

# A Review of “Model Legislation” for Supported Medical Decision-Making Agreements: The Defects are in the Details

by Thomas F. Coleman

An email was distributed recently by the Autistic Self Advocacy Network (ASAN) announcing a “Webinar on Model Legislation for Supported Decision Making” in healthcare contexts.

According to the email, the model legislation, which ASAN developed in collaboration with the Quality Trust for Individuals with Disabilities, “would enable people with intellectual or developmental disabilities to name a trusted person to help communicate with doctors, understand health care information, make informed decisions about health care, and/or carry out daily health-related activities.”

The email contrasts this medical decision-making model with guardianship, stating that supported decision-making arrangements let people with disabilities keep the ability to make their own decisions. Advocates are encouraged to use the model legislation when talking to their state legislators about ways to help people make independent health care decisions.

Dr. Nora Baladerian, Executive Director of the Disability and Abuse Project, asked me to review the proposed law. Is it something that state legislatures should enact? Does it advance the rights of people with intellectual and developmental disabilities?

The legislation is titled: [“An Act Relating to the Recognition of a Supported Health Care Decision-Making Agreement for Adults with Disabilities.”](#) The term “disability” means “a physical or mental impairment that substantially limits one or more major life activities of such individual.”

The stated purpose of the Act is “to create an alternative to guardianship, maximize autonomy, and improve healthcare outcomes for persons with disabilities by permitting adults with disabilities to

name supporters to help them understand health-related information and options so they can make their own health care decisions.”

The section defining the scope of the Act specifies that in a supported decision-making agreement an adult with a disability may authorize a named supporter to (1) access medical documents and information from medical providers; (2) assist the adult with a disability to understand that information; (3) assist the adult to understand the options, responsibilities and consequences of the health care decision(s) to be made so the adult can make his or her own decisions; and (4) to communicate or assist the adult in communicating his or her decisions to other persons, including medical personnel.”

The title, purpose, and section defining the scope of the Act are rather innocuous. HIPAA (Health Insurance Portability and Accountability Act) already allows a person with a disability to designate someone to access his or her medical records and information. People, with or without a disability, may have someone assist them in understanding medical options and help them communicate their decisions to medical personnel. These parts of the proposed bill are merely restatements of existing law.

The next section of the proposal contains a form clarifying that a supported medical decision-making agreement is not a medical power of attorney. The adult with a disability is not authorizing the support person to make medical decisions on his or her behalf. Again, this section is innocuous. It merely clarifies what the agreement is not.

Another section specifies that the designated support person is entitled to have access to medical records and information under HIPAA. Again, this is merely a restatement of existing law.

The offensive and troubling provisions of the proposed legislation are found in Section 8 which deals with “Immunity from Suit for Health Care Providers Who Act Consistently with a Supported Health Care Decision-Making Agreement.” These provisions take away existing rights of people with disabilities.

One clause declares that health care providers are immune from any action alleging that the agreement was invalid, unless the provider has actual knowledge of its invalidity. Actual knowledge of invalidity would be almost impossible to prove unless the provider was present at the time it was executed (which is highly unlikely).

The requirement of “actual knowledge” of invalidity gives an incentive to health care providers not to inquire into the circumstances involved in the execution of such an agreement. The law effectively tells providers that “what you don’t know won’t hurt you.” Under this clause, providers are better off if they don’t ask questions, especially when circumstances may arouse suspicion of undue influence.

Another extremely bothersome provision states that a supported health care decision-making agreement is effective even if the individual who executed it has been or would be found by a court to lack the capacity to independently execute a contract. Normal principles of contract law are to be disregarded, even though a supported health care decision-making agreement is a contract.

Make no mistake about it, this is a contract. The adult designates a support person and gives that person a degree of authority and complete access to medical records and information. The designated person agrees to assume responsibility for providing assistance to the adult with a disability. This is a contract. And yet, this legislation declares that the contract is valid even if a court determines that the adult in question lacked the capacity to contract.

The most dangerous provision in this legislation specifies that the provider, with very few exceptions, is immune from any action alleging that the person with a disability lacked capacity to provide informed

consent. Although the provider must obtain the “consent” of the person with a disability prior to engaging in medical procedures, the consent need not be “informed” consent.

Informed consent is an existing legal right of every patient and the failure to obtain informed consent subjects medical personnel and health providers to liability. Beyond the issue of legal rights and responsibilities, informed consent is also a matter of medical ethics. The failure to obtain informed consent prior to engaging in medical procedures could result in professional discipline or the loss of a license to a credentialed person or agency.

While the idea of supported health care decision-making has an attractive lure, it is imperative to go beneath the veneer to explore the details. What the proponents call “model legislation” is more of a model for removing liability of health care providers than it is for protecting the rights of people with disabilities – especially those with intellectual and developmental disabilities – in health care situations.

This legislation creates a new type of contract, but it specifies that the person with a disability need not have the capacity to enter into a contract. The agreement contemplated by the legislation could be used in situations involving life and death medical decisions, and yet the health care provider would be *immune* from liability for engaging in such procedures *without* the patient’s *informed* consent.

Dr. Baladerian, especially considering the provisions on immunity from liability, I regret to advise you that this proposal does not advance the rights of people with intellectual and developmental disabilities. Unfortunately, I have concluded that state legislatures should not use this proposal as a model.

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