



Alternatives to Guardianship Project

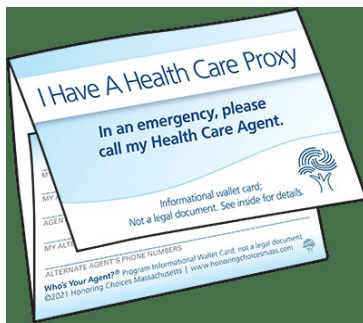
Hulme Resources Inc.

903A SE 7th Street • Lee's Summit, MO 64063

alternativestoguardianship.com • (816) 730-2831

Jennifer Hulme, Director • jennifer@gohulme.com

Proposal: Health Care Proxies for Adults with Developmental Disabilities



Capacity to make medical decisions requires the ability of a person to give informed consent to various medical procedures. Depending on the complexity of the medical procedure, and the risks involved, such capacity may require a degree of understanding and rational thought processes that an adult with a mental or developmental disability may not possess. However, the individual may have sufficient capacity to know who they want making such decisions for them.

There is a difference between capacity to give informed consent to medical procedures and capacity to name a health care proxy (HCP) to make such decisions on one's behalf. Just because capacity for the former is lacking does not mean that capacity for the latter is absent.

Evaluation of capacity to appoint a health care proxy (HCP) was explored in some detail in a manuscript published in the American Journal of Geriatric Psychiatry in 2013.¹ According to the article, "Most statutes do not provide clear legal guidance on capacity to appoint an HCP, but those that do, distinguish this capacity from medical decision-making consent capacity." Missouri law does not give clear guidance.

Having consulted legal definitions in Utah and Vermont, which have specifically addressed this issue, the article explains:


"The evaluation of capacity to execute an HCP may consist of 1) capacity to understand the meaning (a) to give authority to another to make healthcare decisions, (b) through the HCP, (c) in the event of future or considering current diminished capacity to consent to treatment and 2) capacity to (a) determine and (b) express a consistent choice (c) of an appropriate surrogate. An appropriate surrogate may be defined as someone with whom the principal has a social (not professional) relationship, who knows the person's values, and who is willing (expresses interest and concern). This approach, we believe, provides a sufficiently high standard to avoid error and allows for completion

of an HCP for the provision of care but a low enough standard to avoid burdensome challenges of proof and legitimacy. Furthermore, in situations where the identified individual to serve as healthcare agent has a history of inability to fulfill his or her responsibility. . . it should alert clinicians to ask additional questions and engage in a discussion with the patient about their understanding of the individual whom they have chosen. Situations in which there appears to be fluctuation in choice depending on external influences should also alert the clinician to engage in further investigation. For example, a situation in which an individual appears to change his or her choice of agent in proximity to interactions or visits with potential agents might raise concern about coercion, pressure, or lack of voluntariness.”

The Vermont statute says: “An individual shall be deemed to have capacity to appoint an agent if the individual has a basic understanding of what it means to have another individual make healthcare decisions for oneself and of who would be an appropriate individual to make those decisions, and can identify whom the individual wants to make health care decisions for the individual.” (Title18, Ch. 231, Sec. 9701(2)(A).)

In Utah, specific guidance is given to capacity assessment professionals and courts on this issue. Probate Code Section 75-2a-105 (Capacity to complete an advance health care directive) states: (1) An adult is presumed to have the capacity to complete an advance health care directive. (2) An adult who is found to lack health care decision making capacity under the provisions of Section 75-2a-104: (a) lacks the capacity to give an advance healthcare directive, including Part II of the form created in Section 75-2a-117, or any other substantially similar form expressing a health care preference; and (b) may retain the capacity to appoint an agent and complete Part I of the form created in Section 75-2a-117. (3) The following factors shall be considered by a healthcare provider, attorney, or court when determining whether an adult described in Subsection (2)(b) has retained the capacity to appoint an agent: (a) whether the adult has expressed over time an intent to appoint the same person as agent; (b) whether the choice of agent is consistent with past relationships and patterns of behavior between the adult and the prospective agent, or, if inconsistent, whether there is a reasonable justification for the change; and (c) whether the adult's expression of the intent to appoint the agent occurs at times when, or in settings where, the adult has the greatest ability to make and communicate decisions.

The New York Center for Elder Law and Justice commented on the issue of whether someone who lacks capacity to make health care decisions nonetheless may have capacity to name a health care proxy: “Every NYS adult is presumed competent to appoint a health care agent unless determined otherwise pursuant to a court order. As such, an individual with dementia may not have the capacity to make health care decisions, but may still have competency to make a decision to appoint a family member to make health care decisions. All that is needed is a ‘moment of clarity’.”

 **It is recommended** that the Missouri Legislature pass a law, using elements from those in Utah and Vermont, recognizing a lower threshold of capacity 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 he or she 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.

Some adults may have capacity to make their own medical decisions, even complex ones, pursuant to a supported decision-making (SDM) arrangement. But those who can't make their own medical decisions, even with SDM assistance, should have the option of designating a medical decision-maker through a health care proxy.

We would like to hear your views on this proposal. We especially welcome comments from health care professionals, capacity assessment professionals, disability rights and disability service organizations, parents and families, and people with developmental disabilities.

Contact: Jennifer Hulme / jennifer@gohulme.com

Reference:

1. Moye, Sabatino, and Brendel, "Evaluation of the Capacity to Appoint a Healthcare Proxy," 21 *Am J. Geriatr Psychiatry* 326 (2013)
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4859336/>