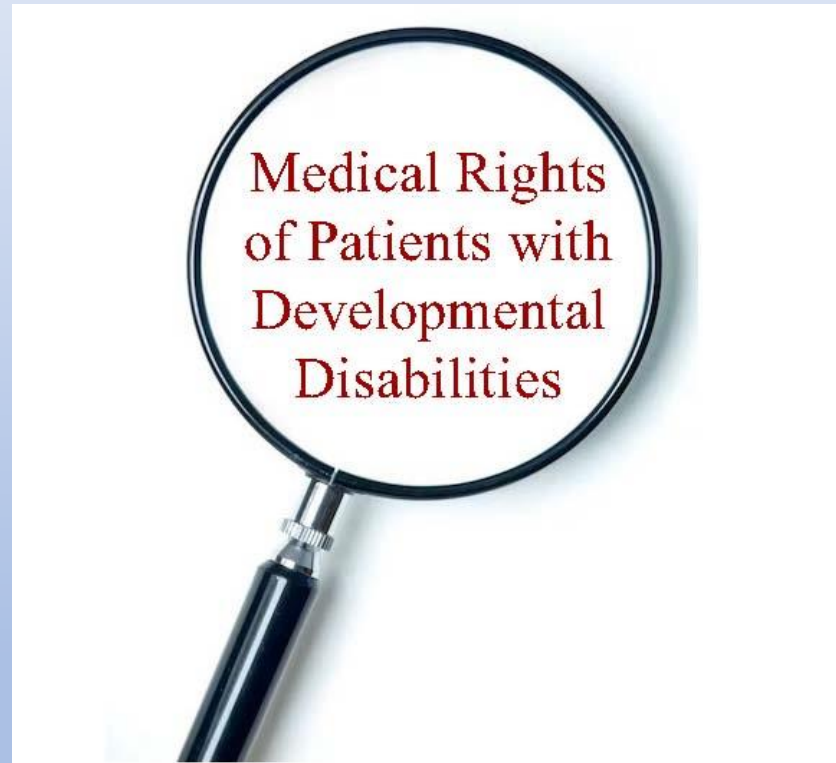


Discrimination Against Patients with Disabilities



An Overview of *New* Federal Rules



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Office for Civil Rights

a presentation to

Missouri Medical Rights Workgroup

exploring decision-making options for patients with developmental disabilities

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Effective July 2024

Section 504 of the Rehabilitation Act of 1973

Comments Made by the Department of Health and Human Services on the Final Rule and Unchanged Provisions of the Proposed Rule for Section 504 – Relevant Regulations

Section 1557 of the Affordable Care Act

HHS Comments on Disability Discrimination Provisions of the Final Rule for Section 1557 – Relevant Regulations

Full Report: <https://alternativestoguardianship.com/final-hhs-report.pdf>

Full Report: <https://alternativestoguardianship.com/final-hhs-rule.pdf>

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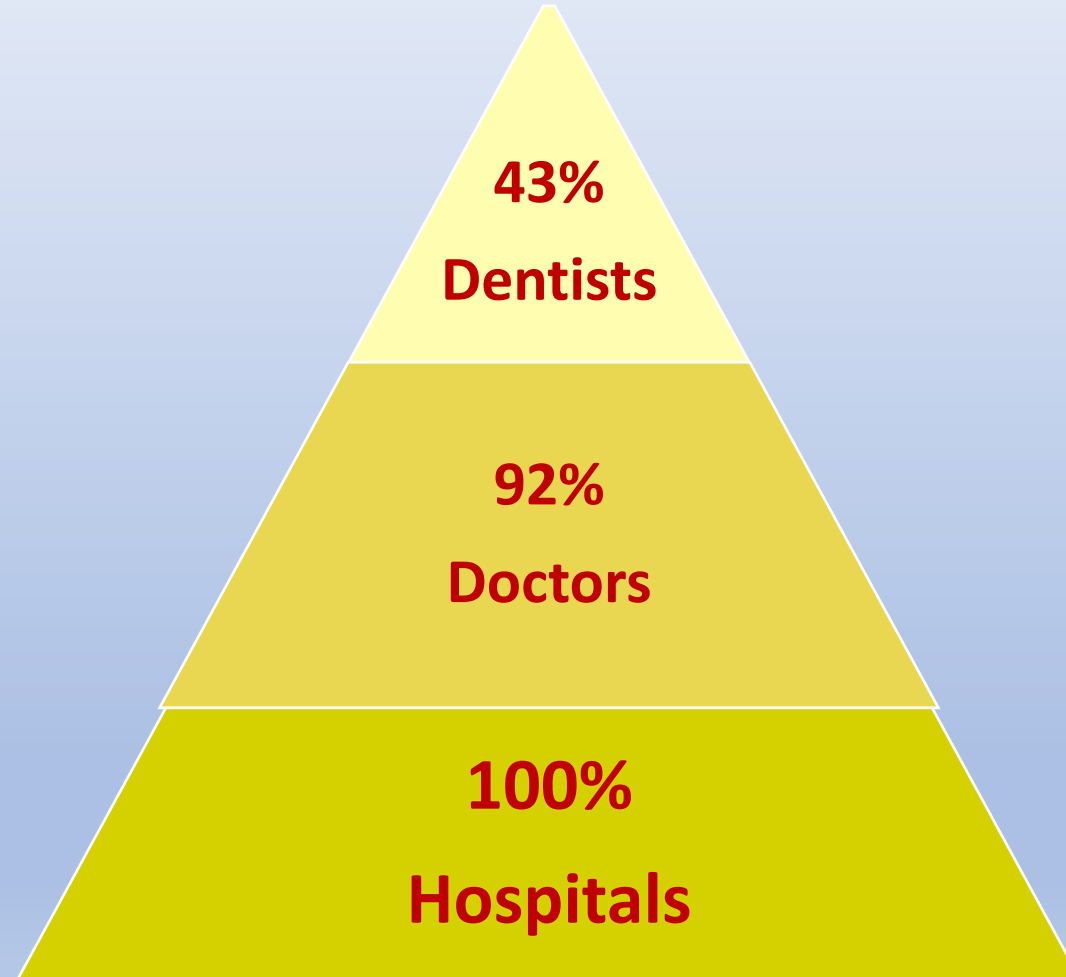
<https://alternativestoguardianship.com/medical-rights.htm>



Funding for the Alternatives to Guardianship Project is being provided by the Missouri Developmental Disabilities Council, grant PGA010-22007 and grant PGA010-22008, as authorized by Public Law 106-402 - Developmental Disabilities Assistance and Bill of Rights Act 2000.

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

217,000 Adult Patients with Cognitive Disabilities

1,300 teens with developmental disabilities transition into adulthood annually

Elements of New Rules

**Discrimination
Prohibited**

**Reasonable
Modifications**

**Effective
Communication**

**Meaningful
Access**

**Individualized
Judgment**

**Supported
Decision-Making**

**Compliance
Officer**

**Grievance
Procedure**

**Employee
Training**

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

**Meaningful
Access**

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**

- 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

**Compliance
Officer**

Providers with 15 or more employees must:

**Designate Someone to
Coordinate Efforts
to Comply with
Section 504**

**Grievance
Procedure**

**Notice of
Nondiscrimination**

Providers with 15 or more employees must:

adopt a grievance procedure that incorporates due process standards and provides for the prompt and equitable resolution of complaints

All covered entities must:

give notice to patients of their policy of nondiscrimination in health care services



Employee Training

Providers with 15 or more employees must:

- **Adopt written policies and procedures designed to comply with federal nondiscrimination rules**
- **Train relevant employees on those policies and procedures**
- **Relevant employees include: those interacting with patients; those making decisions affecting patient health care; executive leadership team and legal counsel**

Complaints to OCR

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.

A patient may be represented in an administrative proceeding with OCR by a lawyer or a nonlawyer of their choice. A patient representative may be a chosen friend or family member.

**Complaints
To State of Missouri
For Hospital Violations**

Effective in 2019, Missouri rescinded its regulations on patient rights in hospitals. It incorporated by reference the federal Medicare conditions of participation which include rules on patient rights.

The Medicare rules require hospitals receiving federal funds to obey all federal nondiscrimination laws. This includes Section 504 and Section 1557.

As a result, a violation of those nondiscrimination rules violates Missouri law. Therefore, a complaint for such violations can be filed with the Missouri Bureau of Hospital Standards.

Link: [ComplaintForm.pdf \(mo.gov\)](#)

More Information



<https://alternativestoguardianship.com/>