



Alternatives to Guardianship Project

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Caryl Goodyear, Ph.D. RN
President
Missouri Nurses Association

Sent via email:
info@missourinurses.org

Re: Medical Decision-Making Options for Adults with Developmental Disabilities

Dear Dr. Goodyear:

I am writing on behalf of Alternatives to Guardianship, a project funded by the Department of Mental Health on behalf of the Missouri Developmental Disabilities Council. Information about our mission and activities is found at: <http://alternativestoguardianship.com/>

The purpose of this letter is to invite the Missouri Nurses Association to explore with us and other disability rights organizations medical decision-making options for adults with developmental disabilities. Such an exploration would benefit physicians, nurses, and other medical professionals as much as it would help patients with developmental disabilities and their families.

A review of [data](#) gathered by Spectrum Institute from the UMKC and the United States Census Bureau suggests that 73,000 or more adults in Missouri have developmental disabilities. Fewer than half of them are living under an order of guardianship. It would therefore appear that most adults with developmental disabilities currently are making their own medical decisions.

Many petitions for guardianship are filed based on concerns expressed by medical professionals that an adult patient with developmental disabilities may lack capacity to give informed consent to medical procedures. In the past, such guardianship petitions were often granted without a serious exploration of less restrictive alternatives such as supported decision-making.

Several years ago, the Missouri Legislature passed legislation ([RSMo Section 475.075\(13\)](#)) to require Missouri courts to consider and rule out less restrictive alternatives. This would include an exploration of medical decision-making alternatives such as a power of attorney for health care, a healthcare proxy, and a supported decision-making arrangement. This Project has been [reaching out](#) to public officials and nonprofit organizations in Missouri to encourage consideration of alternatives to guardianship for this special needs population.

I would appreciate learning the names and contact information of nurses in your organization with whom we could initiate a conversation on this important topic.

Best regards,

Jennifer Hulme
Project Director

cc: Heidi Lucas
Executive Director