



Hulme Resources Inc.

Providing services and supports for individuals with developmental disabilities

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Representative Mike Stephens
Chair, Health and Mental Health Policy Committee
Missouri House of Representatives

Re: Medical Rights of Patients with Developmental Disabilities

Dear Representative Stephens:

Because the Health and Mental Health Policy Committee focuses on health care as well as developmental disabilities, we felt that you and other members of the committee would be interested in a report that was just released. *Protecting Medical Rights of Patients with Developmental Disabilities: We Can Do Better* is found online at <https://spectruminstitute.org/medical-rights.pdf>

The report identifies medical decision-making rights of this patient population under existing law and recommends actions that can be taken by health care providers and medical educators to better protect these rights. Although it does not specifically call for changes to substantive law in Missouri, the Legislature could allocate funds in the next budget that would help reduce unnecessary guardianships and promote less restrictive alternatives. Such funding would implement a policy decision made by the Legislature in 2018 when it enacted a law calling for the use of alternatives to guardianship, such as supported decision-making, when feasible.

For example, the Missouri Medical Rights Workgroup found that county-funded public administrators lack the resources to be proactive in assisting clients to terminate guardianships when they are no longer necessary or to modify guardianships to restore medical rights when a power of attorney or medical supported decision-making would be sufficient protection. The state could augment this funding, perhaps starting with a pilot project in one of the larger counties, specifically designating the funds for this purpose.

The workgroup also found that many families of youth with developmental disabilities are not being educated about alternatives to guardianship. It also found that the language in the existing power of attorney form developed by the Attorney General is too complicated for many adults with developmental disabilities to understand. Missouri needs a modified form for this patient population that would comply with “effective communication” mandates of the Americans with Disabilities Act. Missouri also needs a standard supported decision-making form that individuals with disabilities and their families could use for medical, financial, and other decisions. The Legislature could provide funding to the Department of Mental Health to develop such forms and educational materials.

We would like to educate the committee on options to better protect the medical rights of this patient population. We will call your office soon to request a meeting with you or committee staff.

Best regards,

Jennifer Hulme

cc: Committee Members

Announcement attached