

Missouri Medical Rights Workgroup

Dear Colleagues:

Thank you for agreeing to participate in the Missouri Medical Rights Workgroup. (See the attached workgroup factsheet.)

The workgroup has been convened by the American Academy of Developmental Medicine and Dentistry (AADMD), the Alternatives to Guardianship Project, and Spectrum Institute. The purpose is to have conversations among stakeholders on how to protect the medical rights of adult patients with developmental disabilities while at the same time respecting the legal and ethical duties of health care providers. Conversations will also address how to prepare youth with developmental disabilities as they transition to adulthood at which time they will have the authority to make medical decisions with the level of support they choose.

We have assembled a diverse array of stakeholders who can offer a variety of perspectives to the issues we discuss: self-advocates, parents, health care providers, disability rights advocates, university professors, and government regulators. (See the attached list of participants.)

The workgroup will explore various options for medical decision-making and information sharing. It will also examine how schools of dentistry, medicine, social work, nursing, and psychology, currently educate students about health care services for patients with developmental disabilities. Continuing education programs for health care professionals also will be evaluated to determine if they are adequately addressing the needs of patients with developmental disabilities and the providers who serve this patient population.

The workgroup will hold a zoom meeting once a month for six months. The first meeting will occur during the week of January 22. Please click on [this link](#) to indicate the days of that week when you would be available to meet. Meetings will occur from noon to 1:30 p.m. (Central Time)

A few weeks prior to the first meeting, we will be sending out a pdf of some reading material: a [memo](#) titled “The Basics of Medical Decision-Making: Demographics, Ethics, Law, Process” and an [article](#) recently published in *Helen* magazine titled “Medical Decision-Making Rights: What You Should Know.” If you want to get started with the reading sooner, click on the links in this email for an online version of the [memo](#) and the [article](#).

We would like to hear your thoughts on each of these documents. Are there any areas of disagreement? Do you have questions about anything in these documents? If so, please send Tom Coleman an email identifying those issues or questions. Please specify the page and paragraph of the document for which you have concerns or questions. Your written comments should be received by him no later than one week prior to the meeting. Receiving your views in advance will

help inform the agenda for our first meeting.

Once the meeting starts, we will jump right into a discussion of the issues raised in these documents. Since time is tight, we will bypass an introduction of members. To learn about your colleagues on the workgroup, you can click on the link from their name on [the roster](#) which will take you to biographical information online about them.

Each zoom meeting will be recorded for the benefit of anyone who could not attend or who had to leave a meeting early. Absent workgroup members are encouraged to view the zoom video later and submit comments to the coordinators.

Together we will be doing groundbreaking work. We are not aware of any project such as this having occurred before anywhere in the nation. The results of our conversations and our areas of agreement will be contained in a report which will be shared widely, both in Missouri and elsewhere.

Welcome to the Missouri Medical Rights Workgroup. We look forward to collaborating with you in the coming months.

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