Health Care and Developmental Disabilities

*References for Patients, Families, and Providers**

Complied by Spectrum Institute for
Missouri Medical Rights Workgroup

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Also See: Sample Medical Authorization Forms

* The excerpts in this document paraphrase relevant content of the referenced sources.

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Self-Determination

Supreme Court of Missouri - excerpts
Medical Decision-Making

Autonomy. The common law recognizes the right of individual autonomy over decisions relating to one's health and welfare. *Cruzan, by Cruzan v. Harmon,* 760 S.W.2d 408 (Mo. 1988)

Missouri Department of Mental Health - excerpts
Regulations on Medical Decision-Making

Decision-Making. The department shall honor the right of all competent adult voluntary residents and patients **to make decisions** regarding their health care, including the right to accept or refuse medical or surgical treatment. All competent adult residents and patients shall have the right to **execute advance directives** without regard to their voluntary or involuntary status. An adult is considered "competent" if they have not been adjudicated by a court to be incapacitated.

Patient Rights

DHHS Centers for Medicare and Medicaid Services - excerpts
State Operations Manual on Patient's Rights

Condition of Participation. A hospital must protect and promote each patient's rights. These requirements . . . apply to all parts and locations (outpatient services, provider-based entities, inpatient services) of the Medicare participating hospital.

Notice of Rights. 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. [P]atient's rights information [must be] is provided in a language and **manner that the patient understands**.

Patient Representative. Hospitals are expected to take reasonable steps to determine the **patient's wishes** concerning designation of a representative. A representative has the **right to participate** in the development and implementation of a plan of care.

> **Patient not Incapacitated - Representative**. When a patient who is not incapacitated has designated, either orally to hospital staff or in writing, another individual to be his/her representative, the hospital must provide the designated individual with the required notice of patients' rights in addition to the patient. The explicit designation of a representative **takes precedence over any non-designated relationship and continues throughout the patient's inpatient stay or outpatient visit**, unless expressly withdrawn, either orally or in writing, by the patient.

Patient is Incapacitated - Power of Attorney. In the case of a patient who is incapacitated, when an individual presents the hospital with an **advance directive, medical power of attorney or similar document** executed by the patient and designating an individual to make medical decisions for the patient when incapacitated, then the hospital must, when presented with the document, provide the required notice of its policies to the designated representative. The explicit designation of a representative **takes precedence over any non-designated relationship and continues throughout the patient's inpatient stay or outpatient visit**, unless the patient ceases to be incapacitated and expressly withdraws the designation, either orally or in writing.

Patient is Incapacitated - No Power of Attorney. When a patient is incapacitated or otherwise unable to communicate his or her wishes, there is no written advance directive on file or presented, and an **individual asserts** that he or she is the patient's spouse, domestic partner, parent or other **family member** and thus is the patient's representative, the hospital is expected to accept this assertion, **without demanding supporting documentation**, and provide the required notice to the individual, **unless**: (1) More than one individual claims to be the patient's representative. In such cases, it would be appropriate for the hospital to ask each individual for documentation supporting his/her claim to be the patient's representative. (2) Treating the individual as the patient's representative without requesting supporting documentation would result in the hospital **violating State law**. (3) The hospital has **reasonable cause to believe** that the individual is **falsely claiming** to be the patient's spouse, domestic partner, parent or other family member.

Grievance Procedure. The hospital must establish a process for prompt resolution of patient grievances and must inform each patient whom to contact to file a grievance. The hospital must inform the patient and/or the patient's representative of the **internal grievance process**. The hospital must inform the patient that he/she may lodge a grievance with the **State agency**.

Specific Rights: Plan of Care. The patient has the right to participate in the development and implementation of his or her plan of care. Hospitals are expected to take reasonable steps to determine the patient's wishes concerning **designation of a representative** to exercise the patient's right to participate in the development and implementation of the patient's plan of care.

Specific Rights: Informed Decisions. 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. Information must be provided **in a manner that the patient or the patient's representative can understand**,

Specific Rights: Advanced Directives. 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 the advance directive, the patient may **provide guidance** as to his/her wishes concerning provision of care in certain situations; alternatively the patient may **delegate decision-making authority** to another individual, as permitted by State law. When a patient who is incapacitated has executed an advance directive designating a particular individual to make medical decisions for him/her when incapacitated, the **hospital must**, when presented with the document, **provide the designated individual the information required** to make informed decisions about the patient's care.

Specific Rights: Forced Medication. The application of force to physically hold a patient, in order to administer a medication against the patient's wishes, is considered restraint. The patient has a right to be free of restraint and, in accordance with §482.13(b)(2), also has a **right to refuse medications**, unless a court has ordered medication treatment.

Specific Rights: Visitation. Hospitals are required to develop and implement written policies and procedures that address the patient's right to have visitors. If the hospital's policy establishes restrictions or limitations on visitation, such **restrictions/limitations must be clinically necessary or reasonable**. Furthermore, the hospital's policy must include the **reasons** for any restrictions/limitations. When a hospital adopts policies that limit or restrict patients' visitation rights, the **burden of proof is upon the hospital** to demonstrate that the visitation restriction is reasonably necessary to provide safe care.

Capacity Assessment

Supreme Court of Missouri - excerpts
Cruzon v. Harmon

Legal Standard for Informed Consent. The doctrine of informed consent arose in recognition of the value society places on a person's autonomy and as the primary vehicle by which a person can protect the integrity of his body. There are three basic **prerequisites for informed consent**: (1) the patient must have the **capacity to reason** and make judgments, (2) the decision must be made **voluntarily** and without coercion, (3) and the patient must have a clear **understanding of the risks and benefits** of the proposed treatment alternatives or nontreatment, along with a full understanding of the **nature of the disease and the prognosis**.

Informed Refusal. If one can consent to treatment, one can also refuse it. Thus, as a necessary corollary to informed consent, the right to refuse treatment arose. "The patient's ability to control his bodily integrity ... is significant only when one recognizes that this right also encompasses a right to informed refusal."

Missouri Statutes and Cases – link
Capacity to Give Medical Consent

Medical Consent. Any adult eighteen years of age or older is authorized by law to consent to a medical procedure if the person is **competent to contract**. RSMo Section 431.061(1)).

Capacity to Contract. In determining whether someone has capacity to contract, the question is whether on the day the decision is made, did they have sufficient mental capacity to understand the **nature and effect of the particular transaction**. *McElroy v. Mathews*, 263 S.W.2d 1, 10 (Mo. 1953).

Presumption. The law presumes every person to be of sound mind until the contrary is shown. *State ex Rel. United Mut. Ins. Assn. v. Shain* (Mo. 1942) 349 Mo. 460, 474. Mental or developmental disabilities do not necessarily deprive an adult of having the capacity to make medical decisions. *Ruckert v. Moore*, 317 Mo. 228, 242 (Mo. 1927)

Burden of Proof. When capacity is challenged in court, the burden of proving lack of mental capacity to contract is on the party making that allegation. *Christian Health Care v. Little, 145 S.W.3d 44* (Mo. Ct. App. 2004). Incapacity must be proven by clear and convincing evidence. Matter of Nelson, 891 S.W.2d 181 (Mo. Ct. App. 1995). Evidence is clear and convincing when it establishes a high probability that a fact (e.g. incapacity) is true. *Rinehart v. Shelter* (Mo. Ct. App. 2008) 261 S.W.3d 583, 597.

Situation Specific. The issue of capacity is situation specific. The question is whether on the day the decision is made, did the person have sufficient mental capacity to understand the nature and effect of the particular transaction. *McElroy v. Mathews*, 263 S.W.2d 1, 10 (Mo. 1953)

Risk. Incapacity requires the existence of some physical or mental condition which puts the person at risk. *Matter of Nelson*, 891 S.W.2d 181 (Mo. Ct. App. 1995).

American Society for Health Care Risk Management – link
Clarifying Informed Consent

Simple Consent. 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. Informed consent applies to more invasive procedures that carry more risk, such as surgery, complicated medical plans or research treatments. 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. **A provider must communicate at a level the patient can understand**.

Home & Community Services Protective Service Manual - excerpts
"Decisional Capacity"

Capacity Assessment. If doubt exists regarding the capacity of the eligible adult to consent or refuse services, the [APS] Worker shall determine decisional capacity.

Criteria for Capacity: Although no clear standards exist, a general understanding of decisional capacity can be gained based on the following criteria:

* The ability of the person to comprehend (that is, to grasp mentally or understand) information relevant to the decision, such as the basis for need, the results of various choices, etc.
* The ability to deliberate (that is, give careful, slow, unhurried consideration) in reaching a decision which is consistent with personal values.
* The ability to communicate the decision with another person.

One of the major pitfalls in assessing capacity is that unconventional behavior, atypical character traits, or risk-taking decisions may be confused with incapacity. A person does not lack capacity simply because he/she does things that other people find disagreeable or difficult to understand.

Preliminary Evaluation. The Worker shall first attempt to gain knowledge of the person's historical values, goals, and personality to help establish a benchmark against which current capacity can be assessed. To assess capacity, the Worker shall interview the eligible adult on more than one occasion and at different times of the day. The Worker shall interview the eligible adult, using open-ended questions, to determine whether he/she is able to:

* understand the situation:
* comprehend the possible consequences of the situation:
* realize their own limitations:
* show an awareness of other appropriate or available alternatives

Rule Out Causes. When assessing capacity, many factors shall be taken into consideration that might lead to an incorrect interpretation.

* Impaired vision or hearing often produces non-responsive behaviors that may be confused as a lack of mental capacity.
* Illiteracy can account for misinterpreting a person's actions or responses as incapacity.
* The speed in which a person is able to process information should not be equated to the level of cognitive functioning.
* Was the person given appropriate choices from which to make a sound decision

Standardized Tests. St Louis University Mental Status (SLUMS) exam and Geriatric Depression Scale (GDS) may indicate the possibility of cognitive impairment . . . but they are not diagnostic or capable of dictating a firm conclusion. These tests do not capture the reasons for the impairment that may be acute and reversible (i.e., UTI, medication changes).

However, when used as a preliminary assessment, they can indicate a need for further professional evaluation.

Identify Supports. If it is believed that an eligible adult lacks decisional capacity to consent to protective services, the Worker shall attempt to identify assistance available through independent supports.

Involve a Surrogate. A surrogate should be identified who has personal knowledge of the goals and values of the eligible adult that would be willing to assist in planning service intervention in the best interest of the eligible adult. When appropriate, the Worker shall honor any **advance directive** regarding surrogate decision making.

Legal Intervention. As a last resort, the Worker shall seek legal intervention when it can be determined that an eligible adult:

* lacks decisional capacity; and
* has no one able or willing to act in his/her behalf; and
* refuses to accept protective service intervention; and
* faces a likelihood of serious physical injury or harm due to the lack of ability to meet essential human needs unless someone intervenes.

American Bar Association & American Psychological Association – excerpts
Capacity Assessment Handbook for Psychologists

Capacity to Appoint a Health Care Agent. The capacity to execute an advance directive for health care is quite different than the capacity to make specific medical decisions, thought to be parallel to the capacity to contract. That is, it does not involve understanding and consenting to medical treatment but identifying a person to speak on one's behalf.

Capacity to Make Medical Decisions. The Uniform Health-Care Decisions Act defines capacity as "the ability to understand significant benefits, risks, and alternatives to proposed health care and to make and communicate a health-care decision."

Functional Elements. The ability to consent to medical treatment involves "functional" abilities that are cognitive in nature: (1) expressing a choice; (2) understanding diagnostic and treatment information; (3) appreciating benefits and risks of treatment options; (4) reasoning about options in a rational manner.

Risk Considerations. A "sliding scale" for capacity has been proposed when balancing risk considerations and the threshold for intervention. A relatively low level of capacity may be needed for a relatively low risk procedure. The evaluator will need to carefully consider the level of capacity needed to consent to a treatment or procedure, in view of a careful weighing of the risks of intervention versus non-intervention and how these risks compare to the person's values.

Enhance Capacity During Evaluation. The evaluator should strive to maximize the person's abilities during assessment by addressing sensory deficits and, when possible,

evaluating the individual when most alert and awake. Utilize disclosure formats that are simplified and guided to enhance understanding. This should mimic good doctor-patient dialogues in which information is presented in a manner that maximizes patient participation, as compared to a test-like situation where a patient is required to memorize information. Providing the information in writing, in short phrases, and, with diagrams may enhance understanding of the procedure

Advance Directives

Missouri Statute

A person may execute a power of attorney to delegate to another adult the authority to act in a fiduciary capacity on the person's behalf with respect to all lawful subjects and purposes. RSMo Section 404.810(1). This includes the authority to give consent to or prohibit any type of health care, medical care, treatment or procedure to the extent authorized by law. RSMo Section 404.810(1)(6)(10). The authority of the designated agent commences upon certification by at least one physician that the patient is incapacitated and ends when there is a certification that the patient is no longer incapacitated. RSMo Section 404.825.

Missouri Department of Mental Health - excerpts
Regulations on Medical Decision-Making

All competent adult residents and patients shall have the right to execute advance directives without regard to their voluntary or involuntary status. An adult is considered "competent" unless they have been adjudicated by a court to be incapacitated. An advance directive is a written instrument, such as a living will or durable power of attorney for health care, relating to the provision of health care for an individual when that individual is in a terminal condition or is incapacitated. A durable power of attorney for health care is a written instrument executed by a competent adult, notarized and expressly giving an agent or attorney in fact the authority to consent to or to prohibit any type of health care, medical care, treatment or procedures.

Statutes and Cases – link
Capacity to Execute Medical Power of Attorney

An adult has capacity to execute a durable power of attorney for health care if, at the time it is executed, the patient understands the significance of the document, namely, that the adult is empowering another person to make medical decisions on their behalf. *Pazdernik v. Decker*, 652 S.W.2d 319 (Mo. Ct. App. 1983).

A health care provider acting in good faith and not having been put on notice to the contrary, shall be justified in relying on the representations of a patient purporting to give consent (such as consent for a power of attorney). RSMo Section 431.061(4).

Department of Health and Human Services – link

Advance Directives for People with Developmental Disabilities

Equal Rights. The framework for advance care planning applies equally to all. All individuals have legal rights and personal interests in preparing advance directives. Even those with limited capacity should be encouraged to participate in advance care planning to the extent their abilities allow.

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. People with intellectual disabilities should not be presumed to lack capacity for making health care decisions.

Capacity to Designate Agent. 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.

Citizen Memorial Hospital – excerpts
Patient Rights

Designation of a Decision-Maker. You (the patient) have the right to appoint a surrogate to make health care decisions, on your behalf, including refusal of care and consent for treatment, in accordance with law and regulation. You have the right to formulate, revise and revoke advance directives and to have the hospital staff and practitioners who provide care to you in the hospital comply with these directives which state your wishes. You have the **right to designate a decision-maker** in your Advance Health Care Directive in the event you are, or become incapable of, understanding a proposed treatment or procedure or if you are or become unable to communicate your wishes regarding care.

American Journal Geriatric Psychiatry - excerpts
Evaluation of the Capacity to Appoint a Healthcare Proxy (HCP)

Legal standard. The mental capacity required to execute a general durable power of attorney is essentially the same as and equates to the mental capacity required to enter into a contract. Most statutes do not provide clear legal guidance on capacity to appoint an HCP, but those that do distinguish this capacity from medical decision-making consent capacity.

Criteria. One approach to measuring the capacity to appoint a healthcare surrogate is an individual's understanding of the instrument used to make those appointments, specifically: 1) the right to make decisions about one's own medical treatment, 2) the power to ask someone else to do so if unable, 3) that conferring that power could include a "life or death" outcome, and 4) that there is a document to sign to confer this power. Another approach to measuring the capacity to appoint a healthcare surrogate used in empirical studies has been to simply assess the consistency of a person's choice of proxy.

Evaluation. The evaluation of capacity to execute an HCP may consist of 1) capacity to understand the meaning (a) to give authority to another to make healthcare decisions, (b) through the HCP, (c) in the event of future or considering current diminished capacity to consent to treatment and 2) capacity to (a) determine and (b) express a consistent choice (c) of an appropriate surrogate. An appropriate surrogate may be defined as someone with whom the principal has a social (not professional) relationship, who knows the person's values, and who is willing (expresses interest and concern)

ADA/504 Duties

United States Supreme Court – link
Alexander v. Choate, 469 U.S. 287, 301

Meaningful Access. A recipient of federal funds must provide an individual with a disability meaningful access to the program or service that the recipient offers. To assure meaningful access, reasonable modifications to the program or service may have to be made.

ADA National Network – excerpts
"Accessible Health Care"

ADA Duties. The Americans with Disabilities Act and Section 504 of the Rehabilitation Act require that health care providers provide individuals with disabilities full and equal access to their health care services and facilities. **Title II** of the ADA applies to public hospitals, clinics, and health care services operated by state and local governments. **Title III** of the ADA applies to privately owned and operated hospitals, clinics and health care providers. **Section 504** of the Rehabilitation Act applies to recipients of federal financial assistance, such as Medicaid and federally conducted programs.

Effective Communication. Speech Disabilities. If you have difficulty understanding an individual's speech, be patient, listen attentively, and ask the patient to repeat or write the message if possible. Allow more time to comm u nica te with someone who uses a communication board or device. Cognitive Disabilities. With the patient 's permission, provide a qualified reader. If the individual is having difficulty with communication, be patient, repeat your message, and question the patient to make sure he or she understands. Use diagrams and pictures to improve communication. If a family member or personal care attendant accompanies the patient, remember to speak to the patient first, even if the patient may not be able to understand.

***I/DD Counts* 2022 Summit – excerpts**
"Advancing a Roadmap for Health and Equity Data for Persons with Intellectual and Developmental Disabilities"

Accessible Communication. Communication needs to be improved, and communication specialists can help. Information and data communicated in writing and verbally need to be accessible to people with I/DD. Ways to do that include using plain language, different

communication for different audiences, multiple formats, visual supports, and providing information in different languages, including American Sign Language.

Education and Training. Knowing a person has I/DD is important in clinical and support settings. Health care providers need to know about and understand a person's disability when they are developing care plans. Data should be used to advocate for ongoing training for clinicians and other care providers.

Health Affairs Oct. 2022 – excerpts
"Have Almost Fifty Years of Disability Civil Rights Laws Achieved Equitable Care?"

Accessible Communication. Research suggests that patients often do not receive these accommodations. A large percent of ADA lawsuits involve failures to ensure effective communication. Asking patients which communication accommodations work best for them and then following their preferences would maximize communication access and reduce lawsuit risks.

Education and Training. Relatively few undergraduate or graduate medical education programs offer disability trainings. Evaluations of these disability education initiatives generally have found immediate beneficial changes in attitudes, skills, and knowledge among trainees. In the 2019-20 survey, 35.8 percent of physicians reported knowing little or nothing about their legal responsibilities under the ADA, and 71.2 percent responded incorrectly about who determines reasonable accommodations for patients with disabilities (these decisions require collaboration between patients and clinicians).

Department of Health and Human Services - excerpts
Regulations for Section 504 of Rehabilitation Act

Nondiscrimination. 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.

Prohibited Actions. In providing health, welfare, or other social 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; or
(5) Provide different or separate benefits or services to handicapped persons except where necessary to provide qualified handicapped persons with benefits and services that are as effective as those provided to others.

Department of Health and Human Services - excerpts
Knowledge of Practicing Physicians

Proactive Steps. Disability civil rights laws not only prohibit discrimination but also require entities to "take proactive steps to offer equal opportunity to persons with disabilities." The requirements have implications for individual physicians and are not solely the responsibility of clinical practices. Equal access requires that a patient cannot be refused on the basis of disability; effective communication modalities (that is, auxiliary aids or services) are required; and the practice must engage in reasonable modification of policies, physical space, and procedures when necessary to accommodate patients' needs.

HIPAA Disclosures

Department of Health and Human Services - excerpts
Communicating with a Patient's Family . . .

This guide explains when a health care provider is allowed to share a patient's health information with the patient's family members, friends, or others identified by the patient as involved in the patient's care under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule. Even though HIPAA requires health care providers to protect patient privacy, providers are **permitted, in most circumstances, to communicate with the patient's family**, friends, or others involved in their care or payment for care.

Patient with Capacity. If the patient has the capacity to make health care decisions, a health care provider **may discuss the patient's health information** with a family member, friend, or other person if the **patient agrees** or **does not object**.

Patient without Capacity. If the patient is incapacitated, a health care provider **may share** the patient's information with family, friends, or others if the provider determines, based on professional judgment, that it is in the **best interest of the patient**.

Supported Decision-Making

Center for Public Representation - link
SDM and Health Care Decisions

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

Effective SDM. 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.

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.

Missouri Developmental Disabilities Council – link
Supported Decision-Making and Health Care

Self-Determination. When you make decisions and take actions to shape your life, it's called self-determination. When you're self-determined you do things instead of having things done to you, you make choices instead of someone else telling you what to do.

Getting Help. Being self-determined doesn't mean you never need help. Everyone needs help, every day. Getting help is important when you're taking care of your health. When you go to the doctor, you may not be feeling well, you might be nervous, or the doctor may use words that are hard to understand. It's a good idea to have someone with you, to help you and the doctor talk and work with each other. That way, you'll be able to understand your options and choose the
one that's best for you.

Supported Decision-Making. Supported Decision-Making can help you manage your health, work with your doctors, and make health care decisions.

Complaint Process

Citizen Memorial Hospital – excerpts
Patient Rights

Complaint Process. You (the patient) have the right to file an informal or formal complaint or written grievance and to expect a prompt resolution. You have the right to voice a complaint concerning your treatment, accommodations, hospital personnel, or staff without fear of repercussions or unreasonable interruption of care. You have the right to ask your nurse and/or care provider to help you resolve care issues during your visit. You have the right to ask for the department supervisor to resolve care issues during your visit. You have the right to voice your complaint to the CMH Patient Advocate.

Grievance Process. Any patient service or care issue that cannot be resolved promptly by staff present will be considered a grievance. To file a grievance, contact:

1) **CMH Patient Advocate**. Upon your request, you will be provided with a copy of the hospital's policy and procedure on grievances. Grievances about situations that may endanger the patient will be reviewed immediately. In most cases, CMH will review and respond to all other grievances within seven (7) days or will inform you (the patient) or representative that the hospital is working to resolve the grievance and the anticipated response date.

2) **Health Services Regulation**, MO Department of Health & Senior Services at 1-573-751-6303 to voice a grievance.

U.S. Department of Health and Human Services – link
Complaint Portal

Section 504 Complaint. If you believe that you have been discriminated against because of your race, color, national origin, disability, age, sex, or religion in programs or activities that HHS directly operates or **to which HHS provides federal financial assistance**, you may file a complaint with OCR. You may file a complaint for yourself or for someone else.

ADA Title II Complaint. If you believe that you have been discriminated against because of your disability by a State or local government health care or social services agency, you may file a complaint with the OCR. You may file a complaint for yourself or for someone else.

Missouri Department of Health and Senior Services – link
Complaints Regarding Missouri Hospitals

Bring your complaint or grievance to the attention of the hospital FIRST. Generally, this is done by contacting a patient care advocate, the customer relations department or a representative from the hospital's administration.

If the hospital fails to adequately address your complaint you may forward your complaint to 1- 800-392-0210 or you may complete a complaint form and e-mail it to hospitalcomplaints@health.mo.gov.

When submitting a complaint, provide your name and contact information in case additional information is needed. When you submit your complaint, details are used to aid the investigative activities and ensure hospitals are meeting regulations. Provide as much detail as possible: such as the date of the incident; location(s); the specific complaint(s); and any negative patient outcome(s). Every complaint will be reviewed. The Missouri Department of Health and Senior Services does not address billing issues or payment disputes.

Missouri Board of Registration for the Healing Arts – link
Complaint Against Licensed Medical Professionals

The Board may only impose disciplinary action against licensees regulated by the Board — **physicians and surgeons**, assistant physicians, physician assistants, physical therapists,

physical therapist assistants, speech language pathologists, speech language pathology assistants/aides, audiologists, audiology aides, athletic trainers, anesthesiologist assistants and perfusionists.

If you file a complaint against licensees not regulated by the Board, such as **nurses**, chiropractors, massage therapists, **dentists, psychologists**, or facilities such as **hospitals**, nursing home etc., the complaint will be forwarded to the appropriate agencies, board(s) or commission(s).

Remedies for Violations. If the licensed professional (hereafter "licensee") is found to have violated the **statutes or regulations governing the licensee's profession**, the Board may choose one or more of the following actions against the licensee: requirement for further education, training, tests and/or examinations; public reprimand; limitation or restriction on license; probation of license; suspension of license; revocation of license; surrender of license (voluntary or involuntary).

Missouri Commission on Human Rights – link
Discrimination Complaint

The Missouri Commission on Human Rights (MCHR) investigates complaints of discrimination in places of public accommodations because of disability. Complaints under the Missouri Human Rights Act must be filed with the MCHR within 180 days of the alleged discrimination.

The Act makes it illegal for a place of public accommodation to discriminate because of an individual's disability, including: (1) refusing to provide service; (2) being inaccessible to a person with a disability; (3) setting different terms or conditions for services or facilities, and (4) failing to reasonably accommodate an individual's disability to allow him/her to use and enjoy the place of accommodation.

"Places of public accommodation" are defined as all places or businesses offering or holding out to the general public . . . services, privileges, facilities, advantages or accommodations for the . . . health, . . . of the general public.

The commission has an online complaint form for discrimination by public accommodations.

Petition to Modify or Terminate Guardianship

Missouri Statutes – link
RSMo Section 475.083

At any time the guardian, conservator, or any person on behalf of the ward or protectee may, individually or jointly with the ward or protectee, or the ward or protectee individually may petition the court to restore the ward or protectee, to decrease the powers of the guardian or conservator, or to return rights to the ward or protectee.

The petition from the ward or protectee or on behalf of the ward or protectee may be an **informal letter to the court**.

Upon the filing of a **joint petition** by the guardian or conservator and the ward or protectee, the court, if it finds restoration or modification to be in the best interests of the ward or protectee, may summarily order restoration or a decrease in powers of the guardian or conservator or return rights to the ward or protectee **without the necessity of notice and hearing**.

Upon the filing of a petition **without the joinder** of the guardian or conservator . . . the court shall cause the petition to be set for hearing. If the ward or protectee is not represented by an attorney, the court shall **appoint an attorney** to represent the ward or protectee in such proceeding. The burden of proof by a preponderance of the evidence shall be upon the petitioner. Such a petition may not be filed more than once every one hundred eighty days.

In deciding whether to terminate or modify a guardianship or conservatorship, the court may require a report by and consider the recommendations in the report of a physician, licensed psychologist, or other appropriate qualified professional who has experience or training in the alleged mental, physical, or cognitive impairment of the ward or protectee.

Missouri Protection and Advocacy Services – link
Guardianship in Missouri

A guardianship can be changed to give more rights to an adult. This can include the right to make medical decisions. Mo P&A can **provide legal services** to a person with a disability to help end or change their Guardianship.

If an adult has a guardian and needs help restoring their rights, they can contact the Application Unit of Mo P&A or fill out our **Online Request for Help** form. Contact the Application Unit using one of the following methods: call 1-800-392-8667, or for TDD Users at 1-800-735-2966; send an email to app.unit@mo-pa.org; send a letter to Application Unit, Missouri Protection and Advocacy Services, 925 South Country Club Drive, Suite B, Jefferson City, MO 65109.

Department of Health and Senior Services – link
Abuse and Neglect of Disabled Adults

The Missouri Department of Health and Senior Services (DHSS) investigates abuse, neglect, and exploitation of vulnerable individuals 60 and older and people with disabilities between 18 and 59. These individuals may live in the community or in long-term care facilities.

Abuse is the infliction of physical, sexual, or emotional injury or harm including financial exploitation by any person, firm, or corporation (192.2400, RSMo). **Neglect** is the failure to provide services to an eligible adult by any person, firm or corporation with a legal or contractual duty to do so, when such failure presents either an imminent danger to the health,

safety, or welfare of the client or a substantial probability that death or serious physical harm would result (192.2400, RSMo). **Failure of a caregiver or guardian to secure necessary health care services for an adult under their care may be considered neglect.**

Anyone who suspects someone is being abused, neglected, or exploited can make a report. Certain professionals, however, are mandated by law to report. Click here to find a complete list of mandated reporting laws and mandated reporters.

If the alleged victim lives their own home or community, an investigator will help the alleged victim determine the services or interventions needed to stop or alleviate the abuse or neglect.

Adult Protective Services. For community-dwelling adults and persons with disabilities, the Department of Health and Senior Services provides Adult Protective Services (APS). Protective services are provided on behalf of eligible adults who are unable to: manage their own affairs; carry out the activities of daily living; or, protect themselves from abuse, neglect, or exploitation which may result in harm or a hazard to themselves or others. The purpose of Adult Protective Services is to: promote independence; maximize client choice and provide for meaningful client input for preferences; keep the adult at home by providing quality alternatives to institutional care; and, empower the older adult to attain or maintain optimal self-determination.

Hotline. Missouri's Adult Abuse and Neglect Hotline responds to reports of abuse, bullying, neglect, and financial exploitation. If a person suspects someone is being abused, bullied, neglected or exploited, they can call the hotline at 800-392-0210. The hotline operates 365 days per year from 7 a.m. to 8 p.m. People who are deaf or hard of hearing may utilize Relay Missouri by calling 1-800-735-2466. A report of abuse, neglect, or bullying can be made online: https://apps4.mo.gov/APS_Portal/