

Medical Decision-Making by Adults with Developmental Disabilities

Guidance for Patients, Families,
Providers, State Agencies and
Professional Associations



*Including An Annotated Bibliography
of Statutes, Regulations, and Cases*

Missouri Edition

by Thomas F. Coleman

Produced by Spectrum Institute for
the Alternatives to Guardianship Project

alternativestoguardianship.com/medical-guidance-mo.pdf

July 1, 2023

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.
- 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.

Table of Contents

Fundamentals	i
Guidance	1
For Patients	1
For Families	2
For Providers	3
For State Agencies	4
For Professional and Trade Associations	5
Annotated Bibliography	6
<u>Federal Law</u>	
Section 504 of the Rehabilitation Act of 1973	7
Patient Self Determination Act of 1990	11
Hospital Conditions of Participation in Medicare	12
Home Health Agency Conditions of Participation in Medicare	13
Public Health Care Entities: ADA Title II	15
Private Health Care Providers: ADA Title III	21
Patient Protection and Affordable Care Act	25
HIPAA – Patient Representative	26
HHS Report on Advance Directives	28
<u>State Law</u>	
Missouri Human Rights Act	31
Missouri DHSS Disability Nondiscrimination Policies	32
Case Law on Capacity	34
<u>Other</u>	
Simple Consent vs. Informed Consent	37
Health Care and Supported Decision-Making	39



Alternatives to Guardianship Project

Hulme Resources Inc.
903A SE 7th Street • Lee's Summit, MO 64063
alternativestoguardianship.com • (816) 730-2831

Jennifer Hulme, Director • jennifer@gohulme.com
Thomas F. Coleman, Consultant • tomcoleman@specruminstitute.org

Fundamentals

The following excerpts are taken from various sections of this report. They highlight the key points that patients, families, providers, and agencies should know regarding medical decision-making rights of adult patients with developmental disabilities. [Page citations are to pages in this report.]

Patient Population

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. See: “[Medical Decision-Making Options for Adults with Developmental Disabilities](#),” (Spectrum Institute 2023)

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.

Disability Bias

Adults with intellectual disability “have historically been excluded from various spheres of decisionmaking about their lives, on the presumption that they are incapable of making informed decisions.” Health care providers, administrators, and families commonly assumed a protective stance toward people with intellectual disabilities, even when decision-specific capacity may have existed. Recent trends have encouraged providers, researchers, and advocates to question this paternalistic approach for three reasons. (p. 29)

Presumption of Capacity

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 legal process. (p. 28) People with intellectual disabilities should not be presumed to lack capacity for making health care decisions. (pp. 28-29)

Capacity Determinations

Clinical practice and legal standards have moved away from global determinations of capacity to more finely-tuned task-specific determinations of capacity. The capacity to make health care decisions has been defined as the ability to understand the information about a proposed care plan, appreciate the consequences of a decision, and reach and communicate an informed decision. Unlike competency, which is an “all or nothing” judicial determination, capacity is specific to the decision at hand. This more flexible methodology to assessing abilities creates a multi-tiered approach to decisionmaking. For example, individuals who lack abilities to express preferences or goals of care in a living will may be able to appoint a health care proxy. Similarly, those unable to make decisions about life-sustaining interventions may have the capacity to make less complex decisions, such as on low-risk medications, diet, or recreation. Beltran summarizes the challenge in accurately assessing decisionmaking capacity: “There is a need to balance protection from harm with the patient’s right to self-determination. This balancing requires skilled listening, the proper level of advocacy from caregivers, and pragmatic models of shared decisionmaking.” (p. 29)

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. (p.

Capacity with Support

Many adults with [mild intellectual disabilities], and some adults with [moderate intellectual disabilities], “do indeed have the ability to provide adequate consent to standard low-risk health-related treatments.” Moreover, capacity to consent “could be enhanced with supportive decisionmaking or educational techniques in preparation for treatments or procedures requiring their consent.” (p. 30)

In Missouri, the capacity to delegate medical decision-making to another is presumed to exist unless proven otherwise. Whereas independent decision-making may pose a significant risk for some patients with developmental disabilities, delegating such authority to a trusted person poses little to no risk. (p. 34)

The State of Missouri recognizes supported decision-making agreements as a possible alternative to guardianship. (Mo. Stat. § 475.075 (13) (4)) (p. 39)

Nondiscrimination Obligations

Hospitals, medical clinics, and most doctors have patients whose health care services are paid fully or in part by federal funds, such as Medicare, Medicaid, or other subsidies. Health care providers receiving federal funds are obligated to obey the nondiscrimination mandates of Section 504 of the Rehabilitation Act of 1973. Section 504 gives rights to patients with

disabilities, regardless of how they personally pay for medical services. Patients with mental and developmental disabilities are protected by the nondiscrimination requirements of Section 504 in the receipt of health care services. The medical decision-making process is an important part of the delivery and receipt of medical services. (p. 7)

To avoid discriminating in the delivery of services, health care providers who receive federal funds must take steps to ensure that adult patients with developmental disabilities have meaningful participation in the medical decision-making process. To fulfill this mandate, a provider may need to give such patients reasonable accommodations to assist them in making medical decisions or they may need to make reasonable modifications to their policies and procedures regarding how a patient's consent is obtained. (p. 7)

To fulfill their duties under Section 504, health care providers may need to take affirmative steps to remove barriers to the medical decision-making process for such adult patients. These steps may require: taking extra time to explain; using simplified language; modifying complicated forms to make them more easily understandable; allowing for a support person (designated representative) to assist with the decision-making process; allowing the patient to nominate a trusted person to serve as a proxy or surrogate for decisions in situations in which the patient cannot give informed consent. Providers may also need to have trainings for staff on how to comply with Section 504 in the medical decision-making process when adult patients have mental or developmental disabilities. They may also need to designate a qualified and trained staff member at each facility to interact with such patients. (pp. 7-8)

Case Law

Under the Rehabilitation Act . . . requires that an otherwise qualified handicapped individual be provided with meaningful access to the benefit that the grantee offers. The benefit itself, of course, cannot be defined in a way that effectively denies otherwise qualified handicapped individuals the meaningful access to which they are entitled; to assure meaningful access, reasonable accommodations in the grantees program or benefit may have to be made. *Alexander v. Choate*, 469 U.S. 287, 301.

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). (pp. 34-35)

Provider's Duty to Notify

The federal Patient Self-Determination Act, passed in 1990, requires most health care providers to offer information to patients on health care advance directives. The purpose of this legislation is to enhance patient choice. (p. 11)

The act requires health care providers to inform patients about their right to make medical decisions, personally or through an advance directive. The act should be interpreted in coordination with federal laws prohibiting discrimination against patients with mental or developmental disabilities and the duty under such laws for providers to offer reasonable accommodations or make modifications to policies and practices that enable patients with such disabilities to have meaningful participation in the decision-making process. (p. 11)

Hospital's Duty to Protect Rights

Hospitals must agree to various conditions as a prerequisite to participating in the Medicare program. Among those conditions is a mandate to protect and promote the rights of patients to participate in the development of a plan of care, the right to make decisions to receive or refuse care, and the right to designate another person to make decisions for them if they are incapacitated. Hospitals must inform patients or their chosen representative of these rights.(p. 12)

HHA Patient Representative

If a state court has not adjudged a patient to lack legal capacity to make health care decisions as defined by state law, the patient's representative may exercise the patient's rights in a home health care setting. If they are not under an order of guardianship, a patient with mental or developmental disabilities is the one who selects his or her representative. The patient also determines the role of the representative, to the extent possible. (pp. 13-14)

Title II: ADA Accommodations

A public entity must offer accommodations for known physical or mental limitations. Even without a request, an entity has an obligation to provide an accommodation when it knows or reasonably should know that a person has a disability and needs a modification. (DOJ Guidance Memo to Criminal Justice Agencies, January 2017) It is the knowledge of a disability and the need for accommodation that gives rise to a legal duty, not a request. (Pierce v. District of Columbia (D.D.C. 2015) 128 F.Supp.3d 250) To require a request from those who are unable to make a request would eliminate an entire class of disabled persons from the protection of the ADA. (Brady v. Walmart (2nd Cir. 2008) 531 F.3d 127) (p. 20)

Title III: ADA Accommodations

Privately-operated health care organizations that deliver medical services to the public are

covered by Title III of the Americans with Disabilities Act. Covered health care facilities include, but are not limited to: hospitals, as well as the offices of doctors, dentists, pharmacies, and other forms of health services. (p. 21)

Title III requires that health care providers give patients with disabilities full and equal access to these services. This may require making reasonable modifications to policies, practices, and procedures, and by making communications, in all forms, easily understood (p. 21)

Under Title III, private health care providers must take reasonable steps to ensure that adult patients with developmental disabilities who are not under an order of guardianship have meaningful participation in the medical decision-making process: either personally, with help from a chosen representative, or through a proxy or surrogate they have designated. (p. 21)

Complaint Process

Providers should recommend guardianship only as a last resort. Patients or families who believe that health care providers have not allowed the patient to have meaningful participation in the medical decision-making process – either personally, with help from a designated representative, or through a chosen proxy – may file an administrative complaint under Section 504. A complaint may initially be filed with the provider. If that is not satisfactorily resolved, a complaint also may be filed with the Office of Civil Rights of the United States Department of Health and Human Services. HHS has an online portal for complaints. (p. 8)

State Agency Duties

As public entities, the Department of Health and Social Services and the Department of Mental Health are required by Title II of the ADA to take steps to ensure that patients with developmental disabilities are not subject to discrimination by the health care service providers these departments regulate or contract with. This would include monitoring them to eliminate discrimination in the medical decision-making process. (p. 15)

Need for Training

Frequently, health care professionals (physicians, nurses, social workers, clergy, and others), including hospice and palliative care staff, lack training on the special needs of people with intellectual disabilities and on methods to assess their decisional capacity. Furthermore, staff of public agencies and private organizations serving people with disabilities should be trained in the special needs of people with intellectual disabilities for advance care planning, options for hospice and palliative care to manage life-threatening illnesses, and special concerns in providing and consenting to care.

Guidance for Patients

Know Your Rights

**Adult patients with developmental disabilities should know,
if they are not under an order of guardianship, they . . .**

1. Have the right to make medical decisions independently.
2. Have the right to make medical decisions with assistance from a supporter.
3. Have the right to ask for more time or more information to make a decision.
4. Have the right to bring a support person to medical appointments.
5. Have the right to keep medical records and information confidential.
6. Have the right to give permission to a support person to access medical records.
7. Have the right to name a trusted person to make medical decisions for them if the doctor decides they are unable to make their own decision.
8. Have the right to ask for a supervisor if they think their rights are being violated.
9. Have the right to file a complaint with a state or federal agency if their rights are violated by a doctor, nurse, dentist or other health care worker.
10. Have the right to name a trusted person to help them file a complaint.
11. Have the right to seek advice from a lawyer if their rights are violated.
12. Have the right to contact Missouri Protection and Advocacy to ask for legal help.
13. Have the right to object to a guardianship if a petition is filed against them.

Missouri Protection and Advocacy

<https://www.moadvocacy.org/request-help/>

Call toll-free at 800-392-8667 / TDD users can call 800-735-2966

Email: app.unit@mo-pa.org

Guidance for Families

Be An Advocate

**With permission from an adult patient with developmental disabilities,
a supportive family member can advocate for their rights by . . .**

1. Learning about the rights of such patients under state and federal law.
2. Encouraging the patient to make medical decisions independently, if possible.
3. Assisting the patient in making medical decisions
4. Asking the provider to provide necessary ADA accommodations to the patient.
5. Helping the patient prepare for a medical appointment.
6. Helping the patient fill out forms to designate a patient representative, HIPAA release, medical power of attorney, or supported decision-making agreement.
7. Educating the medical provider about the rights of patients, including supported decision-making.
8. Acting as a patient representative or proxy if authorized by the patient.
9. Asking for a supervisor if staff is not respecting the rights of the patient.
10. Helping the patient file a complaint with state or federal agencies if rights are violated.
11. Help the patient seek advice from a lawyer if their rights are violated.
12. Help the patient contact Missouri Protection and Advocacy to ask for legal help.
13. Seek a limited guardianship for health care decisions if all less restrictive alternatives have been tried unsuccessfully.

Guidance for Providers

Fulfill Your Duties

Hospitals, medical clinics, doctors, nurses, dentists, others that provide services to adult patients with developmental disabilities should protect the rights of patients and fulfill their obligations as providers by . . .

1. Educating yourself and other staff regarding the rights of adult patients to:
 - a. Make their own medical decisions if they are not under a guardianship.
 - b. Have a support person present during office visits or hospital stays.
 - c. Access patient records or designate a representative to do so.
 - d. Have a designated person to help them make medical decisions.
 - e. Receive reasonable ADA accommodations in the decision-making process.
 - d. Designate another person as a proxy if they lack capacity for a decision.
 - e. Speak with a supervisor if the patient or representative is dissatisfied.
 - f. File a complaint with a state or federal agency for violations of rights.
2. Take steps to ensure the patient has equal access to, and meaningful participation in the medical decision-making process, either independently, with assistance from a support person, or through a designated representative or chosen health care proxy.
3. Provide reasonable accommodations or modify standard policies and practices to enable the patient to have equal access to medical services.
4. Adopt formal policies on how adult patients with developmental disabilities may have equal access to the medical decision-making process, either independently, with assistance from a chosen supporter, or through a representative or proxy selected by the patient.
5. Avoid global capacity assessments and instead evaluate capacity to make medical decisions for specific medical situations and procedures. Advise patients of their right to a second opinion on capacity to make a medical decision.
6. Advise patients of their rights, including the right to speak to a supervisor and their right to file a complaint with a state or federal agency for violations of rights.

Guidance for State Agencies

Educate, Regulate, and Investigate

Agencies operated by or funded by the state, should exercise their authority to educate patients and providers, to regulate contractors and licensees, and to intervene when patient rights are violated.

1. The Department of Health and Social Services (DHSS) should share this report with appropriate staff so they become familiar with federal and state laws and other resource materials relevant to the decision-making rights of adult patients with developmental disabilities. Education and training materials for health care professions should address the issues described in this report. DHSS should survey hospitals in the state to determine whether their written policies on patient decision-making, patient representatives, health care directives, proxy decision-makers, and patient capacity address these issues for the patient population of adults with developmental disabilities.
2. The Department of Mental Health (DMH), Office of Developmental Disabilities (ODD) should share this report with appropriate staff in DMH so they are familiar with the issues discussed in the report. ODD should develop brochures and other educational materials, including sample forms, that specifically address: capacity to make medical decisions; the rights of adult patients who are not in a guardianship; medical self-determination; the right of patients with developmental disabilities to accommodations under the ADA; the right to name a patient representative; the right to name a proxy decision-maker; and the use of medical supported decision-making agreements.
3. The Missouri Commission on Human Rights should have its members and staff become familiar with the right of adult patients with developmental disabilities to be free from disability discrimination in health care services and to have access to medical decision-making options on an equal basis with patients who do not have developmental disabilities. The commission should let disability rights organizations know that it will accept and process complaints of disability discrimination by health care providers.
4. Missouri Protection and Advocacy should add information to its website about the medical decision-making rights of adult patients with developmental disabilities and signal its willingness to receive and investigate complaints of discrimination by health care providers. It should assist patients whose medical decision-making rights are violated to file complaints with appropriate state and federal agencies.

Guidance for Professional and Trade Associations

Educate Your Members

Associations for hospitals, doctors, nurses, dentists, pharmacists, and other health care professionals should educate members on protecting patient rights and fulfilling the duties of providers in all aspects of the medical decision-making process.

Missouri Hospital Association
Missouri State Medical Association
Missouri Psychiatric Physicians Association
Missouri Association of Osteopathic Physicians and Surgeons
Missouri Nurses Association
Missouri Dental Association
Missouri Pharmacy Association
Missouri Psychological Association
Missouri Chapter of the National Association of Social Workers
Missouri Health Care Association
Missouri Primary Care Association
Missouri Health Information Management Association
Missouri Association of Local Public Health Agencies
Missouri Society of Health Care Attorneys
Community Health Workers Association
Missouri Rural Health Association
Missouri Behavioral Health Council

These organizations should educate their members about the rights of adult patients with developmental disabilities who are not in a guardianship. This includes their right to make medical decisions independently, with assistance from a chosen supporter, and the right to delegate decision-making authority and give access to medical records to a trusted person if they are found to lack capacity to make a particular medical decision. Educational efforts should address unwarranted assumptions and implicit biases about this patient population.

The organizations should bring this report to the attention of their members, as well as other materials produced by Spectrum Institute for the [Alternatives to Guardianship Project](#), such as “[Transitioning to Adulthood](#)” and “[Medical Decision-Making Options](#).” They should reach out to and collaborate with the American Academy of Developmental Medicine and Dentistry ([AADMD](#)) as well as [Missouri Protection and Advocacy](#).

Adults with Developmental Disabilities

Patient Rights and Provider Duties on Access to Medical Decision-Making

Annotated Bibliography

Consent from a patient is an integral part of health care services. Some procedures only need simple consent. More risky procedures require what is called “informed consent.” For informed consent to exist, providers must give patients sufficient information about a procedure to enable the patient to make an informed choice in the matter. Informed consent is facilitated by effective communication between patient and provider. The provider must provide correct information and then must receive and understand the patient’s decision.

Patients with developmental disabilities have special needs that should be addressed during the process of obtaining consent for medical services. In addition to cognitive and behavioral challenges that may require accommodations, patients may also have physical disabilities that further complicate the communication process between patient and provider. Visual, hearing, or speech disabilities may need to be addressed.

Patients with disabilities, including those with mental or developmental disabilities, are entitled to have equal access to health care services. In order to avoid illegal discrimination, providers must ensure that such patients have meaningful participation and effective communication in all aspects of health care services, including during the process of deciding whether to consent to or decline particular services or medications.

The purpose of this bibliography is to list and describe statutes, regulations, and court cases regarding patient rights and provider duties to ensure equal access to health care services for adults with developmental disabilities, especially as they pertain to the medical decision-making process.

The bibliography focuses on the Patient Self Determination Act, the Americans with Disabilities Act, the Patient Protection and Affordable Care Act, and Section 504 of the Rehabilitation Act of 1973, as well as regulations of the Department of Health and Human Services (HHS) for health care services funded by Medicare and Medicaid. In addition to substantive and procedural rights, the bibliography also contains information on the filing of administrative complaints with HHS for alleged violations of patient rights by health care providers. Additional state laws and other resources and references are also cited and discussed.

Adults with Developmental Disabilities

Patient Rights and Provider Duties for Access to Medical Decision-Making

Section 504 of the Rehabilitation Act of 1973

Comment:

Hospitals, medical clinics, and most doctors have patients whose health care services are paid fully or in part by federal funds, such as Medicare, Medicaid, or other federal subsidies. Health care providers receiving federal funds are obligated to obey the nondiscrimination mandates of Section 504 of the Rehabilitation Act of 1973. Section 504 gives rights to patients with disabilities, regardless of how they personally pay for medical services.

Patients with mental and developmental disabilities are protected by the nondiscrimination requirements of Section 504 in the receipt of health care services. The medical decision-making process is an important part of the delivery and receipt of medical services.

To avoid discriminating in the delivery of services, health care providers who receive federal funds must take steps to ensure that adult patients with developmental disabilities have meaningful participation in the medical decision-making process. To fulfill this mandate, a provider may need to give such patients reasonable accommodations to assist them in making medical decisions or they may need to make reasonable modifications to their policies and procedures regarding how a patient's consent is obtained.

Some adult patients with developmental disabilities may have the capacity to personally give informed consent for some procedures but not for others. Some may be able to make medical decisions, but only with the assistance of a chosen support person (designated representative). Others may have the capacity to designate a trusted person (proxy or surrogate) to make health care decisions for them in situations where they lack the ability to understand and weigh the risks and benefits of complex or high risk procedures, even with the help of a support person.

To fulfill their duties under Section 504, health care providers may need to take affirmative steps to remove barriers to the medical decision-making process for such adult patients. These steps may require: taking extra time to explain; using simplified language; modifying complicated forms to make them more easily understandable; allowing for a support person (designated representative) to assist with the decision-making process; allowing the patient to nominate a trusted person to serve as a proxy or surrogate for decisions in situations in

which the patient cannot give informed consent. Providers may also need to have trainings for staff on how to comply with Section 504 in the medical decision-making process when adult patients have mental or developmental disabilities. They may also need to designate a qualified and trained staff member at each facility to interact with such patients.

The practice of advising families to obtain guardianships for adult patients with mental or developmental disabilities may be a violation of Section 504, unless less restrictive options have been tried by the medical provider are determined to be unfeasible. Adult patients with such disabilities are not presumed to lack capacity to make medical decisions or to designate a patient representative or to execute a health care proxy. (Mo. Rev. Stat. § [630.120](#)) Adult patients who are not under an order of guardianship must be given reasonable opportunities to have meaningful participation in the medical decision-making process – personally, with help from a representative, or through a chosen proxy.

State laws are invalid if they conflict with or undermine the duties of federally-funded health care providers to give adult patients with disabilities reasonable access to the medical decision-making process.

Providers should recommend guardianship only as a last resort. Patients or families who believe that health care providers have not allowed the patient to have meaningful participation in the medical decision-making process – either personally, with help from a designated representative, or through a chosen proxy – may file an administrative complaint under Section 504.

A complaint may initially be filed with the provider. If that is not satisfactorily resolved, a [complaint](#) also may be filed with the Office of Civil Rights of the United States Department of Health and Human Services. HHS has an [online portal](#) for complaints.

Code of Federal Regulations Title 45, Subtitle A, Subchapter A, Part 84

[PART 84](#)—NONDISCRIMINATION ON THE BASIS OF HANDICAP IN PROGRAMS OR ACTIVITIES RECEIVING FEDERAL FINANCIAL ASSISTANCE

§ 84.3 Definitions.

(f) **Recipient** means any state or its political subdivision, any instrumentality of a state or its political subdivision, any public or private agency, institution, organization, **or other entity, or any person to which Federal financial assistance is extended directly or through another recipient**, including any successor, assignee, or transferee of a recipient, but excluding the ultimate beneficiary of the assistance.

(h) Federal financial assistance means any grant, loan, contract (other than a procurement contract or a contract of insurance or guaranty), or any other arrangement by which the Department provides or otherwise makes available assistance in the form of: . . . (1) Funds;

(j) Handicapped person — (1) Handicapped persons means any person who (I) has a physical **or mental impairment** which substantially limits one or more major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment. (2) As used in paragraph (j)(1) of this section, the phrase: (I) . . . mental impairment means . . . (B) **any mental or psychological disorder, such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities.**

(k) Program or activity means **all of the operations of—** (1) (I) A department, agency, special purpose district, or other instrumentality of a State or of a local government; or . . . (3) (I) **An entire corporation, partnership, or other private organization, or an entire sole proprietorship—** (A) If assistance is extended to such corporation, partnership, private organization, or sole proprietorship as a whole; or (B) Which is principally engaged in the **business of providing** education, **health care**, housing, social services, or parks and recreation . . .

§ 84.4 Discrimination prohibited.

(a) General. No qualified handicapped person shall, on the basis of handicap, be excluded from participation in, be **denied the benefits of, or otherwise be subjected to discrimination under any program or activity which receives Federal financial assistance.**

(b) Discriminatory actions prohibited.

(1) A recipient, in providing any aid, benefit, or service, may not, directly or through contractual, licensing, or other arrangements, on the basis of handicap: (I) Deny a qualified handicapped person the **opportunity to participate in or benefit from the aid, benefit, or service;** (ii) Afford a qualified handicapped person an opportunity to participate in or benefit from the aid, benefit, or service **that is not equal to that afforded others;** (iii) Provide a qualified handicapped person with an aid, benefit, or service that is **not as effective as that provided to others;** . . . (vii) Otherwise **limit** a qualified handicapped person in the **enjoyment of any right, privilege, advantage, or opportunity enjoyed by others receiving an aid, benefit, or service.**

(2) For purposes of this part, aids, benefits, and services, to be equally effective, are not required to produce the identical result or level of achievement for handicapped and nonhandicapped persons, but **must afford handicapped persons equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of**

achievement, in the most integrated setting appropriate to the person's needs.

§ 84.10 Effect of State or local law or other requirements and effect of employment opportunities.

(a) The obligation to comply with this part is **not obviated or alleviated by the existence of any state or local law or other requirement that, on the basis of handicap, imposes prohibitions or limits upon the eligibility of qualified handicapped persons to receive services . . .**

Subpart F—**Health, Welfare, and Social Services**

§ 84.51 Application of this subpart. Subpart F applies to **health**, welfare, and other social service programs or activities that receive Federal financial assistance and to recipients that operate, or that receive Federal financial assistance for the operation of, such programs or activities.

§ 84.52 **Health**, welfare, and other social **services**.

(a) General. In providing **health . . . services** or benefits, a recipient may not, on the basis of handicap: (1) Deny a qualified handicapped person these benefits or services; (2) Afford a qualified handicapped person an opportunity to receive benefits or services that is not equal to that offered nonhandicapped persons; (3) Provide a qualified handicapped person with benefits or services that are not as effective (as defined in § 84.4(b)) as the benefits or services provided to others; (4) Provide benefits or services in a manner that limits or has the effect of limiting the participation of qualified handicapped persons; . . .

Case Law: Meaningful Access and Reasonable Accommodation

Under the Rehabilitation Act, in Alexander v. Choate, 469 U.S. 287, the Supreme Court held that: “The balance struck in Davis [Southeastern Community College v. Davis, 442 U.S. 397, 99 S.Ct. 2361, 60 L.Ed.2d 980 (1979)] requires that an otherwise qualified handicapped individual be **provided with meaningful access to the benefit that the grantee offers**. The benefit itself, of course, cannot be defined in a way that effectively denies otherwise qualified handicapped individuals the meaningful access to which they are entitled; **to assure meaningful access, reasonable accommodations in the grantees program or benefit may have to be made**. Id. at 301.”

References:

“Fact Sheet: Your Rights under Section 504 of the Rehabilitation Act,” HHS (2006) - [Link](#)

Adults with Developmental Disabilities

Patient Rights and Provider Duties for Access to Medical Decision-Making

Patient Self-Determination Act of 1990

Comment:

The federal Patient Self-Determination Act, passed in 1990, requires most health care providers to offer information to patients on health care advance directives. The purpose of this legislation is to enhance patient choice. It applies to Medicare providers through 42 U.S. Code § 1395cc(f) and Medicaid providers through 42 U.S. Code § 1396a(w).

The act requires health care providers to inform patients about their right to make medical decisions, personally or through an advance directive. The act should be interpreted in coordination with federal laws prohibiting discrimination against patients with mental or developmental disabilities and the duty under such laws for providers to offer reasonable accommodations or make modifications to policies and practices that enable patients with such disabilities to have meaningful participation in the decision-making process.

Code of Federal Regulations

Title 42, Ch. 4, Subchapter G, Part 489, [Subpart 1](#)

§ 489.100 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.

§ 489.102 Requirements for providers. (a) Hospitals . . . skilled nursing facilities, nursing facilities, home health agencies, providers of home health care . . . must maintain written policies and procedures concerning advance directives with respect to all adult individuals receiving medical care, . . . 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 . . . to make decisions concerning such medical care . . . and (ii) The written policies of the provider or organization respecting the implementation of such rights . . .

References:

“Implementation Strategies for Ethics Committees,” Center for Practical Bioethics - [Link](#)

Adults with Developmental Disabilities

Patient Rights and Provider Duties for Access to Medical Decision-Making

Hospital Conditions of Participation in Medicare

Comment:

Hospitals must agree to various conditions as a prerequisite to participating in the Medicare program. Among those conditions is a mandate to protect and promote the rights of patients to participate in the development of a plan of care, the right to make decisions to receive or refuse care, and the right to designate another person to make decisions for them if they are incapacitated. Hospitals must inform patients or their chosen representative of these rights.

Code of Federal Regulations Title 42, Ch. 4, Subchapter G, Part 482, [Subpart B](#)

§ 482.11 Condition of participation. Compliance with federal, state, and local laws. (a) The hospital must be in compliance with applicable Federal laws related to the health and safety of patients.

§ 482.13 Condition of participation: Patient's rights. A hospital must protect and promote each patient's rights.

(a) Standard: Notice of rights. (1) A hospital must inform each patient, or when appropriate, the patient's representative (as allowed under State law), of the patient's rights, in advance of furnishing or discontinuing patient care whenever possible. . .

(b) Standard: Exercise of rights. (1) The patient has the right to participate in the development and implementation of his or her plan of care. (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. (3) The patient has the right to formulate advance directives and to have hospital staff and practitioners who provide care in the hospital comply with these directives, in accordance with § 489.100 of this part (Definition), § 489.102 of this part (Requirements for providers), and § 489.104 of this part

Adults with Developmental Disabilities

Patient Rights and Provider Duties for Access to Medical Decision-Making

Home Health Agency Conditions of Participation in Medicare

Comment:

Home health agencies (HHA) that deliver medical services at the home of a patient must agree to various conditions as a prerequisite to participating in the Medicare program. Among those conditions is a mandate to protect and promote the rights of patients to participate in the development of a plan of care, the right to make decisions to receive or refuse care, and the right to designate a representative to participate in medical decision-making, or to choose a proxy to make decisions for them if they become incapacitated. Hospitals must inform patients or their chosen representative of these rights.

If a state court has not adjudged a patient to lack legal capacity to make health care decisions as defined by state law, the patient's representative may exercise the patient's rights. If they are not under an order of guardianship, a patient with mental or developmental disabilities is the one who selects his or her representative. The patient also determines the role of the representative, to the extent possible.

Code of Federal Regulations Title 42, Ch. 4, Subchapter G, Part 484, [Subpart B](#)

§ 484.2 Definitions. As used in subparts A, B, and C, of this part— Representative means the patient's legal representative, such as a guardian, who makes health-care decisions on the patient's behalf, **or a patient-selected representative** who participates in making decisions related to the patient's care or well-being, including but not limited to, a family member or an advocate for the patient. **The patient determines the role of the representative, to the extent possible.**

§ 484.50 Condition of participation: Patient rights. The patient and representative (if any), have the right to be informed of the patient's rights **in a language and manner the individual understands**. The HHA must protect and promote the exercise of these rights.

(a) Standard: Notice of rights. The HHA must— (1) Provide the patient and the patient's legal representative (if any), the following information during the initial evaluation visit, in

advance of furnishing care to the patient: (i) Written notice of the patient's rights and responsibilities under this rule, and the HHA's transfer and discharge policies as set forth in paragraph (d) of this section. Written notice must be understandable to persons who have limited English proficiency and accessible to individuals with disabilities; . . .

(b) Standard: Exercise of rights. (1) If a patient has been adjudged to lack legal capacity to make health care decisions as established by state law by a court of proper jurisdiction, the rights of the patient may be exercised by the person appointed by the state court to act on the patient's behalf. (2) **If a state court has not adjudged a patient to lack legal capacity to make health care decisions as defined by state law, the patient's representative may exercise the patient's rights.** (3) If a patient has been adjudged to lack legal capacity to make health care decisions under state law by a court of proper jurisdiction, the patient may exercise his or her rights to the extent allowed by court order.

(c) Standard: Rights of the patient. The patient has the right to— . . . (4) **Participate in, be informed about, and consent or refuse care in advance of and during treatment, where appropriate,** with respect to— (i) Completion of all assessments; (ii) The care to be furnished, based on the comprehensive assessment; (iii) Establishing and revising the plan of care; (iv) The disciplines that will furnish the care; (v) The frequency of visits; (vi) Expected outcomes of care, including patient-identified goals, and anticipated risks and benefits; (vii) Any factors that could impact treatment effectiveness; and (viii) Any changes in the care to be furnished. (5) Receive all services outlined in the plan of care. (6) Have a confidential clinical record. Access to or release of patient information and clinical records is permitted in accordance with 45 CFR parts 160 and 164.

(f) Standard: Accessibility. Information must be provided to **patients in plain language and in a manner that is accessible** and timely to— (1) **Persons with disabilities**, including accessible Web sites and the provision of auxiliary aids and services at no cost to the individual **in accordance with the Americans with Disabilities Act and Section 504 of the Rehabilitation Act.** (2) Persons with limited English proficiency through the provision of language services at no cost to the individual, including oral interpretation and written translations.

Adults with Developmental Disabilities

Patient Rights and Provider Duties for Access to Medical Decision-Making

Public Health Care Entities: ADA Title II

Comment:

Title II of the Americans with Disabilities Act prohibits public entities from discriminating against people with disabilities in the delivery of services. Government entities, such as the Missouri Department of Health of Senior Services, Department of Mental Health (DMH), and public hospitals and other public medical providers are regulated by Title II. Pursuant to authority granted by Congress, the federal Department of Justice (DOJ) has promulgated regulations to implement Title II.

The Missouri Department of Health and Senior Services (DHSS) has the authority to adopt rules necessary to carry out its duties. DHSS has a general duty and responsibility to safeguard the health of the people in the state. (Mo. Rev. Stat. § 192.020) DHSS may regulate basic health care services provided in the state, including emergency care, inpatient hospital and physician care, and outpatient medical services. (Mo. Rev. Stat. § 34.400(1))

DHSS had regulations governing patient rights in hospitals until 2019 when they were [rescinded](#). The Missouri State Hospital Association has explained that these regulations were repealed because they duplicated federal regulations. As a result, DHSS now uses federal regulations in its oversight of hospitals licensed in the state. ([19 CSR 30-20.013](#))

Hospitals are inspected to determine whether regulations are being met. Inspections can be based on complaints received by the Bureau of Health Facility Regulation.

The Missouri Division of Developmental Disabilities operates within the Department of Mental Health. It provides services for individuals with developmental disabilities such as intellectual disabilities, cerebral palsy, Down syndrome, autism, and epilepsy. Among its functions, the Division implements a statewide system of supportive services that focuses on assuring the health of this population.

As public entities, DHSS and DMH are required by Title II of the ADA to take steps to ensure that patients with developmental disabilities are not subject to discrimination by the health care service providers these departments regulate or contract with. This would include monitoring them to eliminate discrimination in the medical decision-making process.

Public hospitals and other public health care providers have independent obligations to comply with Title II of the ADA. These obligations would include providing accommodations to adult patients with developmental disabilities, ensuring effective communications with such patients, and if necessary making modifications to policies and procedures to ensure that these patients have meaningful participation in the medical decision-making process, either personally or with assistance from representative of their choice, or through decision-making made by a surrogate or proxy of their choice.

United States Codes
Title 42, [Subchapter II](#)

Sec. 12131. Definitions. As used in this subchapter: (1) Public entity. The term “public entity” means (A) any State or local government; (B) any department, agency, special purpose district, or other instrumentality of a State or States or local government . . .

Sec. 12132. Discrimination. Subject to the provisions of this subchapter, no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.

Code of Federal Regulations
28 CFR [Part 35](#)

§ 35.130 General prohibitions against discrimination. (a) No qualified individual with a disability shall, on the basis of disability, **be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any public entity.** (b)

(1) A public entity, in providing any aid, benefit, or service, may not, directly or through contractual, licensing, or other arrangements, on the basis of disability— (i) Deny a qualified individual with a disability the opportunity to participate in or benefit from the aid, benefit, or service; (ii) Afford a qualified individual with a disability an opportunity to participate in or benefit from the aid, benefit, or service **that is not equal to that afforded others;** (iii) Provide a qualified individual with a disability with an aid, benefit, or service **that is not as effective in affording equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement as that provided to others;** . . .

(3) A public entity may not, directly or through contractual or other arrangements, **utilize criteria or methods of administration—** (i) That have the effect of subjecting qualified individuals with disabilities to discrimination on the basis of disability.

(7) (i) A public entity shall **make reasonable modifications in policies, practices, or**

procedures when the modifications are **necessary to avoid discrimination** on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity.

(8) A public entity shall **not impose or apply eligibility criteria** that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities from **fully and equally enjoying any service, program, or activity**, unless such criteria can be shown to be necessary for the provision of the service, program, or activity being offered.

ADA Title II

Technical Assistance Manual

II-1.1000 General. Title II of the ADA covers programs, activities, and services of public entities. It is divided into two subtitles. This manual focuses on subtitle A of title II, which is implemented by the Department of Justice's title II regulation. Subtitle A is intended to protect qualified individuals with disabilities from discrimination on the basis of disability in the services, programs, or activities of all State and local governments. It additionally extends the prohibition of discrimination on the basis of disability established by section 504 of the Rehabilitation Act of 1973, as amended, to all activities of State and local governments, including those that do not receive Federal financial assistance. By law, the Department of Justice's title II regulation adopts the general prohibitions of discrimination established under section 504, and incorporates specific prohibitions of discrimination from the ADA.

I-1.2000 Public entity. . . . Title II is intended to apply to **all programs, activities, and services provided or operated by State and local governments**.

II-1.4200 Other Federal and State laws. Title II does not disturb other Federal laws or any State laws that provide protection for individuals with disabilities at a level greater or equal to that provided by the ADA. It does, however, **prevail over any conflicting State laws**.

II-2.1000 General. . . . Title II protects three categories of individuals with disabilities: 1) Individuals who have a physical **or mental impairment that substantially limits one or more major life activities**; 2) Individuals who have a record of a physical or mental impairment that substantially limited one or more of the individual's major life activities; and 3) Individuals who are regarded as having such an impairment, whether they have the impairment or not.

II-2.2000 Physical or mental impairments. The first category of persons covered by the definition of an individual with a disability is restricted to those with "physical or mental impairments." . . . Mental impairments include mental or psychological disorders, such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning

disabilities.

II-2.4000 Substantial limitation of a major life activity. To constitute a "disability," a condition must substantially limit a major life activity. Major life activities include such activities as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working. . . . An impairment substantially interferes with the accomplishment of a major life activity when the individual's important life activities are restricted as to the conditions, manner, or duration under which they can be performed in comparison to most people.

II-3.0000 GENERAL REQUIREMENTS

II-3.3000 Equality in participation/benefits. The ADA provides for **equality of opportunity**, but does not guarantee equality of results. The foundation of many of the specific requirements in the Department's regulations is the principle that individuals with disabilities must be provided an **equally effective opportunity to participate in** or benefit from a public entity's aids, benefits, and services.

I-3.5000 Eligibility criteria

II-3.5100 General. A public entity may not impose eligibility criteria for participation in its programs, services, or activities that either screen out or tend to screen out persons with disabilities, **unless it can show that such requirements are necessary** for the provision of the service, program, or activity.

II-3.6000 Reasonable modifications

II-3.6100 General. A public entity must **reasonably modify its policies, practices, or procedures to avoid discrimination**. If the public entity can demonstrate, however, that the modifications would fundamentally alter the nature of its service, program, or activity, it is not required to make the modification. . . . Modifications . . . might include simplifying [an] application process or providing applicants who have mental disabilities with individualized assistance to complete the process.

II-7.0000 COMMUNICATIONS

Regulatory references: 28 CFR 35.160-35.164.

II-7.1000 Equally effective communication. A public entity **must ensure that its communications with individuals with disabilities are as effective as communications with others**. This obligation, however, does not require a public entity to take any action that it can demonstrate would result in a fundamental alteration in the nature of its services,

programs, or activities, or in undue financial and administrative burdens. In order to provide equal access, a public accommodation is required to make available appropriate auxiliary aids and services where necessary to ensure effective communication.

II-8.0000 ADMINISTRATIVE REQUIREMENTS

Regulatory references: 28 CFR 35.105-35.107; 35.150(c) and (d).

II-8.1000 General. Title II requires that public entities take several steps designed to achieve compliance. These include the preparation of a self-evaluation. In addition, public entities with 50 or more employees are required to – 1) Develop a grievance procedure; 2) Designate an individual to oversee title II compliance; . . .

II-8.4000 Notice to the public. A public entity **must provide information on title II's requirements to applicants, participants, beneficiaries, and other interested persons.** The notice shall explain title II's applicability to the public entity's services, programs, or activities. A public entity shall provide such information as the head of the public entity determines to be necessary to apprise individuals of title II's prohibitions against discrimination.

II-8.5000 Designation of responsible employee and development of grievance procedures. A public entity that employs 50 or more persons shall **designate at least one employee to coordinate its efforts to comply** with and fulfill its responsibilities under title II, including the investigation of complaints. A public entity shall make available the name, office address, and telephone number of any designated employee. In addition, the public entity **must adopt and publish grievance procedures** providing for prompt and equitable resolution of complaints alleging any action that would be prohibited by title II.

II-9.0000 INVESTIGATION OF COMPLAINTS AND ENFORCEMENT

II-9.1000 General. Individuals wishing to **file title II complaints** may either file – 1) An administrative complaint with an **appropriate Federal agency**; or 2) A lawsuit in Federal district court. . . . Individuals who believe that they have been discriminated against in employment by a State or local government in violation of title II may file a complaint – 1) With a Federal agency that provides financial assistance, if any, to the State or local program in which the alleged discrimination took place; . . . 3) With the **Federal agency designated in the title II regulation to investigate complaints in the type of program in which the alleged discrimination took place.** . . . Department of Health and Human Services: All programs, services, and regulatory activities **relating to the provision of health care** and social services, including schools of medicine, dentistry, nursing, and other health-related schools, the operation of health care and social service providers and institutions, including "grass-roots" and community services organizations and programs, and

preschool and day care programs. Complaints should be sent to: **Office for Civil Rights, Department of Health & Human Services**, 330 Independence Avenue, S.W., Washington, D.C. 20201. . . . Exhaustion of a public entity's grievance procedure is not a prerequisite to filing a complaint with either a Federal agency or a court. . . . A State is not immune from an action in Federal court for violations of the ADA.

Duty to Provide Accommodation or Modify Policies without a Request

A public entity must offer accommodations for *known* physical or mental limitations. (Title II Technical Assistance Manual of DOJ)

Even without a request, an entity has an obligation to provide an accommodation when it knows or reasonably should know that a person has a disability and needs a modification. (DOJ Guidance Memo to Criminal Justice Agencies, January 2017)

Some people with disabilities are not able to make an ADA accommodation request. A public entity's duty to look into and provide accommodations may be triggered when the need for accommodation is obvious. (*Updike v. Multnomah County* (9th Cir 2017) 870 F.3d 939)

It is the knowledge of a disability and the need for accommodation that gives rise to a legal duty, not a request. (*Pierce v. District of Columbia* (D.D.C. 2015) 128 F.Supp.3d 250)

A request for accommodation is not necessary if a public entity has knowledge that a person has a disability that may require an accommodation in order to participate fully in the services. Sometimes the disability and need are obvious. (*Robertson v. Las Animas* (10th Cir. 2007) 500 F.3d 1185)

The failure to expressly request an accommodation is not fatal to an ADA claim where an entity otherwise had knowledge of an individual's disability and needs but took no action. (*A.G. v. Paradise Valley* (9th Cir. 2016) 815 F.3d 1195)

The import of the ADA is that a covered entity should provide an accommodation for *known* disabilities. A request is one way, but not the only way, an entity gains such knowledge. To require a request from those who are unable to make a request would eliminate an entire class of disabled persons from the protection of the ADA. (*Brady v. Walmart* (2nd Cir. 2008) 531 F.3d 127)

Adults with Developmental Disabilities

Patient Rights and Provider Duties for Access to Medical Decision-Making

Private Health Care Providers: ADA Title III

Comment:

Privately-operated health care organizations that deliver medical services to the public are covered by Title III of the Americans with Disabilities Act. Covered health care facilities include, but are not limited to: hospitals, as well as the offices of doctors, dentists, pharmacies, and other forms of health services.

Title III requires that health care providers give patients with disabilities full and equal access to these services. This may require making reasonable modifications to policies, practices, and procedures, and by making communications, in all forms, easily understood.

Under Title III, private health care providers must take reasonable steps to ensure that adult patients with developmental disabilities who are not under an order of guardianship have meaningful participation in the medical decision-making process: either personally, with help from a chosen representative, or through a proxy or surrogate they have designated.

United States Codes Title 42, [Subchapter III](#)

SUBCHAPTER III - PUBLIC ACCOMMODATIONS AND SERVICES OPERATED BY PRIVATE ENTITIES

Sec. 12181. Definitions. As used in this subchapter: (7) Public accommodation. The following private entities are considered public accommodations for purposes of this subchapter, if the operations of such entities affect commerce: (F) . . . professional office of a health care provider, hospital, or other service establishment;

Sec. 12182. Prohibition of discrimination by public accommodations.

(a) General rule. No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who owns, leases (or leases to), or operates a place of public accommodation.

(b) Construction. (1) General prohibition. (A) Activities. (i) Denial of participation. It shall be discriminatory to subject an individual or class of individuals on the basis of a disability or disabilities of such individual or class, directly, or through contractual, licensing, or other arrangements, to a denial of the opportunity of the individual or class to participate in or benefit from the goods, services, facilities, privileges, advantages, or accommodations of an entity. (ii) Participation in unequal benefit. It shall be discriminatory to afford an individual or class of individuals, on the basis of a disability or disabilities of such individual or class, directly, or through contractual, licensing, or other arrangements with the opportunity to participate in or benefit from a good, service, facility, privilege, advantage, or accommodation that is not equal to that afforded to other individuals.

(2) Specific prohibitions. (A) Discrimination. For purposes of subsection (a) of this section, discrimination includes (i) the imposition or application of **eligibility criteria** that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities from fully and equally enjoying any goods, services, facilities, privileges, advantages, or accommodations, unless such criteria can be shown to be necessary for the provision of the goods, services, facilities, privileges, advantages, or accommodations being offered; (ii) **a failure to make reasonable modifications in policies, practices, or procedures**, when such modifications are necessary to afford such goods, services, facilities, privileges, advantages, or accommodations to individuals with disabilities, unless the entity can demonstrate that making such modifications would fundamentally alter the nature of such goods, services, facilities, privileges, advantages, or accommodations; (iii) **a failure to take such steps as may be necessary** to ensure that no individual with a disability is excluded, denied services, segregated or otherwise treated differently than other individuals because of the absence of auxiliary aids and services, unless the entity can demonstrate that taking such steps would fundamentally alter the nature of the good, service, facility, privilege, advantage, or accommodation being offered or would result in an undue burden;

Code of Federal Regulations 28 CFR [Part 36](#)

§ 36.201 General.

(a) Prohibition of discrimination. No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any private entity who owns, leases (or leases to), or operates a place of public accommodation.

§ 36.202 Activities.

(a) Denial of participation. A public accommodation shall not subject an individual or class

of individuals on the basis of a disability or disabilities of such individual or class, directly, or through contractual, licensing, or other arrangements, to a denial of the opportunity of the individual or class to participate in or benefit from the goods, services, facilities, privileges, advantages, or accommodations of a place of public accommodation.

(b) Participation in unequal benefit. A public accommodation shall not afford an individual or class of individuals, on the basis of a disability or disabilities of such individual or class, directly, or through contractual, licensing, or other arrangements, with the opportunity to participate in or benefit from a good, service, facility, privilege, advantage, or accommodation that is not equal to that afforded to other individuals.

§ 36.204 Administrative methods. A public accommodation shall not, directly or through contractual or other arrangements, utilize standards or criteria or methods of administration that have the effect of discriminating on the basis of disability, or that perpetuate the discrimination of others who are subject to common administrative control.

§ 36.301 Eligibility criteria. (a) General. A public accommodation shall not impose or apply eligibility criteria that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities from fully and equally enjoying any goods, services, facilities, privileges, advantages, or accommodations, unless such criteria can be shown to be necessary for the provision of the goods, services, facilities, privileges, advantages, or accommodations being offered.

§ 36.302 Modifications in policies, practices, or procedures. (a) General. A public accommodation shall make reasonable modifications in policies, practices, or procedures, when the modifications are necessary to afford goods, services, facilities, privileges, advantages, or accommodations to individuals with disabilities, unless the public accommodation can demonstrate that making the modifications would fundamentally alter the nature of the goods, services, facilities, privileges, advantages, or accommodations.

§ 36.303 Auxiliary aids and services. (a) General. A public accommodation shall take those steps that may be necessary to ensure that no individual with a disability is excluded, denied services, segregated or otherwise treated differently than other individuals because of the absence of auxiliary aids and services, unless the public accommodation can demonstrate that taking those steps would fundamentally alter the nature of the goods, services, facilities, privileges, advantages, or accommodations being offered or would result in an undue burden, i.e., significant difficulty or expense. (c) Effective communication. (1) A public accommodation shall furnish appropriate auxiliary aids and services where necessary to ensure effective communication with individuals with disabilities.

ADA Title III

Technical Assistance Manual

This technical assistance manual discusses the requirements of title III of the Americans with Disabilities Act which applies to public accommodations, including privately-operated health care providers. Most of the information is the same as that included in the technical assistance manual for compliance with Title II and therefore will not be repeated here.

References:

“Access to care for patients with disabilities: Strategies for ensuring a safe, accessible and ADA compliant practice,” American Medical Association (2018) - [Link](#)

“32 years later, most doctors still clueless about the Americans with Disabilities Act,” Study Finds (2022) - [Link](#)

Adults with Developmental Disabilities

Patient Rights and Provider Duties for Access to Medical Decision-Making

Patient Protection and Affordable Care Act

Comment:

This Act incorporates the nondiscrimination provisions of Section 504 of the Rehabilitation Act of 1973. It also promotes the concept of shared decision-making in health care services.

United States Codes Title 42, [Chapter 157](#)

Section 18116. Nondiscrimination. (a) In General. [A]n individual shall not, on the ground prohibited under . . . section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794), 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, . . . The enforcement mechanisms provided for and available under . . . section 504 shall apply for purposes of violations of this subsection. (b) Continued Application of Laws. Nothing in this title (or an amendment made by this title) shall be construed to invalidate or limit the rights, remedies, procedures, or legal standards available to individuals aggrieved under . . . section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794).

Section 299b–36. Program to Facilitate Shared Decisionmaking. (a) PURPOSE.—The purpose of this section is to facilitate collaborative processes between patients, caregivers or authorized representatives, and clinicians that engages the patient, caregiver or authorized representative in decisionmaking, provides patients, caregivers or authorized representatives with information about trade-offs among treatment options, and facilitates the incorporation of patient preferences and values into the medical plan. (d)(1) The Secretary . . . shall establish a program to award grants or contracts— “(A) to develop, update, and produce patient decision aids for preference sensitive care to assist health care providers in educating patients, caregivers, and authorized representatives concerning the relative safety, relative effectiveness (including possible health outcomes and impact on functional status), and relative cost of treatment or, where appropriate, palliative care options; “(B) to test such materials to ensure such materials are balanced and evidence based in aiding health care providers and patients, caregivers, and authorized representatives to make informed decisions about patient care and can be easily incorporated into a broad array of practice settings; and “(C) to educate providers on the use of such materials, including through academic curricula.

Adults with Developmental Disabilities

Patient Rights and Provider Duties for Access to Medical Decision-Making

HIPAA - Patient Representative 45 CFR 164.502(g)

Comment:

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) gives adult patients the right to designate a representative to have access to their health care information and records. See: “Guidance: Personal Representatives,” Health Information Privacy (HHS - [Link](#)). The following are excerpts from this guidance memorandum.

Excerpts:

The HIPAA Privacy Rule establishes a foundation of Federally-protected rights which permit individuals to control certain uses and disclosures of their protected health information. Along with these rights, the Privacy Rule provides individuals with the ability to access and amend this information, and the right to an accounting of certain disclosures. The Department recognizes that there may be times when individuals are legally or otherwise incapable of exercising their rights, **or simply choose to designate another to act on their behalf with respect to these rights.**

Under the Rule, a person authorized (under State or other applicable law, e.g., tribal or military law) to act on behalf of the individual in making health care related decisions is the individual’s “**personal representative.**”

Section 164.502(g) provides when, and to what extent, the personal representative must be treated as the individual for purposes of the Rule. In addition to these formal designations of a personal representative, the Rule at 45 CFR 164.510(b) addresses situations in which family members or other persons who are involved in the individual’s health care or payment for care may receive protected health information about the individual even if they are not expressly authorized to act on the individual’s behalf.

General Provisions. Subject to certain exceptions, the Privacy Rule at 45 CFR 164.502(g) **requires covered entities to treat an individual’s personal representative as the individual** with respect to uses and disclosures of the individual’s protected health information, as well as the individual’s rights under the Rule.

The personal representative stands in the shoes of the individual and has the ability to act for the individual and exercise the individual's rights.

Where the authority to act for the individual is limited or specific to particular health care decisions, the personal representative is to be treated as the individual only with respect to protected health information that is relevant to the representation.

Who Must Be Recognized as the Individual's Personal Representative. The following chart displays who must be recognized as the personal representative for a category of individuals:

An adult

The Personal Representative Is:

A person with legal authority to make health\ care decisions on behalf of the individual

Examples: Health care power of attorney
Court appointed legal guardian
General power of attorney or durable power of attorney that includes the power to make health care decisions

* * * * *

**Missouri Statute
Release of Medical Records
Mo. Rev. Stat. 191.227.**

1. All physicians, chiropractors, hospitals, dentists, and other duly licensed practitioners in this state, herein called "providers", shall, upon written request of a patient, or guardian or legally authorized representative of a patient, furnish a copy of his or her record of that patient's health history and treatment rendered to the person submitting a written request .
2. Health care providers may condition the furnishing of the patient's health care records to **the patient, the patient's authorized representative or any other person or entity authorized by law** to obtain or reproduce such records

**Form
Authorization for Disclosure of Consumer Medical/Health Information**

Adults with Developmental Disabilities

Patient Rights and Provider Duties for Access to Medical Decision-Making

HHS Report on Advance Directives

Comment:

A report published by the Department of Health and Human Services provides helpful information for patients with developmental disabilities, their families, and health care providers regarding the use of advance directives by this patient population. See: Advance Directives and Advance Care Planning for People with Intellectual and Physical Disabilities (HHS - 2007) - [Link](#). The following excerpts are taken from that report. (Footnotes omitted)

Excerpts:

This paper describes the current status of advance directives and advance care planning in the disability community and identifies where gaps exist in policy, practice, and research. The aim is to better assure that the needs and issues of people with disabilities are considered and integrated into new policies designed to promote effective advance care planning. This report reviews professional literature, consumer materials, and Internet sites pertaining to advance care planning, surrogate decisionmaking, and end-of-life care for people with physical and intellectual disabilities. (p. 1)

As a starting point, the framework for advance care planning applies equally to all. All individuals have legal rights and personal interests in preparing advance directives and engaging in planning conversations with family members, significant others, and health care professionals. Although these rights may be constrained by diminished decisionmaking capacity, **even those with limited capacity should be encouraged to participate in advance care planning to the extent their abilities allow.** (p. 5)

There is an extensive history of discrimination and stigma against people with disabilities that has often impeded their full participation in society. . . Unfortunately, such discrimination has also included mistreatment by the health care system and lack of access to care. Such bias may come in the form of paternalistic attitudes, institutional abuse, environmental barriers, and questionable care. (p. 5)

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 legal process. However,

adults with intellectual disability “have historically been excluded from various spheres of decisionmaking about their lives, on the presumption that they are incapable of making informed decisions.” Health care providers, administrators, and families commonly assumed a protective stance toward people with intellectual disabilities, even when decision-specific capacity may have existed. Recent trends have encouraged providers, researchers, and advocates to question this paternalistic approach for three reasons. (p. 10)

First, medical advances are increasing the longevity of people with intellectual disabilities. For example, life expectancy for people with Down’s Syndrome has doubled during the 1980s and 1990s. As individuals with intellectual disabilities age, they and their caregivers face issues of aging and chronic illness as never before. Second, this time period has witnessed significant cultural changes regarding medical decisionmaking, end-of-life care, and advance care planning, as bioethical principles evolved from a paternalistic to an autonomy-based approach. Third, although the needs of people with intellectual disabilities were largely absent from early discussions to promote advance care planning and palliative approaches to care, providers and advocates have sought to bolster the autonomy of community members and brought their concerns to the table. (pp. 10-11)

People with intellectual disabilities should not be presumed to lack capacity for making health care decisions. A panel convened by the Midwest Bioethics Center (now known as the Center for Practical Bioethics) in 1996 issued guidelines to facilitate individual decisionmaking and more accurate professional assessments of decisional capacity. The guidelines provide recommendations to assess “whether patients meet a minimum level of understanding.” Limitations in intellect and communication abilities are bolstered by supporting areas of individual strength and by offering assistance. (pp. 11-12)

Clinical practice and legal standards have moved away from global determinations of capacity to more **finely-tuned task-specific determinations of capacity**. The capacity to make health care decisions has been defined as the ability to understand the information about a proposed care plan, appreciate the consequences of a decision, and reach and communicate an informed decision. Unlike competency, which is an “all or nothing” judicial determination, **capacity is specific to the decision at hand**. This more flexible methodology to assessing abilities creates a multi-tiered approach to decisionmaking. For example, individuals who lack abilities to express preferences or goals of care in a living will **may be able to appoint a health care proxy**. Similarly, those unable to make decisions about life-sustaining interventions may have the **capacity to make less complex decisions**, such as on low-risk medications, diet, or recreation. Beltran summarizes the challenge in accurately assessing decisionmaking capacity: “There is a need to balance protection from harm with the patient’s right to self-determination. This balancing requires skilled listening, the proper level of advocacy from caregivers, and pragmatic models of shared decisionmaking.” (P. 12)

A 2003 study assessed health care capacity among adults with mild, moderate, and no mental retardation to make “low-risk” medical treatment decisions. The study used standardized treatment vignettes to measure the capacity of adults to reason about treatment-related information. Cea and Fisher found that “most adults with mild [86%] and no [95%] mental retardation and almost half of adults with moderate mental retardation [45%] were able to make and justify treatment choices and fully or partially understand treatment information.” These findings are used to support claims that **many adults with [mild intellectual disabilities], and some adults with [moderate intellectual disabilities], “do indeed have the ability to provide adequate consent to standard low-risk health-related treatments.”** Moreover, capacity to consent “could be enhanced with supportive decisionmaking or educational techniques in preparation for treatments or procedures requiring their consent.”(p. 12)

Is it possible to augment the decisionmaking capacity of individuals with cognitive limitations? Friedman supports the concept of “assisted capacity,” through which “individuals who may be unable to make advance directives decisions completely independently, but **who could participate in decisionmaking with the proper degree of assistance and support from others.**” (p. 14)

Frequently, **health care professionals** (physicians, nurses, social workers, clergy, and others), including hospice and palliative care staff, **lack training on the special needs of people with intellectual disabilities and on methods to assess their decisional capacity.** Furthermore, **staff of public agencies and private organizations** serving people with disabilities **should be trained** in the special needs of people with intellectual disabilities for advance care planning, options for hospice and palliative care to manage life-threatening illnesses, and special concerns in providing and consenting to care. (p. 16)

Adults with Developmental Disabilities

Patient Rights and Provider Duties for Access to Medical Decision-Making

Missouri Human Rights Act

Comment:

The Missouri Human Rights Act (MHRA) prohibits discrimination on the basis of disability. MHRA incorporates the provisions of the Americans with Disabilities Act. Complaints of violations of the MHRA are investigated by the Missouri Commission on Human Rights.

It is against the law for a place of public accommodation to discriminate against a person because of that person's disability. Public accommodations include businesses offering health services. (Mo. Stat. § 213.010(19)) Also included is any public facility owned, operated, or managed by or on behalf of this state or any agency or subdivision thereof, or any public corporation; and any such facility supported in whole or in part by public funds.

Qualified individuals with a disability may not be excluded from participation in, or be denied the benefits of services or activities of, a public entity, including state or local governments and their departments, nor may they be subjected to discrimination by any such entity. (Mo. Stat. § 23.070)

Missouri Statutes

Mo. Stat. § 213.065

1. Discrimination in public accommodations prohibited, exceptions. — 1. All persons within the jurisdiction of the state of Missouri are free and equal and shall be entitled to the full and equal use and enjoyment within this state of any place of public accommodation, as hereinafter defined, without discrimination or segregation because of . . . disability.

2. It is an unlawful discriminatory practice for any person, directly or indirectly, to refuse, withhold from or deny any other person, or to attempt to refuse, withhold from or deny any other person, any of the accommodations, advantages, facilities, services, or privileges made available in any place of public accommodation, as defined in section 213.010 and this section, or to segregate or discriminate against any such person in the use thereof because of . . . disability.

Adults with Developmental Disabilities

Patient Rights and Provider Duties for Access to Medical Decision-Making

Missouri DHSS Disability Nondiscrimination Policies

Comment:

The Missouri Department of Health and Social Services (DHSS) has a policy manual on nondiscrimination in the delivery of services by the department and by entities regulated by the department, including hospitals, and entities that contract with the department.

The *Methods of Administration* describe policies and procedures that are necessary to assure that all program benefits administered by and through the Department are made available to all persons and provided to all eligible individuals without regard to their . . . disability, which is considered a “protected category” under applicable federal and state laws.

Complaints may be filed with the department if DHSS-regulated or DHSS-contracted health care providers do not take reasonable steps to make the medical decision-making process accessible to adult patients with developmental disabilities.

DHSS Administrative Manual [Policy](#)

1.1 It is the policy of the Department to provide equal treatment in . . . provision of services to applicants, . . . and clients without regard to a protected category.

1.3 It is the policy of the Department to assure that no person will be excluded from participation in, be denied the benefits of, or be otherwise subjected to discrimination for any services because of a protected category.

1.4 The Department's commitment to Sections 503 and 504 of the Rehabilitation Act of 1973, the Americans with Disabilities Act Amendments Act of 2008 (ADAAA), the Missouri Public Accommodations Act, and Executive Orders 94-03 and 10-24 is hereby reaffirmed.

2.1 The Department responsibility for implementation and administration of compliance activities for . . . Rehabilitation Act of 1973, Section 504; and ADAAA is assigned to the

Human Relations Officer who is assigned to the Office of Human Resources. The working title for this position is Civil Rights Compliance Coordinator.

2.2 Under authority from the Department Director, the Human Relations Officer is administratively responsible for the following: . . . * assessment of the compliance level of covered contractors . . . * handling complaints of discrimination relative to provision of services . . . * development of policies and procedures for implementation of . . . the Rehabilitation Act and the ADAAA relative to non-discrimination in delivery of services . . . * technical assistance to vendors, contractors, and licensees.

2.4 The Department will notify contractors, vendors, and suppliers of prohibitions against discrimination based on protected categories in the “Invitation for Proposal” (IFP) and by inclusion of said requirement in all contracts. The Department policy statement is to be provided to contractors with a signed copy of their contract

3.1 The Department requires all designated service contractors, service vendors; and subcontractors and suppliers to agree to the non-discrimination in provision of services and Equal Employment Opportunity clauses as stated in all Departmental contractual agreements. These clauses are an assurance by the vendor that it will comply with . . . Sections 503 and 504 of the Rehabilitation Act of 1973; . . . Title II and Title III of the ADAAA and Rule 19.CSR10-2.010 of the Missouri Code of State Regulations.

3.3 To ensure that service contractors and/or vendors are reaching all potentially eligible persons, the Department requires that contractors maintain a public notification system that explicitly states the program availability and the non-discrimination statement: “Services Provided on a Non-Discriminatory Basis.”

7.1 Any applicant for service(s) provided by the Department or any of its service vendors, contractors, or providers of services, financial aid or other benefits, having reason to believe that he/she has been discriminated against in the delivery of health care services because of a protected category may file a verbal or written grievance/complaint with the local agency dispensing the necessary service(s) and/or any of the following agencies: * U.S. Department of Health and Human Services, Office for Civil Rights, 601 East 12th Street, Kansas City, MO 64106; * Office of Human Resources, Missouri Department of Health and Senior Services, P.O. Box 570, Jefferson City, MO 65102-0570; or * Missouri Commission on Human Rights, P.O. Box 1129, Jefferson City, MO 65102.

8.1 The Department has established and will maintain a monitoring system that assures that no policy or practice of the Department and/or its contractors is, or has the effect of, discriminating against clients, employees, applicants or participants on the basis of a protected category. Therefore, periodic on-site and desk compliance reviews are made based on neutral criteria.

Adults with Developmental Disabilities

Patient Rights and Provider Duties for Access to Medical Decision-Making

Case Law on Capacity

Comment:

Whether someone has legal capacity to make a decision or to delegate decision-making authority depends on the complexity of the decision in question. Someone may have the capacity to consent to simple medical procedures (blood test, x-ray, teeth cleaning, etc.) but not for a complex surgery that may have life-threatening side effects.

The fact that a person may lack capacity to make independently some medical decisions, does not deprive them of capacity to delegate medical decision-making authority to an agent, or health care surrogate. This principle is aptly explained by the New York Office for Persons with Developmental Disabilities regarding capacity to execute a [health care proxy](#):

“An individual does not need to have the capability of making and understanding all medical care decisions for themselves in order to be able to make a health care proxy. An individual simply has to understand that they are giving another person (the health care agent) the authority to make medical care decisions on their behalf if and when they are not capable of making these decisions.”

In Missouri, similar to New York, the capacity to delegate medical decision-making to another is presumed to exist unless proven otherwise. Whereas independent decision-making may pose a significant risk for some patients with developmental disabilities, delegating such authority to a trusted person poses little to no risk.

If a patient with a developmental disability understands they are selecting someone to make medical decisions for them if a doctor thinks a procedure is too complicated for them to understand, and if they name this person voluntarily, then they have the requisite capacity to make such a delegation.

Missouri Cases:

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

The concept of capacity has to do with the ability to handle basic requirements for food, shelter, safety and health. 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. Section 475.010(8) RSMo 1986. Thus, an incapacity requires the existence of some physical or mental condition which **puts the person at risk**. . . .

[I]ncapacity 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** . . .

This requirement of the law [least restriction option], together with the requirement that disability be proven by clear and convincing evidence, shows a desire to defer in close cases to the dignity and personhood of the alleged incapacitated or disabled person rather than to take a strict paternalistic approach of utmost security. . .

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

It is well-settled law that the burden of proving lack of mental capacity to contract rests upon the party making that allegation. . . . [A] finding of incompetency operates prospectively only and is inadmissible to show prior mental disability. . . .

New York Cases:

In re Mildred, 844 N.Y.S.2d 539 (N.Y. App. Div. 2007)

Supreme Court properly determined that petitioner failed to meet her burden of showing that the AIP lacked capacity when she signed the 2004 power of attorney and the 2004 health care proxy. A person is incompetent to authorize a transaction only if "the person's mind was `so affected as to render him [or her] **wholly and absolutely incompetent to comprehend and understand the nature of the transaction**" (*Feiden v Feiden*, 151 AD2d 889, 890, quoting *Aldrich v Bailey*, 132 NY 85, 89). Although there was testimony at the hearing on the petition that the AIP suffered from moderate dementia, **there is no presumption that a person suffering from dementia is wholly incompetent**. "Rather, it must be demonstrated that, because of the affliction, the individual was incompetent at the time of the challenged transaction" (*Gala v Magarinos*, 245 AD2d 336, 336). Here, the record contains the testimony of a physician and nurse practitioner that the AIP would have been able to understand questions such as whom she would like to make her health care decisions if she were unable to do so and whether she would like her grandson to handle her financial affairs. Additionally, the attorneys who were present at the execution of the documents in question testified that, when they met with the AIP and discussed the documents, she was **capable of understanding the nature of the transactions** that she was authorizing.

Durkin v. Petrie, 155 N.Y.S.3d 893 (N.Y. App. Div. 2021)

It is well settled that " '[a] party's competence is presumed and **the party asserting incapacity bears the burden of proving incompetence**' " (*Crawn v. Sayah* , 31 A.D.3d 367, 368, 819 N.Y.S.2d 61 [2d Dept. 2006] ; see *Matter of Mildred M.J.* , 43 A.D.3d 1391, 1392, 844 N.Y.S.2d 539 [4th Dept. 2007]). "**A person is incompetent to authorize a transaction only if the person's mind was so affected as to render him [or her] wholly and absolutely incompetent to comprehend and understand the nature of the transaction**" (*Mildred M.J.* , 43 A.D.3d at 1392, 844 N.Y.S.2d 539

Adults with Developmental Disabilities

Patient Rights and Provider Duties for Access to Medical Decision-Making

Simple Consent vs. Informed Consent

Comment:

The American Society for Health Care Risk Management (ASHRM) is a professional membership group of the American Hospital Association (AHA). It has published guidance explaining the difference between simple consent versus informed consent for health care services. While adult patients with moderate to severe intellectual disabilities may lack the capacity to give informed consent for invasive and high risk procedures, they may have the ability to give consent for noninvasive and low risk medical services. **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.** See: “Clarifying Informed Consent,” Enterprise Risk Management (ASHRM 2019) - [Link](#). The following are excerpts from this article.

Excerpts:

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.

Common law indicates that every competent adult has the fundamental right of self-determination. The Patient Self Determination Act is a federal law and compliance is mandatory. Those who can’t consent for themselves would include a minor patient or an adult patient who has been deemed incompetent to make medical decisions. When these situations occur, each patient has the right to be represented by another person who has the capacity to make medical decisions. Best practices are that this should not be the treating provider.

Informed consent is a conversation when the risks, benefits and alternatives of medical care and treatment are discussed with a patient and/or his/her representative. All

procedures require consent, but not all are required to be “informed consent.” Informed consent is a process in which a medical provider gives patients and/or their representative enough information to decide whether or not to go forward with care, treatments or medical procedures.

Informed Consent Basics

1. Outline the risks, benefits, alternative treatment available
2. Involve the patient in decision making
3. **Communicate at a level the patient can understand**
4. Contain enough information for the patient to make an informed decision
5. Explain refusal of care and the risks associated
6. Include the Informed consent in the medical record
7. Obtain a language interpreter if patient requires one; family alone is not acceptable

Adults with Developmental Disabilities

Patient Rights and Provider Duties for Access to Medical Decision-Making

Health Care and Supported Decision-Making

Comment:

The Center for Public Representation (CPR) provides educational information for patients and families on how to develop and implement a supported decision-making arrangement in the context of health care services. See: “SDM and Health Care Decisions,” CPR - [Link](#)

Success in using SDM for health care decisions depends on three factors: (1) using tools like a health care proxy and release of information, (2) planning in advance when for both a planned meeting and for the unexpected, and (3) educating health care providers about SDM, people with disabilities can successfully use SDM to make complex health care decisions.

The State of Missouri recognizes supported decision-making agreements as a possible alternative to guardianship. (Mo. Stat. § 475.075 (13) (4))

Excerpts:

Tools: Health Care Proxy. A health care proxy is an essential tool for individuals with disabilities to prepare for a crisis in advance. A health care proxy is someone who a person chooses to make health care decisions for him or her if something happens to the person and he or she cannot make decisions for him or herself. . . . We recommend individuals using SDM select a health care proxy so that there is a plan in place in case of an emergency.

Tools: Release of Information. Having access to information about a health care decision is essential for a supporter to assist a person with making a decision. Health care information is protected by strict confidentiality laws. The Health Insurance Portability and Accountability Act (HIPAA) is a federal law that prevents your health care providers from sharing information about someone without consent. There are also state laws that protect confidentiality of health information. The individual with the disability using SDM must sign a release of information if he or she wants a supporter to access protected health information. . . . Many health care providers require a particular form be executed. It may also be possible to use a standard HIPAA compliant release. Copies of signed releases of information should be shared with appropriate providers. It may also be helpful to attach copies of releases to any SDM agreements.

Planning: Preparation before appointments. A successful medical appointment begins before the person with the disability steps foot in the medical office. It is essential to do as much advanced planning as possible before a medical appointment takes place.

Education: Preparation of health care providers before appointments. To ensure that the provider respects the decisions being made, health care providers should have information about supported decision-making in advance of an appointment. The individual with the disability should be the person educating the provider about supported decision-making, with assistance from supporters as needed. . . Consider providing a copy of the supported decision-making agreement, health care proxy, and any releases of information in advance of an appointment.

Supported Decision-Making vs. Shared Decision-Making. Health care professionals, particularly mental health professionals, have long been interested in the process of decision-making and the ability of people with disabilities to make treatment decisions. In recent years there has been an increased interest in using shared decision-making in the context of mental health treatment. . . . Shared decision-making is a distinct concept from supported decision-making, though the terms are frequently confused. . . .

Shared decision-making is a method to ensure understanding, promote informed choice, and engage the person in health care decisions. Supported decision-making, on the other hand, goes more deeply to the very concept of capacity or competence to make decisions. Shared decision making does not address the ability of the person to engage in decision-making. Supported decision-making does.

Because shared decision-making is often confused with supported decision-making, you should make sure that health care providers you are working with understand that you are using the supported decision-making model. This may require some education.

Resources:

Getting Started With Supported Decision-Making - [Link](#).

Sample Supported Decision-Making Agreements - [Link](#)

Sample SDM Agreement created by Missouri organizations – [Link](#)

Putting Supported Decision Making in Action for Medical Professionals - [Link](#)

Frequently Asked Questions for Medical Professionals - [Link](#)

SDM Resources: Missouri Council on Developmental Disabilities - [Link](#)