

# Medical Decision-Making Options for People with Intellectual Disabilities and Parents in Nevada

## A Response to Testimony on AB 128

by Thomas F. Coleman, J.D.

A public hearing on [Assembly Bill 128](#) occurred on February 23, 2015 in the Nevada Assembly Judiciary Committee. The bill would create a new medical power of attorney form that could be signed by adults with intellectual disabilities. Only people with an IQ lower than 70 would be able to use the new form.

I submitted a [legal analysis](#) of the bill to the committee, raising concerns about its ramifications. My colleague, Dr. Nora Baladerian, submitted a [clinical analysis](#) of the bill, from the perspective of a psychologist who has worked with this population for several decades.

I saw and heard the proceedings through the committee's website. This is intended to respond to some of the points raised at the hearing, as well as to explain the current options in Nevada for medical decision making for people with intellectual disabilities.

The AB 128 form is not patterned after a law adopted in Michigan. The Michigan Legislature has never approved such a form. I could not find any other state that has approved a form similar to the one in AB 128.

It appears that AB 128 is the first legislation of its kind in the nation. That is why it is important to have the AB 128 form tested on some control groups of people with intellectual disabilities at various IQ levels to see if they understand what they would be signing. Such testing should be done by a neutral and objective agency before the bill is next heard in committee, much less approved.

Some of the witnesses characterized AB 128 as creating a type of supported decision making. This characterization of the bill is erroneous.

One legislator clarified that in several places in the bill, it is clear that after the power of attorney form is signed by the adult, it is the agent who makes the medical decisions, not the person with a disability.

One witness said the purpose of AB 128 is to allow parents to avoid a guardianship. Guardianship was labeled as complicated process that, when granted, takes

away all of the adult's rights. No one advised legislators that these assertions were incorrect.

Adult guardianship in Nevada is not an all-or-nothing process. It is not complicated or overly burdensome. Admittedly, it is not as simple as having an adult sign a form. There is a capacity assessment of the adult and a home visit by a court investigator. But a parent can handle the court process without an attorney. Self-help instructions are available.

There are two types of adult guardianship in Nevada – a general guardianship and a limited guardianship. In a general guardianship, if the court finds an adult to be “incompetent,” all major decisions will be made by a guardian. This is often used for seniors with dementia.

In contrast, a “limited capacity” guardianship is available when an adult can make some decisions but not others. A petition asks the court to give the guardian authority to make decisions only in areas in which capacity is lacking. It is tailored to the specific needs of each adult.

Parents seeking a limited guardianship need not label their adult child “incompetent” in order to obtain a limited guardianship. They only need to acknowledge that their child has limited capacity to make medical decisions. There is nothing pejorative in that.

Decision-making options for adults with intellectual disabilities should be considered by parents the year before their child becomes an adult. Parents should discuss future options with their primary care provider when the child is 17. Planning should occur in pre-adulthood so there is no gap in services because the provider can no longer accept the consent of the parent when a child-patient becomes an adult-patient.

A medical provider can assess whether the patient has capacity to give informed consent a few months prior to the patient turning 18. If the provider believes capacity is lacking or has serious doubts, this is the cue for the parent to seek a limited guardianship.

If a patient has capacity to give informed consent at 17, then he or she will likely have such capacity after turning 18. However, to cover the possibility of a loss of capacity due to an illness or accident, the parents of a child who does have medical decision-making capacity can ask their child to sign the currently-authorized power of attorney form when he or she turns 18.

Current federal law prohibits medical care providers from discriminating on the basis of disability. Ignoring an adult patient, or showing disrespect to patients because of their intellectual disability is a form of illegal discrimination. A new bill such as AB 128 is not needed to require medical providers to show respect to patients with disabilities. That is already mandated by law. Education of medical providers about people with intellectual disabilities is a better approach to making sure all patients receive respectful treatment.

### **Current Options for Health Care Decisions**

As explained above, if a person with an intellectual disability has the capacity to give informed medical consent, AB 128 is not necessary. The medical provider interacts with the patient and obtains consent from the patient. The patient, with or without a disability, can authorize the provider to allow a parent or other person to be privy to medical records and to be part of the decision-making process. The provider must follow such instructions. But in the end, it is the patient who decides.

If the patient lacks capacity to make medical decisions, AB 128, as currently written, cannot fix that situation. A person without such capacity also lacks the capacity to sign a health care power of attorney since signing that form is itself a major medical decision. Likewise, if a patient lacks the capacity to enter into a contract, the patient lacks the capacity to sign an AB 128 delegation of authority to an agent since that is a contract. AB 128 cannot fix the lack of capacity to enter into a contract.

The testimony presented at the hearing was vague on the issue of capacity. There is no lower limit of IQ in the bill. Therefore, as written now, a person with an IQ of 20 or lower is allowed to sign this contract. Proponents were unwilling to make any distinction between someone with an IQ of 70 and someone with an IQ of 20 or lower.

As written, AB 128 is unnecessary for those who have the capacity to give informed consent. An AB 128 form would be invalid when signed by people who lack such capacity. It is not needed for someone with capacity and it is invalid if used by someone without capacity. The necessity of AB 128, therefore, is more than dubious.

An attorney at the hearing said that AB 128 will create a form that parents can use without a problem until someone questions its validity. That usually won't occur until something bad happens to the patient and someone sues the medical provider.

When a lawsuit is filed, it will be the medical provider who faces the risk of liability, not the parents. The plaintiff may be a surviving sibling of the patient or a surviving parent estranged through divorce. Whether a medical provider can claim a "good faith" defense is addressed in a [separate commentary](#).

It is noteworthy that the hearing did not have testimony from medical providers in support of the bill. Doctors are a constituency who need to weigh in on this bill, after considering the liability issues I have raised elsewhere.

### **Amendments to the Bill**

One witness testified against the bill. He is a parent of an adult daughter with autism. He is also an advocate for people with developmental disabilities. He referred to the analyses submitted by Spectrum Institute.

One legislator asked this witness if he thought the bill could be amended so that he would change his position of opposition to a position of support. The reply was a cautious "maybe." I agree.

A procedural protection against undue influence should be included in the process. A doctor should certify that when the form is signed, the patient has the capacity to enter into this contract. Several names should be given to the patient as options for an agent, not just one name selected by someone with authority over the adult.

Before AB 128 is passed, the proposed form should be field tested on cohorts of individuals with IQs in the 70s, 60s, 50s, and lower to see if they really understand what they are signing. The results would determine what other amendments may be needed. ♦♦♦

*Attorney Thomas F. Coleman is the Executive Director of the Disability and Guardianship Project of Spectrum Institute. (tomcoleman@spectruminstitute.org)*



9420 Reseda Blvd. #240, Northridge, CA 91324  
www.spectruminstitute.org • (818) 230-5156