

Framework for Model Legislation on Medical Supported Decision Making Agreements

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A statewide disability services organization may soon sponsor a bill in the California Legislature which, if adopted, would authorize medical service providers to recognize supported decision making or “SDM” agreements executed by patients who have disabilities. Such agreements would assist such patients to make their own medical decisions with the assistance of a support person designated by the patient in the SDM agreement. A medical SDM agreement is intended to be used, if possible, instead of a guardianship or a durable power of attorney for health care.

Prior to drafting legislation, proponents of such a bill should be clear about the purpose for the new law and have a basic framework in mind as to how it would operate in a medical context. Such a framework will inform the rest of the process of writing a bill and gaining support for it.

The Disability and Abuse Project offers the following suggestions as a “Framework for Model Legislation on Medical Supported Decision Making Agreements.”

1. The underlying purpose of such a bill is to provide a legal mechanism that would enable adults with disabilities to be at the center of medical decision making that affects their lives.
2. Another purpose is to establish legal requirements to inform participants in such medical decision making about their duties. This includes the person selected by the adult to provide support, as well as the professionals and staff who are involved in providing medical services to the adult.
3. Various legal principles should guide the drafting of legislation for medical SDM agreements:
 - a. A medical SDM agreement is a contract between the adult and the person chosen by the adult to provide support for medical decision making.
 - b. In such an agency agreement, the adult is the principal and the supporter is an agent who assists the adult to navigate through the medical decision making process.
 - c. The agent assumes a fiduciary relationship with the adult and therefore has legal responsibilities as a fiduciary. Laws governing fiduciaries apply to this relationship.
 - d. The agent is not a substitute decision maker but rather is assuming the role of a facilitator to help the adult make his or her own decisions. The agent helps the adult to communicate with the medical provider and helps the medical provider to communicate with the adult.
 - e. Since this is a legal contract, the adult (principal) must have the capacity to enter into such an agreement at the time it is signed, and must have a basic understanding of the nature and consequences of such an agreement. The adult must in fact consent to the terms of the agreement at the time it is entered into.

f. When such an agreement is signed, there is a presumption of capacity to contract, but evidence may be produced at a later time showing that such capacity did not in fact exist at that time or that the adult did not in fact consent to the terms of the agreement when it was entered into.

g. Medical providers must allow the supporter to have access to medical information and records and must allow the supporter to assist the adult in making medical decisions.

h. Medical providers must not treat the supporter as a substitute decision maker, but instead as someone who is assisting the adult in making his or her own decisions.

i. When a medical decision is made, a medical provider has a legal and ethical duty to make sure that the adult has the ability to and is giving informed consent to the procedure. If there is a question about the ability of the adult to give informed consent, there must be further inquiry by the medical provider. If, after further inquiry, the provider is not satisfied that the adult is giving informed consent, then medical services may not be provided, absent an emergency situation, unless there is informed consent from another adult who has legal authority to make medical decisions on behalf of the adult, such as a guardian or an agent under a durable power of attorney for health care.

j. If, at any time, a medical provider has a reasonable doubt about whether the adult had the capacity to enter into the SDM medical agreement at the time it was signed, the provider shall inquire further. If further inquiry causes the provider to believe that such capacity was lacking, the provider may not provide services pursuant to that agreement.

k. Prior to performing medical services, a provider should ask the adult if he or she signed the SDM medical agreement and if it still represents the wishes of the adult or if it has been revoked. If the provider has a reasonable doubt about whether the adult has revoked or wants to revoke the agreement, there should be further inquiry. If further inquiry causes the provider to believe the adult has revoked or wants to revoke the agreement, the provider should not rely on that agreement for any purpose.

l. If, at any time, a medical provider has reasonable suspicion that the adult was under undue influence from another person at the time the agreement was executed or may be under undue influence at the time the decision is being made for a medical procedure, the provider shall inquire further. If further inquiry causes the provider to believe that undue influence has occurred or is occurring, the provider may not provide services pursuant to that agreement.

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