

# Intellectual Disability and Medical Decision Making Bills: New Legislation May Not Avoid the Need for Guardianships

by Thomas F. Coleman, J.D.

I was contacted recently by the director of a disability services organization in California to discuss a possible bill on medical supported decision making for adults with intellectual and developmental disabilities.

The director had read [commentaries](#) I have written raising several concerns about “model legislation” that has been promoted on this topic. I perked up because, if the California Legislature were to enact such a bill, it would be the first legislature in the nation to do so.

I explained that the model bill was missing several important provisions to protect people who would sign such a medical supported decision making agreement from abuse, exploitation, or undue influence. He asked how the model could be improved. I responded by drafting a “[Framework for Model Legislation on Medical Supported Decision Making Agreements](#).”

The idea behind the model legislation is to allow an adult with a disability to enter into a written agreement with someone whom they trust to assist them in making medical decisions. The supporter does not make the decisions. The adult with a disability does.

Under the agreement, medical providers must give the supporter access to medical records, allow the supporter to be present during doctor-patient discussions, and respect the right of the patient to be assisted by the supporter in understanding the medical information and in making decisions. The doctor must speak with the supporter as well as the patient.

After reviewing what was missing from the model legislation, I drafted the framework to identify various components that would need to be added to any such legislation. Any model bill would need to explain that: (1) this is a legal contract; (2) the adult must have capacity to understand its terms and to enter into such a contract; (3) the contract creates a fiduciary relationship between the supporter and the adult; (4) the supporter is not the one making the medical decisions but the adult is; (5) for each procedure, the medical provider must assess whether the adult has the capacity to give informed consent; and (6) the provider must inquire further if he or she has a reasonable belief that undue influence was used at the time the contract was signed or is being used at the time informed consent is being obtained.

I was contacted a few days later by an attorney who had participated with a team of lawyers in drafting the model legislation on medical supported decision making agreements. He was open to suggestions on how to improve the bill.

We discussed the items I had listed in the framework. He promised to share my concerns with his legal team and would get back to me with a revised model bill. I recently received the amended bill. To my delight, all of the concerns are addressed in the revised legislation.

Any legislature that adopts the new model bill would be creating a state-law version of the reasonable accommodations requirements of the Americans with Disabilities Act. Federal law requires medical providers to allow patients to have the support they need in order to receive medical services equal to patients without disabilities.

That means if they need a support person of their choice to have access to records, to assist them in understanding options, and to help them communicate with their medical providers, then they have a right to such support services. Enactment of this improved model bill by a state legislature would create a state-mandated ADA medical accommodation law. That would be helpful.

However, the enactment of such a new law may not dispense with the need for guardianship. Many people with disabilities will not have the capacity to give informed medical consent or have capacity to enter into this contract. Doctors will continue to assess such capacities on a case-by-case basis and make situation-specific determinations of capacity.

If a doctor doubts that such capacity existed when the document was signed, or whether it exists when the medical procedure is contemplated, he or she may require someone to be appointed as a guardian. A model bill will not end the need for some guardianships.

Two weeks ago, Dr. Nora Baladerian and I were contacted by Mark Olson, a member of the Disability and Abuse Project’s listserv. He has been following Dr. Baladerian’s work with abuse issues and my work with guardianship issues.

Mark, the parent of an adult daughter with an intellectual disability, is also a disability rights advocate. Mark was

concerned about a new bill introduced in the Nevada Legislature. He asked us to review it.

AB 128 would create a more simplified medical power of attorney form. It could only be used by adults with intellectual disabilities – people with an IQ of 70 or less. The bill had the support of disability rights and disability services agencies. There was no opposition.

I did a legal analysis and Dr. Baladerian did a clinical analysis of the bill. When Mark read our reviews, he decided to oppose the bill. When the bill was heard in the Assembly Judiciary Committee on February 23, 2015, everyone but Mark testified in support of AB 128.

I listened to the oral testimony and Dr. Baladerian read the corresponding written testimony. We were amazed that critical issues were overlooked. We were more amazed that misinformation was presented.

Legislators were told that AB 128 was a type of supported medical decision making. It isn't. By signing the new form, an adult is authorizing an agent to make medical decisions on his or her behalf. Therefore, AB 128 is just another type of substituted decision making. The agent makes the decisions, not the adult in question.

Parents who testified said that AB 128 empowers their adult children to be independent and to make their own choices. This is not so. By signing the new form, they surrender the right to make their own medical decisions.

When questioned about legal issues of capacity, witnesses at the hearing either gave vague responses or deflected the conversation to another issue. Legislators received no hard answers about capacity at the hearing.

What they did hear, however, is that the primary purpose of AB 128 is to allow parents to avoid the need for a guardianship – even a limited guardianship for medical purposes only. Such a limited guardianship is not a complicated procedure in Nevada. Parents do not need an attorney. A guardianship can be limited to medical decisions only, leaving all other rights intact.

Mark testified against the bill. He referred legislators to my legal analysis and to Dr. Baladerian's clinical analysis for the basis of his opposition.

After the hearing, we responded to the testimony of the proponents – correcting the misstatements that were made and filling in the gaps on the topic of capacity.

We also submitted a separate analysis of liability issues that could arise for witnesses and notaries who sign the

new power of attorney form and for doctors who accept it. That analysis was sent to Nevada medical, nurses, dental, and psychological associations, with a suggestion that they independently review the bill and share their views with the Assembly Judiciary Committee.

We created a [webpage](#) with links to AB 128 and the various analyses we submitted to the Legislature.

Any new law on medical supported decision making or creating a simplified power of attorney cannot eliminate the need for a medical provider to determine if the patient has capacity to give informed medical consent or the capacity to enter into a contract. The issue of potential undue influence cannot be swept under the rug. Guardianship, or limited medical guardianship, will still be needed for many adults with intellectual disabilities.

Adult guardianship laws are not going to be repealed. They reflect a longstanding societal commitment to protect people who are vulnerable to abuse or exploitation. For many adults with intellectual disabilities, there simply is no substitute for guardianship.

Guardianships for people with intellectual and developmental disabilities – known as limited conservatorships in California – will be used for many people in decades to come. Therefore guardianship reform should be placed on the agendas of disability rights and disability services organizations and agencies.

Spectrum Institute is holding an [informational briefing](#) for advocates to explain the deficiencies in the limited conservatorship system in California. The briefing will also propose ways to improve each stage of the procedure and the performance of all participants – judges, attorneys, court investigators, regional centers, self-help centers, and would-be conservators.

The briefing is free and will be held on August 7, 2015 in Los Angeles. Attorneys, parent advocates, sibling advocates, and self advocates may request an invitation.

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