



Hulme Resources Inc.

Providing services and supports for individuals with developmental disabilities

Jennifer Hulme, Founder and Executive Director

<https://hulmeresources.com> • jennifer@gohulme.com • 816-730-2831

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Health Care Providers Should Do More to Protect the Rights of Patients with Developmental Disabilities

Medical Rights Should be Included in Transition Planning for Teenagers

A report developed in consultation with self-advocates, families, health care providers, disability rights advocates, educators, and government agencies, made several recommendations to protect the decision-making rights of patients with developmental disabilities. Too often, young adults with disabilities are being placed into guardianships when less restrictive alternatives, such as powers of attorney and supported decision-making arrangements, would adequately address their needs.

The report is the product of a study conducted by the Missouri Medical Rights Workgroup – a collaboration of a wide range of health care stakeholders that was partially funded with a federal grant administered by the Missouri Developmental Disabilities Council. The project was convened by Spectrum Institute, the American Academy of Developmental Medicine and Dentistry (AADMD), and Hulme Resources Inc.

“When considering national trends, Missouri places a much higher percent of adults with developmental disabilities into guardianship than most other states,” according to Thomas F. Coleman, a legal expert on medical rights and alternatives to guardianship. “Transition planning by schools and county service coordinators for teenage students with developmental disabilities generally ignores the issue of medical rights,” observed Jennifer Hulme, the director of a nonprofit in Missouri providing services and supports for children and adults with such disabilities. “Better education of health care providers is essential to disrupt the ‘hospital to guardianship pipeline’ that all too often recommends guardianship for young adults when other options would suffice,” remarked Dr. Emily Johnson, the policy and advocacy director of AADMD.

The report recommends that professional and trade associations for doctors, dentists, nurses, hospitals, and social workers should provide better educational opportunities for their members on the medical rights of patients with developmental disabilities. It also encourages universities and colleges that train such professionals to expand curricula and clinical programs to better address the needs of this patient population.

The report is being sent to the Governor, the Health and Welfare Committee of the Senate, and the Health and the Mental Health Policy Committee of the House of Representatives. With legislative approval, the state could become a funding partner with counties so that public administrators could take an active role in helping clients terminate guardianships that are unnecessary. The Legislature also could authorize funding for the Department of Mental Health to develop educational materials and programs on alternatives to guardianship, a simplified medical power of attorney form for use by adults with developmental disabilities, and a standard supported decision-making agreement.

The report is available online at <https://spectruminstitute.org/medical-rights.pdf>

“ Comments from Workgroup Participants ”

Mr. Coleman,

Thank you for sharing the final report. The report is excellent!

Many thanks to you and the workgroup participants.

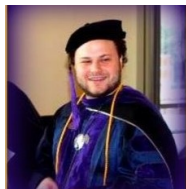
With gratitude,



Dwight E. McLeod, D.D.S., M.S.
Professor of Periodontics and Dean
Missouri School of Dentistry and Oral Health – A. T. Still University

This project has been an excellent review of the medical rights of people in Missouri, and I am proud of the report that the group produced!

I hope that it will spark an ongoing conversation and let more people know how they can exercise their right to make medical decisions.



Will Hack
Disability Rights Attorney

The Missouri Medical Rights Workgroup was an exceptional consortium dedicated to advancing the rights and support mechanisms for individuals with cognitive disabilities. This group comprised professionals, advocates, and stakeholders with a deep commitment to ensuring that medical care for individuals with cognitive impairments is both accessible and minimally restrictive. Their dedication to this cause was evident through their collaborative efforts and shared goal of enhancing the quality of life for this vulnerable population. Personally, the workgroup's mission resonated deeply with me, given my familial connections to individuals with disabilities, which added a layer of personal significance to my involvement.

Throughout the process, the workgroup demonstrated a remarkable breadth of experience and expertise, creating an environment where every participant's voice was valued and considered. The collaborative nature of the discussions facilitated a comprehensive and inclusive approach to addressing the medical rights of people with cognitive disabilities. The collective effort resulted in a robust set of recommendations and strategies aimed at improving medical care and support structures. This process not only highlighted the group's commitment to their cause but also underscored the effectiveness of a well-coordinated, multi-disciplinary approach in producing meaningful outcomes for those in need.



Wendy Jackson, MSW, LCSW
Clinical Assistant Professor
Social Work Program
Missouri State University

I am deeply thankful for the chance to be a participant in the Missouri Medical Rights Workgroup. Being involved in a mission dedicated to identifying obstacles and developing strategies that enable individuals with developmental disabilities to secure medical rights without relying on guardianship has been immensely fulfilling. This effort is crucial for fostering independence and ensuring all individuals have equitable access to necessary healthcare.

As registered nurse and secondary health science educator, it is important to me that all patients and students be free from any form of disability discrimination. Thus, I recommend other healthcare professionals, health associations and academic institutions review the findings and recommendations outlined in the Missouri Medical Rights Workgroup report, to determine where they can improve on protecting the medical rights of one of our most vulnerable populations.

I appreciate the opportunity to contribute to such impactful work!



Felicia Hampton, BSN, RN
Missouri Nurses Association
Vice President of Advocacy

The Missouri Association of Public Administrators (MAPA) appreciates the collaborative nature of this project and the dedication of workgroup participants. We recognize the complex nature of medical decision-making for individuals with or without a guardian. As the guardians of last resort, Public Administrators do our best to provide informed decision-making in less-than-ideal circumstances. Where possible, we employ informal supported decision-making processes within the structure of guardianship. We also utilize substituted judgment in our decisions, striving to make choices that the person would make if they did not require a court-appointed guardian. We view restoration of guardianship as an ongoing conversation within each guardianship relationship.

Public Administrators do not have access to any additional resources than individuals who do not have a guardian. We are adept at linking individuals to services that enhance independence while maintaining safety. Yet in the most serious cases, which are typically individuals with a dual-diagnosis of serious mental illness and developmental disability, our state resources are sorely inadequate, as identified by the recent Department of Justice [report](#). For individuals with serious mental illness, there is a complete lack of community resources available in our state for individuals who require a high level of supervision and care. We urge our state and federal officials to provide more solutions for guardians to assure care for those individuals we are assigned by the courts to help.



Danielle L. Boggs, LCSW, NMG
Webster County Public Administrator
MAPA Past President

The Adair County SB40 Developmental Disability Board has been honored to participate in the Missouri Medical Rights Workgroup. We deeply appreciate the opportunity to contribute to this important initiative. Ensuring that individuals with developmental disabilities, their families, and healthcare professionals are informed and empowered about medical rights is vital. Education and awareness in this area are key to fostering a healthcare environment that respects and protects the dignity, autonomy, and well-being of individuals with developmental disabilities. We look forward to working alongside other advocates to ensure equitable healthcare for all.



Crystal Aminirad
Executive Director
Adair County SB40 Board

We at Neighborhood LTC Pharmacy believe it is essential to continue promoting IDD-focused education for healthcare providers to empower patients with intellectual and developmental disabilities (IDD) to make their own medical decisions. Healthcare providers should be trained to presume capacity in patients with IDD, avoiding assumptions about their abilities. By fostering an expectation of decision-making capacity, providers can better support autonomy and independence. Supported decision-making (SDM) models offer a valuable alternative to guardianship, allowing patients to retain control over their choices with appropriate assistance. Training healthcare professionals on SDM, along with alternatives to guardianship, helps promote dignity and respect for individuals with IDD. This training should also include strategies for clear communication and collaborative care that actively involves the patient, ensuring they are informed and empowered. Ultimately, respecting the autonomy of individuals with IDD and providing ongoing education for healthcare providers helps dismantle barriers to self-advocacy and improves the overall quality of care.



Stacy Wilson
Director of Business Development
Neighborhood LTC Pharmacy

The Arc of the Ozarks has been dedicated to serving individuals with IDD since 1964. The Arc has been enhancing the lives of people with intellectual and developmental disabilities who live, work, play and learn in our community. We believe in listening to each individual to find the best solutions that will meet their needs. Today, we offer a variety of services for individuals and families in the communities we serve. Our Mission aligns with the Missouri Medical Rights Workgroup by supporting individuals with disabilities in directing their own lives as valued members of the community.



Dr. Kayette Glass
Licensed Clinical Psychologist
Health Service Provider
The Arc of the Ozarks
