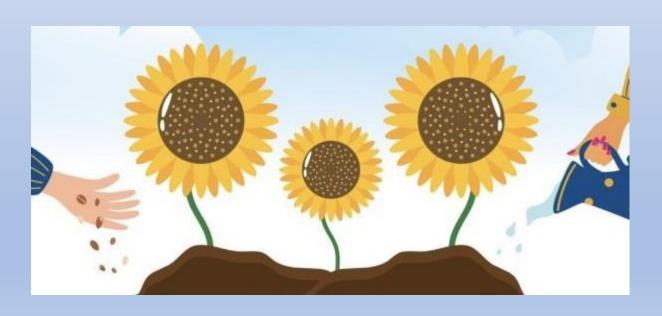
Empowering Transition-Age Youth and Beyond:Navigating Medical Decision-Making

a presentation to

2024 MACDDS ANNUAL CONFERENCE



Medical Decision-Making

Part One

Part Two

Understanding Legal Rights

Implementing
Best Practices

Thomas F. Coleman Spectrum Institute

Jennifer Hulme Hulme Resources Inc.

Part One Understanding Legal Rights

MACDDS VALUES

Self-Determination – We believe it is the right of all people to make their own choices and experience acceptance in their communities. We help create opportunities and advocate for systems, processes and communities that support self- determination.

Self-Determination is a Legal Right

Missouri State Law

Autonomy. The common law recognizes the right of individual autonomy over health care decisions. Medical self-determination is a constitutional right. *Cruzan v. Missouri Dept. Health,* 760 S.W.2d 408 (Mo. 1988), 497 U.S. 261, 278 (1990).

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)). An adult is considered "competent" if they have <u>not been adjudicated by a court</u> to be incapacitated. Mo. Code Regs. tit. 9 § 10-5.180.

Presumption. The law presumes every person to be of sound mind. 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)

Federal Law

HHS Regulations Against Disability Discrimination

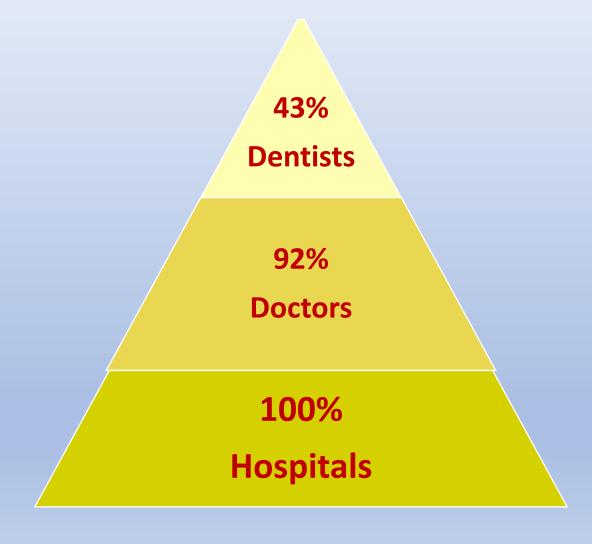
Effective July 2024

Section 504 of the Rehabilitation Act of 1973

Section 1557 of the Affordable Care Act

Rules Apply To

Providers Receiving Federal Funds



Data on Patients in Missouri

86% of adult patients
with mental or
developmental
disabilities are
presumed competent

30,000 in guardianships

73,000 Adult Patients with Developmental Disabilities

1,300 teens with developmental disabilities transition into adulthood annually

217,000 Adult Patients with Cognitive Disabilities

Elements of New Federal Rules

Discrimination **Prohibited**

Effective Communication

Meaningful Access

Supported Decision-Making

Reasonable Modifications

Individualized Judgment

Discrimination

Not Allowed

Denying or Limiting Treatment Due To

- Biases or stereotypes
- Generalizations
- Perception of Disability

Refusing to Allow Assistance

- Presence of Support Person
- Supported Decision-Making
- Valid Power of Attorney

Permitted

Basing Treatment Decisions On

- Individualized Assessments
- Evidence of Incapacity to Consent
- Judgments on Best Medical Knowledge

Refusing to Allow Assistance

- Patient Objects
- Evidence of Abuse by Supporter
- POA is Objectively Invalid



Decision-making is a central component of medical services. Therefore, providers must give patients with disabilities "meaningful access" to the medical decision-making process.

Levels
of
Patient
Access

Most Involvement To Least Involvement **Solo – Makes Decisions Independently**

Companion – Presence of Support Person

Supporter – Makes Decisions with Advice/Help

POA – Chosen Agent Makes Decisions

Guardian – Makes Decisions for the Patient

Reasonable Modifications

For Patients with Developmental Disabilities

Scheduling

Extra Time

Companion

Simple Language

Photos Graphics SDM*

^{*} Supported Decision-Making

Individualized Judgment

- O Disability Diagnosis ≠ Incapacity
 - Capacity Analysis is Situation Specific
 - Presume Capacity Unless Contrary Evidence

Effective Communication

- False assumptions hinder communication
 - Ask about communication preferences
 - Allow support person if requested
 - Use images and graphics
 - 🔷 Provide extra time 🔷

Supported
Decision-Making

Supported Decision-Making May Be Necessary to:

Avoid Discrimination in Medical Treatment

Obtain Informed Consent

Have Effective Communication

Offer Reasonable Modifications of Policies

Complaints to Feds

A patient, or someone on their behalf, may file a complaint with the Office for Civil Rights of HHS for alleged violations of Section 504 or Section 1557 by a covered entity.

Complaints To State

A violation of HHS Rules violates Missouri law.
Therefore, a complaint for such violations can be filed with the Missouri Bureau of Hospital Standards.

Education of MCDDS Clients of Medical Rights

To promote self-determination of its clients and to assist families to advocate for the medical rights of supported individuals, Support Coordinators, Providers, Caregivers and family members should:

- Advise adults of the right to medical self-determination
- Advise adults they are presumed to be competent
- Encourage families to explore alternatives to guardianship
- Refer clients to Missouri Protection & Advocacy if medical rights are denied
- Inform clients/families of the right to file complaints against providers
- Include medical rights in transition planning and education of youth

References & Resources

Resources for Patients, Families, and Providers

Brochures * Memos * Reports * Sample Forms

https://spectruminstitute.org/references-and-resources.pdf

Medical Decision-Making

Part Two

Implementing
Best Practices

Jennifer Hulme
Executive Director
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ROLES

Role of Support Professionals in Medical Decision-Making

Key Responsibilities

- Advocating for the individual's medical rights and preferences.
- Facilitating communication between the individual, family members, and entire support team.
- Ensuring the individual's voice is heard in all medical decisions.

Common Challenges

- Balancing family or caregiver expectations and the individual's autonomy.
- Navigating complex medical systems and jargon.
- Addressing capacity and competency concerns in medical contexts.

Implementing Person-Centered Practices in Medical Decision-Making

Understanding the Individual's Medical Goals:

Conducting comprehensive assessments to understand the individual's medical history, preferences, and goals. (HRST, DD HEALTH HOME collaboration)

Building Effective Support Networks

- Engaging family members, healthcare providers, and other key stakeholders in creating a cohesive support network.
- Facilitating regular communication and meetings to keep all parties informed and aligned with the individual's goals.
- Encouraging the use of Supported Decision-Making (SDM) to involve the individual in their care planning actively.

Documenting and Communicating Medical Preferences

- Creating clear and accessible documentation of the individual's medical preferences, using tools like health passports or communication charts.
- Ensuring that these documents are readily available during medical appointments and emergencies.

Best Practices for caregivers to provide Advocacy and Support in Medical Settings

Pre-Appointment Planning:

- Preparing the individual for medical appointments by reviewing key topics, possible questions, and concerns.
- Providing visual aids or communication tools to help the individual understand what to expect during the appointment.
 - Services such as Individualized Skill Development,
 Community Specialist, Family Peer Support are potential waiver services that can be used

Best Practices for caregivers to provide Advocacy and Support in Medical Settings

During the Appointment:

- Acting as an advocate to ensure that healthcare providers respect the individual's preferences and communication needs.
- Supporting the individual in asking questions and expressing their concerns.
- Using <u>plain language and visual supports</u> to help explain medical information.

Best Practices for caregivers to provide Advocacy and Support in Medical Settings

Post-Appointment Follow-Up:

- Reviewing the outcomes of the appointment with the individual, ensuring they understand the next steps and any prescribed treatments.
- Coordinating follow-up care and ensuring all parties are informed about the individual's ongoing needs.

Supporting Complex Medical Decisions

- Advocating for the individual's right to participate in decisions to the maximum extent possible.
- Strategies for addressing disagreements between family members and healthcare providers.

Navigating Medical Crises

- Developing emergency plans that include the individual's preferences and directives.
- Establishing protocols for caregivers, friends, family to follow in medical emergencies to ensure the individual's voice is respected.
- Utilizing emergency medical IDs or documentation to inform providers of critical information quickly.

Case Study Discussion

Transition Planning for Youth Aging Out of Pediatric Care

- ➤ Background: A transition-age youth is already receiving Waiver services, including educational support and personal assistance, is about to turn 18 and will need to transition from pediatric to adult healthcare services. The individual also receives DD Health Home support for chronic health conditions.
- Challenges: The youth and their family are anxious about navigating the adult healthcare system and ensuring continuity of care. There are concerns about how the new healthcare providers will understand the youth's complex needs and also allow as much autonomy as realistically possible.