



Missouri Medical Rights Workgroup

References and Resources

for patients, families, providers, educators, officials

These materials were produced by Spectrum Institute for the Alternatives to Guardianship Project of Hulme Resources Inc.

<https://alternativestoguardianship.com/references.pdf>

Decision-Making Rights (in General)

Reports

1. “Basics of Medical Decision-Making” (9 pages)

for
everyone

This report explains the basics of medical decision-making. Basics include the demographics of this patient population; ethical requirements for medical professionals; legal considerations such as the right of medical self-determination, evidentiary presumptions, and the nondiscrimination duties of medical providers; potential alternatives to guardianship; and protocols for assessing a patient’s functional capacity to make medical decisions with and without reasonable accommodations. This report provided a foundation for the Medical Rights Workgroup.

<https://alternativestoguardianship.com/consensus-basics.pdf>

2. “Medical Decision Making Options” (24 pages)

for
everyone

This report contains a commentary explaining various levels of medical decision-making by adults with developmental disabilities – independent, with support, delegated to another, and usurped by a guardian. It also contains a detailed list of medical references and legal authorities, with comments on how they apply to this patient population.

<https://alternativestoguardianship.com/medical-decisions.pdf>

3. “Legal References for Patients, Families, and Providers” (17 pages)

for
everyone

This report lists federal and legal authorities (statutes, regulations, cases) governing patient’s rights, self-determination, capacity assessments, advance directives, ADA/504 duties, HIPAA disclosures, supported decision-making, complaint procedures, petitions to modify or terminate guardianships, and reporting abuse or neglect of people with developmental disabilities. Excerpts and explanations are provided. Sample medical authorization forms are include

<https://alternativestoguardianship.com/how-to-references.pdf>

4. **“New Federal Regulations On Disability Discrimination”** (37 pages)



This report explains how key provisions in new federal regulations for health care providers apply to patients with developmental disabilities. This report was the basis for a PowerPoint and a video, both of which are listed in this bibliography.

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

5. **“Supported Decision-Making: Options for Missouri”** (42 pages)



The Missouri Legislature designated supported decision-making as an alternative that must be considered by judges prior to placing an adult in a guardianship. The 2018 statute did not define supported decision-making. Based on a review of the statutes of 21 other states that have supported decision-making laws this report suggests a model statute that should be considered by the Missouri Legislature to give guidance to people with disabilities, their families, and those with whom they interact, such as health care providers, schools, and businesses.

<https://alternativestoguardianship.com/options.pdf>

Guidance Materials

6. **“Medical Decision-Making by Adults with Developmental Disabilities”** (48 pages)



This document contains guidance on how to protect the medical decision-making rights of patients with developmental disabilities. It has sections directed to: patients, families, providers, state agencies, and professional associations. The annotated bibliography lists federal and state statutes and case law that govern this area of patient’s rights, with commentary explaining each citation.

<https://alternativestoguardianship.com/medical-guidance.pdf>

Articles

7. **“Medical Decision-Making Rights: What You Should Know”** (12 pages)



This article was published in the September 2023 issue of *Helen* – the official magazine of the American Academy of Developmental Medicine and Dentistry (AADMD). It contains advice for patients, families, and health care providers about how to maximize access to the medical decision-making process for adults with developmental disabilities and how to complain if providers fail to live up to their legal and ethical duties to this patient population.

<https://alternativestoguardianship.com/helen-article.pdf>

8. **“How Dentists are Prohibited from Disability Discrimination”** (6 pages)



This article, published in the January 2024 issue of *Helen*, explains how prohibitions against disability discrimination by dentists are contained both in the Principles of Ethics and Code of Professional Conduct of the American Dental Association as well as Section 504 of the Rehabilitation Act of 1974. Section 504 applies to providers who receive federal funds.

<https://helenjournal.org/january-2024/xxvil80d4fswrjpm1as518hdubhl>

9. “Proposal: Health Care Proxies for Adults with Developmental Disabilities” (3 pages)



This article proposes that the Missouri Legislature pass a law, using elements from those in Utah and Vermont, to clarify that a lower threshold of capacity is necessary to designate a healthcare proxy than to make one’s own medical decisions. An individual may not have capacity to give specific instructions to the proxy on what decisions to make under various circumstances, but they may have the capacity to know who they want to make such choices. Courts and capacity assessment professionals in Missouri would benefit from such statutory guidance.

<https://alternativestoguardianship.com/medical-proxy-mo.pdf>

PowerPoints

10. “Disability Discrimination: An Overview of New Federal Rules” (19 pages)



These PowerPoint slides were used in a presentation to the Missouri Medical Rights Workgroup about new federal rules prohibiting disability discrimination by federally-funded health care providers. It is based on a detailed report that is listed in this bibliography.

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

Videos

11. “Key Elements of New Federal Nondiscrimination Rules Explained” (54 min.)



In this video, attorney Thomas F. Coleman explains how new federal rules prohibiting disability discrimination by health care providers receiving federal funds applies to adult patients with developmental disabilities. Special emphasis is placed on medical decision-making rights. A question and answer session follows the presentation.

<https://www.youtube.com/watch?v=zVY2Ny-JvL0>

Brochures

12. “Sample Medical Authorization Forms” (1 page)



This document lists a variety of useful forms for patients with developmental disabilities (with links to the forms online), including: designating an ADA support person; HIPAA authorization; designation of patient representation; designation of health care agent; power of attorney and advance directives; complaint to Bureau of Hospital Standards; supported decision-making form; health care passport; certificate of understanding and voluntariness.

<https://alternativestoguardianship.com/sample-medical-authorization-forms.pdf>

13. “Health Care and Developmental Disabilities: A Message to Patients” (5 pages)



This booklet advises patients with developmental disabilities about their medical decision-making rights and what they can do if those rights are denied.

<https://alternativestoguardianship.com/how-to-patients.pdf>

14. “Health Care and Developmental Disabilities: A Message to Families” (4 pages)



This booklet makes specific suggestions on how parents and other family members can effectively advocate for the medical rights of loved ones with developmental disabilities.

<https://alternativestoguardianship.com/how-to-families.pdf>

15. “Health Care and Developmental Disabilities: A Message to Providers” (8 pages)



This booklet makes specific suggestions to assist hospitals, doctors, nurses, dentists, and other health care providers respect the medical decision-making rights of adult patients with developmental disabilities while also complying with their ethical and legal duties as medical professionals.

<https://alternativestoguardianship.com/how-to-providers.pdf>

16. “Quick Tips for Providers” (1 page)



This flier provides information to help health care providers comply with their duties under state and federal laws that prohibit discrimination against patients with developmental disabilities.

<https://alternativestoguardianship.com/tips-for-providers.pdf>

17. “All Missouri Hospitals Should Have a Section 504 Coordinator” (1 page)



This flier explains that federal law requires that all health care providers receiving federal funds who have 15 or more employees must designate a staff person to coordinate the entity’s efforts to comply with the nondiscrimination provisions of Section 504 of the Rehabilitation Act of 1973.

<https://alternativestoguardianship.com/504-coordinator.pdf>

Background Data

18. “Building on an Established Framework” (1 page)



This document explains how the Missouri Legislature passed a law in 2018 that required the consideration of less restrictive alternatives, such as powers of attorney and supported decision-making before courts should place an adult into a guardianship. It also explains how a consensus by 133 participants emerged from a symposium held that year on supported decision-making.

<https://alternativestoguardianship.com/building-on-framework.pdf>

19. “National Core Indicators: Intellectual and Developmental Disabilities” (5 pages)



This document contains excerpts from surveys done in Missouri from 2017 to 2022 as part of a project coordinated by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). Results of the surveys show that Missouri has been overusing guardianships compared to the rest of the nation and that a majority of families in Missouri have not been advised of alternatives to guardianship.

<https://alternativestoguardianship.com/nci-idd-mo.pdf>

Transition Planning

Reports

20. “Medical Decision-Making Rights Should be Part of IEP & ISP Transition Planning” (9 pages)



This report calls on lawmakers, state agency officials, school administrators, and disability service coordinators, to include a health care transition process in the development and implementation of education plans and service plans for youth with developmental disabilities as they prepare to assume adult responsibilities. References to relevant federal and state regulations are included.

<https://alternativestoguardianship.com/iep-isp-transition-plan-medical.pdf>

Booklets

21. “Transitioning to Adulthood: Resources for Patients, Families, and Providers” (7 pages)



This pamphlet contains resources to help the process when minors transition from pediatric care to primary care as adults. There are separate sections for patients, families, and health care providers.

<https://alternativestoguardianship.com/transitioning-resources.pdf>

Articles

22. “Pediatric Journal: Need for Collaboration, Integration of Rights and Protections (1 page)



This document contains excerpts from a journal article explaining that, unlike transition services in education and service coordination, federal law does not require a mandate that medical providers offer transition planning for youth with developmental disabilities. This gap must be voluntarily filled through the cooperation and collaboration of state agencies and medical providers.

<https://alternativestoguardianship.com/hct-wiley.pdf>

PowerPoints

23. “Medical Transition Planning in IEP/ISP” (12 pages)



This presentation gives an overview of the education, training, and counseling, being done by Hulme Resources Inc, through the Alternatives to Guardianship Project, to help build capacity within schools and with families to include medical decision making in the usual IEP and ISP processes.

<https://alternativestoguardianship.com/Hulme-Presentation.pdf>

Education of Students and Professionals

Reports

24. “Survey on Developmental Disability Issues in Current Educational Programs” (12 pages)



This report documents the findings of a survey of university degree programs training students to become medical professionals and continuing education programs of professional associations for doctors, nurses, dentists, and social workers in Missouri.

<https://alternativestoguardianship.com/education-survey.pdf>

Articles

25. “Missouri is Lagging on Alternatives to Guardianship” (1 page)



This article argues that the lack of education of medical and legal professionals is a major factor in such a high percentage of adults with developmental disabilities being placed into guardianships. Judges and attorneys are not screening cases to determine when alternatives to guardianship would be more appropriate. Better educational programs and materials are needed for families, educators, medical professionals, judges, and attorneys.

<https://alternativestoguardianship.com/missouri-lagging.pdf>

Bibliography

26. Reading Materials on Education of University Students and Health Care Professionals (1 page)






This list of reading materials for the Missouri Medical Rights Workgroup provides links to information online regarding a wide range of educational materials for university students, professionals, judges, and court-appointed attorneys.

<https://alternativestoguardianship.com/apr-2024-reading-materials.pdf>

Missouri Medical Rights Workgroup

exploring decision-making options for patients with developmental disabilities

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