



Final Report of the Missouri Medical Rights Workgroup

Protecting Medical Rights of Patients with Developmental Disabilities: We Can Do Better

Findings & Recommendations

September 2024

<https://spectruminstitute.org/medical-rights.pdf>

Contents

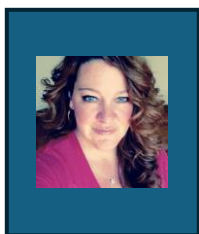
Recommendations Index	3
Workgroup Process	4
Workgroup Participants	5
Demographics and Data	
Adult Patients with Developmental Disabilities	6
Findings & Recommendation 1 (Assume Capacity)	
Transitioning Teens	7
Findings & Recommendation 2a-b (Providers & IEP/ISP Teams)	
Overuse of Guardianships	8
Findings & Recommendation 3 (Explore Alternatives)	
Role of Public Administrators	9
Findings & Recommendation 4 (Increase Funding)	
Students and Professionals	10
Findings and Recommendation 5 (Improve Training)	
Legal Considerations	
Presumption of Capacity	11
Findings & Recommendation 5 (Know the Law)	
Disability Discrimination	12
Findings & Recommendation 6 (Avoid Discrimination)	
Decision-Making Alternatives	13
Findings & Recommendation 7 (Respect Patient Options)	
New Options	14
Findings & Recommendation 8 (Pass a New Law)	
Judges and Attorneys	15
Findings & Recommendations 9a-c (Training, Standards, Fees)	
Ethical Principles	
Autonomy and Consent	16
Findings and Recommendation 10 (Honor Patient Autonomy)	
Continuing Education	
For Providers	17
Findings and Recommendation 11 (Educate Professionals)	
For and By State Agencies	18
Findings and Recommendations 12a-d) (Provide Leadership)	
Appendix (Annotated Bibliography)	19

Recommendations (per organization or agency)

Recommendation Directed to:	Page
Associations for Hospitals, Doctors, Dentists, Nurses and Social Workers	10, 11, 14, 16, 17
Bureau of Hospital Standards	13
Circuit Court Judges	15
Department of Health and Social Services	18
Department of Mental Health	18
Health Care Providers (in general)	6, 7, 8, 12
Hospitals and Providers (Section 504 Compliance Officers) . .	13
IEP/ISP Teams	7
Missouri Commission on Human Rights	13, 18
Patients, Families, Providers	8
Public Administrators	9
Schools of Medicine, Dentistry, Nursing, and Social Work . . .	10, 11, 12, 16
Supreme Court	1
U.S. Department of Justice	9

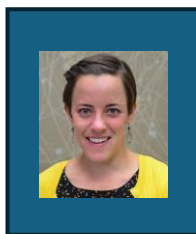
Workgroup Process

Convenors of the workgroup were the Alternatives to Guardianship Project, the American Academy of Developmental Medicine and Dentistry, and Spectrum Institute. The workgroup was coordinated by Jennifer Hulme, Emily Johnson MD, and Thomas F. Coleman JD.



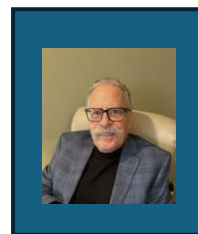
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Participants in the workgroup represented a wide range of perspectives, including patients with disabilities, family members, health care providers, disability service providers, disability rights advocates, professional associations, university educators, and government agency officials. Their names and affiliations are listed on the following page.

Reading materials which were sent to participants to review and discuss included reports, articles, guidance materials, brochures, and PowerPoints. An annotated bibliography of these materials is attached as an Appendix.

Meetings were held on zoom each month from January through May of 2024. Materials were explained by the author. Participants offered comments and made suggestions.

Findings and recommendations in this report were developed by the coordinators in consultation with workgroup participants. The report was reviewed by participants in July and discussed at a meeting in August.

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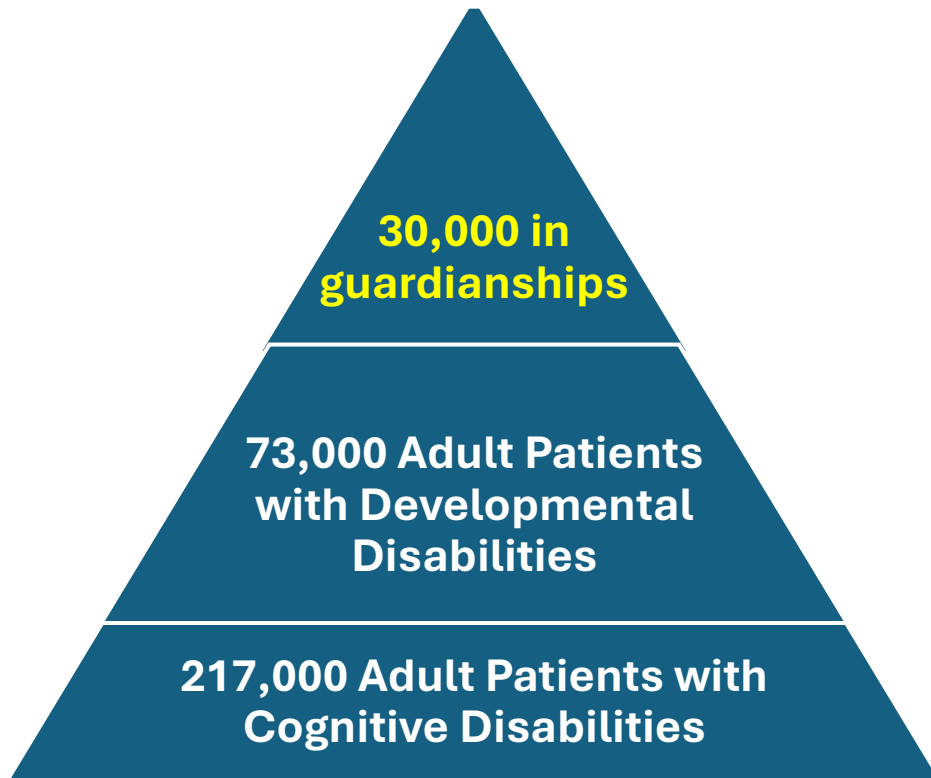
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Missouri Hospital Association

Demographics and Data

Adult Patients with Developmental Disabilities

Findings. Approximately 4.7 million adults live in Missouri. Some 217,000 of these adults have cognitive disabilities, about 73,000 of which are developmental disabilities.

Only 14% of adults with mental or developmental disabilities in Missouri – approximately 30,000 – are under an order of guardianship. The vast majority (86%) of adults who have mental or developmental disabilities in Missouri make medical decisions without any court intervention. They make decisions independently, with informal support from chosen advisors, with a formal supported decision-making agreement, or through a power of attorney.



Recommendation 1 – Assume Capacity. Unless an adult patient is in a guardianship, health care providers should assume the patient has capacity to make medical decisions, either independently or with support, until reliable evidence shows the contrary. This assumption is consistent with the legal presumption of capacity of adults with developmental disabilities.

Demographics and Data

Transitioning Teens

Findings. About 82,000 teenagers turn 18 each year in Missouri. About 1.58% of the population has an intellectual or developmental disability. (I/DD) Therefore, about 1,300 teens with intellectual or developmental disabilities become adults each year in Missouri. This is the “transitioning to adulthood” I/DD population, many of whom will benefit from education, support, and assessment about medical capacity decision-making. Such education and support should occur throughout life, but especially from ages 14 to 17. Many don’t need additional education on these issues as they reach adulthood because they already have been successfully participating in medical decision-making as teenagers and will continue to do so as adults.

The IEP process at schools generally does not include medical decision-making or alternatives to guardianship in transition planning or transition services. The same is true with service coordinators as they assist teenagers with developmental disabilities. Transition planning and services should include these issues.



**1,300 teens with
developmental disabilities
transition into adulthood
annually in Missouri**

Recommendation 2a – Medical Providers. Health care providers should explore all available medical decision-making options with transitioning teens and young adults with developmental disabilities. Guardianship should be recommended by providers only as a last resort, and only after an assessment by a qualified professional shows a lack of capacity to make medical decisions, a lack of capacity to execute a power of attorney, and that supported decision-making is not a viable option.

Recommendation 2b – IEP/ISP Teams. IEP teams for special education students should include medical decision-making options in transition planning as should ISP coordinators as they help their young clients transition to adulthood. Medical rights should not be overlooked.

Demographics and Data

Overuse of Guardianships

Findings. According to a 2019 report from the National Council on Disability (NCD), Missouri was among the top three states in terms of the percent of adults with developmental disabilities who had been ordered into a guardianship.

Despite a new law in 2018 requiring that less restrictive alternative be considered and ruled out as options before a guardianship may be instituted, the number of guardianships has remained constant.

The school system and the health care industry are the major “pipelines to guardianship” that cause parents to file guardianship petitions.

In a recent survey of families with a minor who had I/DD (2021-2022), 86% of respondents said they did not have information on supported decision-making. Some 50% of families with an adult who had I/DD said they were unaware of alternatives to guardianship

It takes time and costs money to train medical professionals about alternatives to guardianship. It is easier and more efficient for providers to obtain informed consent from a guardian than from an adult with a developmental disability. Thus, providers have financial incentives to recommend guardianships rather than explore alternatives.



Alternatives to Guardianship

Recommendation 3 – Explore Alternatives. Patients, families, and providers should learn about alternatives to guardianship and how to implement them in the context of health care services. Providers should train staff that the viability of alternatives to guardianship must be considered when capacity assessments are conducted.

Demographics and Data

Role of Public Administrators

Findings. Some 30,500 adults with cognitive or developmental disabilities are living under an order of guardianship. About 11,000 of them have a public administrator as a guardian. About 3,520 (32%) of these adults have intellectual or developmental disabilities.

A 2020 report from the Missouri Association of Public Administrators said the national standard caseload for a professional guardian is 20 clients. Public administrators in Missouri have an average caseload of 91 clients.

If public administrators had sufficient funding, they could be proactive in assisting clients living under an order of guardianship to explore less restrictive alternatives, such as medical powers of attorney or supported decision-making. This could enable more clients to file petitions to terminate existing guardianships or modify the terms to restore medical decision-making rights.

Underfunding of public administrators adversely affects the medical rights of adults with developmental disabilities whose lives are managed by these offices.

A recent report by the Department of Justice found that underfunding of public administrators is contributing to ongoing violations of the Americans with Disabilities Act. The DOJ will be negotiating with state officials to remedy this problem. County officials should be included in these conversations.



Missouri Public Guardianship Report

Recommendation 4 -- Increase Funding. The U.S. Department of Justice should press the state for funding reforms for public administrators. Perhaps funding should be provided by the state rather than by counties, with greater state supervision of adults whose cases are managed by public administrators. Since state judges appoint guardians and supervise guardianship cases, the state has a duty to ensure compliance with the ADA in these cases. If public administrator underfunding is causing ADA violations, the state should take action to increase such funding.

Demographics and Data

Students and Professionals

Findings. There are about 15,000 medical, dental and nursing students and about 45,000 doctors, dentists, and nurses in Missouri.

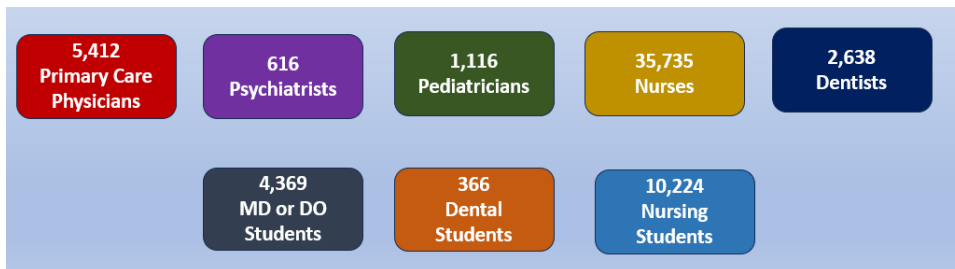
Some schools of medicine, dentistry, nursing, and social work have expanded curricula and clinical programs to include training on health care services for patients with developmental disabilities. Others have little or no training about this patient population.

Some trade and professional associations have continuing education programs that mention services to such patients, while others do not.

Some national associations offer training on core competencies on health care services for patients with developmental disabilities. However, only a small percentage of health care professionals avail themselves of such training.

Professional publications, such as newsletters and journals, are not sufficiently addressing the needs of this patient population. Some have not mentioned this topic at all.

The American Association of Developmental Medicine and Dentistry (AAIDD) has a model curricula for dental and medical schools and has a monthly publication with articles for patients, families, and practitioners. It also offers webinars for members. Any practitioner can join AAIDD.



Recommendation 5 – Improve Training. Schools that train students to be health care providers and professional associations for doctors, dentists, nurses, pharmacists, and social workers, should collaborate with AAIDD to develop or expand curricula, clinical programs, and continuing education courses to address the needs and patients with developmental disabilities.

Legal Considerations

Presumption of Capacity

Findings. 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 is presumed to exist unless proven otherwise. Patients can designate one or more support persons to assist them in making 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. A patient may lack capacity to make a specific medical decision and yet have capacity to designate an agent to make decisions for them through a power of attorney.

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, unless the person is found to be totally incapacitated.



Recommendation 6 –Know the Law. Basic legal principles of medical decision-making, such as the presumption of capacity, should be taught in schools of medicine, dentistry, nursing, social work, and pharmacology. Such principles also should be included in continuing education programs conducted by trade and professional associations for health care providers.

Legal Considerations

Disability Discrimination

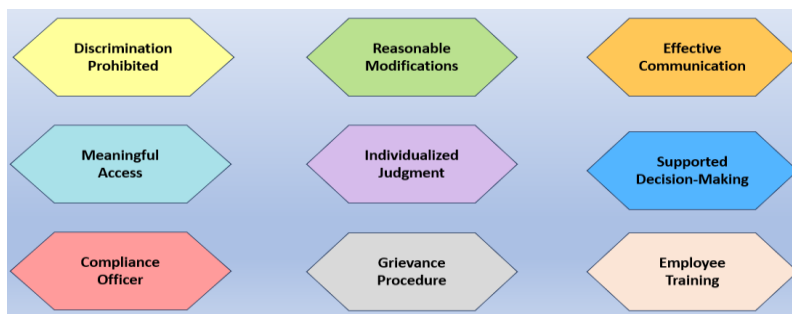
Findings. Discrimination by health care providers is prohibited by state and federal law. These laws apply to the medical decision-making process.

New federal rules clarify that providers who receive federal funds must not make decisions based on assumptions or stereotypes, must ensure effective communication with patients, and must provide reasonable accommodations to ensure that patients have meaningful participation in the health care process. These rules specifically mention supported decision-making.

Restrictions on the decision-making process of adult patients with disabilities are only allowed if they are medically or legally necessary. Recommending a guardianship or refusing to accept a power of attorney or supported decision-making arrangement is discrimination unless it is based on a scientifically valid evaluation of capacity by a qualified professional. Assumptions of capacity based on a mere disability diagnosis or a patient's IQ are not allowed.

Providers have duties to inform patients of their rights, train staff on disability nondiscrimination laws, and establish grievance procedures.

Patients or their supporters may file discrimination complaints with state civil rights agencies, professional licensing boards, and the Office of Civil Rights of the United States Department of Health and Human Services.



Recommendation 7 – Avoid Discrimination. Providers should have a written policy of nondiscrimination, inform patients of their medical decision-making rights, train staff on those rights, and have a grievance procedure to resolve complaints of discrimination. Medical, dental, nursing, pharmacy, and social work schools should train students about the decision-making rights of adult patients with disabilities and the legal duty of providers to respect those rights, as well as the potential legal consequences for violations.

Legal Considerations

Decision-Making Alternatives

Findings. Powers of attorney and supported decision-making arrangements have been recognized by the Legislature as less restrictive alternatives to guardianship that should be used when feasible. (RSMo Section 475.075(13))

The American with Disabilities Act requires health care providers to refrain from disability discrimination and to offer reasonable accommodations to adult patients with disabilities so they can make medical decisions independently, with support, or through a power of attorney.

Section 504 of Rehabilitation Act has similar nondiscrimination requirements for providers who receive federal funds. HHS has adopted new regulations prohibiting disability discrimination by health care providers. The new regulations require providers to recognize powers of attorney and supported decision-making agreements unless they are clearly invalid.

An adult has capacity to execute a power of attorney for health care if, when 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 notice to the contrary, is 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))



Recommendation 8 – Respect Patient Options. The Missouri Commission on Human Rights, the Bureau of Hospital Standards, and Section 504 Compliance Officers at health care providers should receive training on laws prohibiting disability discrimination in health care services so that complaints can be properly and effectively resolved. Training should include information on patient options for medical decision-making -- whether it is independent, with support, delegated to another person of the patient’s choice, or through a guardianship as a last resort.

Legal Considerations

New Options

Findings. There are several medical decision-making options for adult patients:

- (1) Solo - patient makes decisions independently;
- (2) ADA - patient makes decisions with disability accommodations;
- (3) SDM - patient makes decisions with supported decision-making agreement;
- (4) POA - patient delegates authority to an agent through a power of attorney;
- (5) Surrogate - patient delegates authority to a surrogate orally or in writing;
- (6) Surrogate - primary care physician selects a surrogate to make a specific decision if a doctor finds the patient to be incapacitated;
- (7) Guardian - court appoints a guardian to make decisions if the court finds the patient to be incapacitated.

All but option 6 is allowed under current law in Missouri. Option 5 can be achieved in Missouri when a patient executes an abbreviated medical power of attorney document in which an agent is designated to make decisions when the patient is incapacitated and the agent is not given specific instructions.. It would be better is the Legislature specifically authorized a simplified form to designate a medical surrogate decision-maker. Option 6 is available in other states through legislation.

Missouri would benefit from legislation clarifying that patients with limited capacity can select a surrogate to make medical decisions for them. It would also benefit from a law allowing doctors to select a surrogate to make such decisions for an incapacitated adult when there is no patient-designated agent.



Recommendation 9 – Explore Options 5 and 6. The Hospital Association and Medical Association should collaborate with the Alternatives to Guardianship Project and other stakeholders in Missouri to explore ways to implement and enhance medical decision-making options for patients with mental or developmental disabilities without the need to initiate adult guardianship proceedings.

Legal Considerations

Judges and Attorneys

Findings. Missouri law was amended in 2018 to require less restrictive alternatives, such as powers of attorney and supported decision-making, to be considered and ruled out before a guardianship is instituted. Despite this new law, the number of guardianships has remained relatively constant.

Judges decide whether to order a guardianship. They rely on court-appointed attorneys to advocate for less restrictive alternatives if they are feasible. Unfortunately, neither the judges or the attorneys are required to receive training on the rights of people with disabilities or less restrictive alternatives.

There are no performance standards for court-appointed attorneys. The lack of accountability, low rate of pay, and inadequate resources for these attorneys, results in very few cases being dismissed in favor of less restrictive alternatives.

The lack of training and performance standards has an adverse effect on the medical rights of adults with developmental disabilities. A guardianship generally gives another person the power to make such decisions.



Recommendation 10a – Require Training. The Supreme Court should adopt rules requiring court-appointed attorneys in guardianship cases to be trained in topics essential to effective advocacy for people with disabilities.

Recommendation 10b – Adopt Standards. The Supreme Court has adopted performance standards for guardians ad litem in juvenile and family law cases. It should adopt standards for court-appointed attorneys in guardianship cases.

Recommendation 10c – Increase Compensation. Judges who appoint attorneys to represent adults in guardianship cases should order the funding source (counties for indigents or the estate of the client for nonindigents) to pay reasonable attorney fees and ancillary costs, including for experts who can help identify and develop less restrictive alternatives.

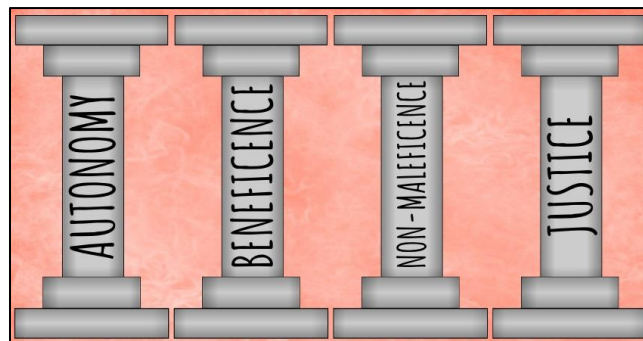
Ethical Principles

Autonomy and Consent

Findings. Informed consent to medical treatment is fundamental in both ethics and law. Patients have the right to receive information about treatments so that they can make well-considered decisions about care. Successful communication in the patient-physician relationship fosters trust and supports shared decision making. (American Medical Association Code of Ethics)

There are five fundamental principles of ethics. Autonomy: Allow adult patients to make their own choices, either independently, with help from chosen support person(s), or by a chosen agent in a power of attorney. Justice: Treat all patients fairly and with equality. Avoid discrimination. Provide reasonable accommodations for decision-making. Beneficence: Do good to patients and for society. Learn how to better provide medical services to patients with developmental disabilities. Self educate. Non-maleficence: Protect patients from harm. Take appropriate action if there are signs of abuse or undue influence. (American Dental Association Code of Ethics)

A pharmacist respects the autonomy and dignity of each patient. A pharmacist promotes the right of self-determination and recognizes individual self-worth by encouraging patients to participate in decisions about their health. A pharmacist communicates with patients in terms that are understandable. A pharmacist avoids discriminatory practices that impair professional judgment. (American Pharmaceutical Association Code of Ethics)



Recommendation 11 – Honor Patient Autonomy. Curricula for students being trained to be health care professionals should emphasize the ethical duties of providers to respect the right of adult patients to medical self-determination to avoid disability discrimination. Continuing education programs for health care professionals should do the same.

Continuing Education

For Providers

Findings. The lack of comprehensive disability clinical-care education and disability competency training among medical, nursing and other healthcare professionals perpetuates discrimination in healthcare against people with disabilities. (2020 Report, National Council on Disability)

An abundance of research indicates the lack of disability competency and interdisciplinary training among medical professionals contributes to health inequities for people with disabilities across the nation. (2020 Report, National Council on Disability)

Medical literature, government agency reports, and court decisions demonstrate that individuals with disabilities face discrimination at every stage of the medical treatment process. (HHS Section 504 Rule)

Biases and stereotypes about the impact of disability affect decisions in different contexts, including diagnoses, day-to-day treatment decisions, emergency care decisions, and the allocation of scarce medical resources in health crises. (HHS Section 504 Rule)



Recommendation 12 – Educate Professionals. The Missouri Hospital Association, Missouri State Medical Association, Missouri Dental Association, Missouri Nurses Association, Community Health Workers Association, Missouri Coalition for Oral Health, Missouri Primary Care Association, and the Missouri Chapter of the National Association of Social Workers should alert their members to educational materials produced by the Missouri Medical Rights Workgroup. A **booklet** titled “Health Care and Developmental Disabilities: A Message to Providers” and a **brochure** titled “Tips for Providers” can help health care professionals understand the rights of patients with developmental disabilities and their duties to this patient population.

Continuing Education

For and By State Agencies

Findings. State agencies in Missouri have an important role to play in protecting the medical decision-making rights of patients with developmental disabilities. They can provide leadership by educating their staff on the rights of patients and the duties of health care providers. They can also share educational materials about these issues on their websites.



Recommendation 13a– 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. 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.

Recommendation 13b– The **Department of Mental Health (DMH)**, Division of Developmental Disabilities (DDD) should share this report with appropriate staff in DMH so they are familiar with the issues discussed in the report. DDD should develop 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 disabilities to accommodations under the ADA; the right to name a proxy decision-maker; and the use of medical supported decision-making agreements.

Recommendation 13c– 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.



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. Their inclusion here does not imply an endorsement by the workgroup.

<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 included.

<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

----- Coordinators -----

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



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