For patients with disabilities, including developmental disabilities, communications may require the use of auxiliary aids and services, a support person or persons, or additional time in order to be effective.

✓ **Reasonable Accommodation.** In order to ensure that patients with developmental disabilities have access to the decision-making process, a provider may need to offer supplemental assistance or modify normal procedures.

* **Support person.** The patient has a right to involve a chosen support person to assist them with understanding or communicating about medical options. The patient has a right for the support person (i.e. personal representative) to have access to otherwise confidential medical information or records.

* **Health care agent.** If a doctor has reasonable cause to believe that the patient currently lacks capacity to make a specific medical decision, the provider must allow for delegated decision-making by a chosen health care agent through an existing durable power of attorney for health care. Unless a patient has been declared incompetent by a court, the patient has the right to delegate medical decision-making through a power of attorney. Rejecting the agent named in such a document would constitute disability discrimination unless evidence exists that the patient lacked the minimal capacity to designate a health care agent at the time the power of attorney was executed.

*** No reasonable alternatives.** Refusing to provide medical services without a guardianship would constitute disability discrimination unless there is clear evidence that: (1) informed consent is needed for a procedure and the patient does not understand the risks and benefits (even with assistance); (2) supported decision-making is not feasible to ensure informed consent; and (3) the patient does not have a designated health care agent or lacked the minimal capacity to execute a health care power of attorney. It would not be disability discrimination to recommend a guardianship if independent decision-making is not feasible, supported decision-making does not work, and a valid power of attorney does not exist.

2. How to Comply with the Ethical and Legal Duty of Informed Consent



Health care providers have a duty to obtain the consent of a patient or the patient's representative prior to treatment. Such consent must also be obtained prior to releasing medical information or records to persons other than the patient. Providers must also refrain from performing medical services over the objection of a patient or a patient's representative. These duties are grounded in medical ethics and state law.

A. Simple Consent

Simple consent is sufficient to give permission to provide routine medical services that have little or no risk. Such assent may be implied from a failure to object to a simple procedure such as testing for temperature or blood pressure, listening to heartbeat, taking an x-ray, or drawing blood. Dental exams or cleaning of teeth are procedures requiring only simple consent. There is no need for providers to explain risks and benefits and to obtain informed consent when procedures have no risk or when benefits undoubtedly outweigh minor risks and the patient consents to the procedure.

B. Informed Consent

Informed consent is required before providing a treatment that carries significant risk or when benefits do not clearly outweigh risks. For such procedures, patients must be advised of the risks and benefits and be allowed to consent to or refuse such treatment.

Adult patients who are not under an order of guardianship are presumed to have capacity to consent to or refuse treatment. However, if objective evidence causes a health care provider to have a reasonable belief that the patient may lack the capacity to give informed consent to or informed refusal of a treatment, the provider may inquire further into the matter. A reasonable belief exists when a provider is unsure that such a patient understands the risks or benefits or is unsure that the patient is capable of communicating their decision. In such a situation, medical ethics (do no harm) and legal constraints (malpractice) may require the provider to evaluate a patient for decision-making capacity.

3. When and How to Evaluate Capacity



Capacity is not an all-or-nothing proposition. A patient may have capacity to understand the risks and benefits for a minor procedure but lack the capacity to give informed consent for a treatment that is complicated. Assessment for capacity is specific to a particular procedure. Also, capacity to consent to treatment is not the same as capacity to delegate medical decision-making to a trusted person. The latter requires less capacity.

A. Consent for Treatment

Capacity is first assessed for a patient acting independently. Can the patient give informed consent for treatment without assistance from anyone other than the provider? If the answer is yes, the evaluation process ends there. If there is reasonable doubt on this, a provider should evaluate whether the patient can give informed consent with the assistance of a chosen support person or with the use of auxiliary aids or services. If informed consent exists with such support, the evaluation process ends there.

B. Designation of Agent

If a preliminary evaluation indicates a lack of capacity to give informed consent, a provider should determine if the patient has designated a chosen agent in a durable power of attorney for health care. If such a document has been executed, a formal capacity evaluation may not be necessary unless the patient currently objects to the agent acting on their behalf.

Adult patients who are not under an order of guardianship are presumed to have capacity to designate an agent through a power of attorney. Therefore, a medical power of attorney is presumed to be valid unless the provider has objective evidence that the document was executed through fraud or undue influence.

Capacity to execute a power of attorney requires much less understanding than capacity to consent to medical treatment. The patient simply must understand that they are selecting a trusted person to make medical decisions for them in the event a medical provider believes they can't do so themselves. Delegating such authority must be done voluntarily.

C. Formal Evaluation

If a preliminary assessment raises a significant doubt regarding capacity to give informed consent for a procedure, with or without support, and the patient has not executed a medical power of attorney, a more formal evaluation of capacity may be necessary. In a hospital setting, staff may refer the case to an ethics committee. In other medical settings, a provider may consult with a professional who has expertise in capacity assessments. If a professional assessment indicates a lack of capacity to make the medical decision in question, the provider may recommend a temporary guardianship. Such a referral would not constitute disability discrimination if less restrictive alternatives have been considered and were ruled out as unfeasible.

D. Referral to Protective Services

A health care provider sometimes may have a duty to refer a patient to a protective services agency. Such would be the case when the patient clearly needs treatment but there is no one to give informed consent. Such a referral would also be warranted when it appears that a patient who lacks capacity and does not have a health care agent is refusing treatment and such refusal could result in serious harm or death. A referral would also be appropriate when a provider reasonably believes that a patient's medical decision or power of attorney was the result of coercion or undue influence. A referral to Adult Protective Services would also be warranted if a provider believes medical attention or evaluation is needed and a guardian refuses to provide consent for the procedure. This would be reported as medical neglect to APS. Such a referral to APS would be especially important if abuse is suspected and a medical exam is necessary to verify if this is true. As a last resort, if abuse is suspected, the guardian refuses to consent to an evaluation, and a referral to APS does not remedy the situation, a medical provider can alert the court of the problem and recommend that the judge intervene.

4. How to Implement Public Policy on Least Restrictive Alternatives



The law specifies that an adult should not be placed under an order of guardianship unless (1) they lack capacity to make decisions; (2) as a result they are at risk or serious harm; and (3) no less restrictive alternatives are feasible to protect them from harm. The law also precludes a guardianship from being instituted unless each of these elements is proven in court by clear and convincing evidence. Health care providers should be aware of these requirements before recommending that a patient be placed into a guardianship. They should themselves explore less restrictive alternatives for medical decision-making before making such a recommendation.

A. Supported Decision-Making

Missouri law specifies that supported decision-making is a less restrictive alternative that should be considered and ruled out before an adult is placed under an order of guardianship. Such an agreement may be formal or informal. It may provide decision-making support to an adult who has mental or developmental disabilities on a wide range of matters, such as education, employment, finances, and health care.

Missouri Protection and Advocacy Services has a sample supported decision-making agreement on its website. It includes a provision for supported decision-making in the context of health care services. Health care providers who are concerned that a patient with developmental disabilities may not have the capacity to make medical decisions independently, but would benefit from supported decision-making, should consider referring patients and their families to this organization for assistance in executing such an agreement for use in medical care.

B. Other Supportive Services

The challenge to a patient with a developmental disability may be cognitive in nature. It may stem from communication disabilities. Or both. When informed decision-making (consent or refusal) is required for treatment, a provider should identify the source of any barriers and explore methods to overcome them. The ADA requires such an approach.

If a patient has a support person who they want to involve in the process, this should be documented and then allowed. If the patient gives consent for the support person to have access to their medical records and information, this too should be documented and then allowed. If the patient already has designated a personal representative and has a HIPAA waiver, these documents should be placed in the patient's medical record. If such documents do not exist, the provider should assist the patient in executing these or similar forms.

It may be necessary to take extra time or to reschedule an appointment in order to allow a patient to participate in medical decision-making with the assistance of a support person. The use of other supports and services may also be necessary, such as a sign language interpreter for patients with hearing disabilities. The use of large print or simple words or diagrams and images may be necessary for patients with intellectual disabilities. It is important that a provider involve the patient and their family members to devise the most effective set of support services to enable the patient to participate in the decision-making process.

C. Durable Power of Attorney

Missouri allows patients to delegate medical decision-making authority to a trusted person if and when a doctor determines the patient lacks the capacity to make their own decisions, even with assistance of a supporter or the use of supportive services or devices. Two separate, but related, documents are available.

Through a durable power of attorney for healthcare, a patient can designate a primary and secondary agent to make medical decisions for them if they are determined to be incapacitated. There is also an option of executing an advance directive with specific instructions for the agent under a variety of scenarios. Either one or both provisions can be chosen by a patient for future use when needed.

While the law indicates the types of information that should be included in these documents, no specific form is mandated. Some hospitals have designed their own forms. The State Bar of Missouri has a sample form that includes the power of attorney in one part and the advance directive in another part, with instructions to cross out one part of both will not be used.

If a patient has executed their own form(s) in advance of a medical crisis, a provider should honor that document even if the provider has its own preferred form. Rejecting the patient's existing power of attorney at a time the patient does not have capacity to execute



a new one, would deny the patient participation in the decision-making process without a valid reason. This could be considered disability discrimination which could subject the provider to complaints with state and federal agencies or even a lawsuit.

5. How to Avoid Complaints, Grievances, and Lawsuits



As patients with developmental disabilities become more aware of their rights, and families are educated on how to advocate for their loved ones in a medical setting, the likelihood of complaints and lawsuits against providers increases. Patients and families are learning that they can complain internally to managers and supervisors, ask for a formal capacity assessment by a qualified professional, and file a formal grievance if a supported decision-making agreement or medical power of attorney is not honored.

On their own or with the help of Missouri Protection and Advocacy or other advocacy organization, patients and their families may file a complaint with state or federal agencies for alleged disability discrimination.

In any event, as patients and their families become more aware of patient rights, education and training of students and medical professionals on such issues becomes ever more important.

A. Education in medical, nursing, and dental schools

Education about patients with developmental disabilities, and the responsibility of health care providers to protect their rights, is the best way for doctors, nurses, dentists, and hospitals to avoid unwanted liability. The same is true for social workers, psychologists, and psychiatrists who may be involved in capacity assessments or identifying supports and services that can augment capacity and make guardianships unnecessary. Such education should start in the schools that train such professionals.

B. Continuing education for health care providers

The need for such education and training continues after students receive their degrees in medicine, nursing, dentistry, hospital administration, social work, psychology, and psychiatry. Obtaining a license from the state to practice in these disciplines merely opens the door to treating this patient population. General training by schools should be augmented by continuing education about patients with developmental disabilities.

Health care practitioners should assume they will provide services to such patients at some point in their careers. It would be illegal to refuse to treat patients with developmental disabilities. Because hundreds of thousands of people in Missouri have cognitive or developmental disabilities, contact with such patients is not unlikely. Therefore, practitioners should educate themselves about communicating with such patients, accommodating their special needs, and respecting their right to self-determination.

Large employers should incorporate the needs of this patient population, and the

duties of providers toward such patients, in continuing education classes and materials. Statewide professional associations should offer continuing education of this nature for doctors, nurses, dentists, and other health care professionals who work for employers who do not provide such training for their employees

C. Designating an ADA/504 Coordinator

Health care providers should have someone on staff who is designated to ensure compliance with the Americans with Disabilities Act and Section 504 of the Rehabilitation Act of 1973. The coordinator should be trained about the various disabilities that patients may have, the likely needs of such patients in a health care setting, and what staff must do to comply with state and federal nondiscrimination mandates.

D. A Role for State Agencies

The Department of Mental Health in coordination with the Department of Health and Senior Services should develop materials for health care providers on how to ensure nondiscrimination, engage in effective communication, and provide reasonable accommodations to patients with mental and developmental disabilities.

Relevant forms should be made available on agency websites to help patients with such disabilities to participate in medical decision-making, to have support in decision-making, and to delegate decision-making to a chosen agent if capacity to do so independently or with support is absent. Such forms should be accompanied by instructions that will enhance the ability of patients with such disabilities to understand them and for families and other supporters to help patients use them.

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