

Clinical Concerns About AB 128: A Medical Power of Attorney for People with Intellectual Disabilities

by Nora J. Baladerian, Ph.D. February 22, 2015

The Executive Director of the Disability and Guardianship Project has already analyzed AB 128 and its implications from a legal perspective. His analysis raised many serious concerns with this bill.

As a clinical psychologist who has provided therapy for people with intellectual disabilities for decades – and who has done forensic analysis of the capacities of such individuals for attorneys in civil and criminal cases – I am analyzing AB 128 from a clinical perspective. Presumably, the idea behind this bill is to provide an efficient way for parents to make medical decisions for their adult children without the necessity of being appointed their guardians.

I will not speak about the presumed use of an AB 128 document to avoid a guardianship procedure. That is an issue that will no doubt be addressed by others. I will note, however, that each year in California thousands of parents obtain guardianships for their adult sons or daughters with intellectual disabilities. Approximately 90 percent of them do so without the need for an attorney. Court fees are usually waived. The process is efficient and is completed in a few months. Perhaps a streamlined guardianship procedure also exists in Nevada. If not, it should.

Nevada already allows adults to sign a durable power of attorney for health care. Since this is a contract that creates an agency relationship between the principal and agent, contractual requirements must be met. The principal must be 18, of sound mind, and have the capacity to understand the power that he or she is delegating and the consequences of doing so. Delegating the authority to make medical decisions – including decisions with life and death consequences – is in itself a medical decision. Therefore, I assume that Nevada law would require people who sign the current power of attorney form to have the capacity to give informed medical consent at the time they sign such an agreement.

Since Nevada law allows a parent to obtain a guardianship to gain authority to make medical decisions for their adult child, and since there is already a medical power of attorney form that can be used for people with disabilities to delegate medical decision making power to a parent or other person, there must be some other reason for AB 128.

I am familiar with BRD 13-18 in which a legislative committee last year asked for a bill to be drafted that "would enable adults over 18 years of age with intellectual or developmental disabilities to receive assistance in making medical decisions." AB 128 is not parallel to that request.

If AB 128 was limited to enabling people with disabilities to receive assistance in making medical decisions (as requested in BRD 13-18), the bill would create a type of supported decision making. In that event, there would be no need for a clinical analysis of AB 128. But AB 128 creates a new legal form that, when signed, immediately triggers substituted decision making.

Because there is an immediate transfer of authority from the principal to the agent when the document is signed, questions arise about the capacity of the principal to understand the words used in the new form, as well as whether the principal has the capacity to contract and the capacity to make an informed medical decision (which is what a medical power of attorney is). Another question is what safeguards are in AB 128 to minimize the risk of undue influence. These are questions that I will now address.

Definition of Intellectual Disability

The bill creates a medical power of attorney form that can only be used by adults who have an intellectual disability. "Intellectual disability" is defined as "significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period."

By definition, this excludes seniors whose cognitive disabilities occur later in life. It also excludes people who have cognitive disabilities due to brain trauma, a medical disease, or a mental illness. This bill is for people with intellectual disabilities that occur before the age of 18. Their intellectual disability is not transient. It is permanent. The capacity for reasoning and decision making they have in their 20s is likely to be the same when they are in their 30s, 40s, or older.

The phrase "significantly subaverage general intellectual functioning" means that the adult in question has an IQ of 70 or less. The need for concurrent "deficits in adaptive behavior" means they have deficits in at least one of the following functions: communication, self-care, home living, social, work, leisure, health, or safety.

Language Used in the New Form

The form authorized by AB 128 would be used by adults who have an IQ of 70, or 60, or 50, or lower. Someone with an IQ of 10 would be authorized to sign the form.

I have read the new form and have considered the ability of people with intellectual disabilities to understand that language it contains. People with an IQ of 70 might have the ability to understand some, or perhaps all of the language, but I doubt it. People with an IQ of 60 or lower would not understand terms such as: durable, power of attorney, designate, agent, decisions, medical records, or authorized.

Being someone who has worked professionally with this population for decades, I was surprised that terms such as these are used in this form. Most people with intellectual disabilities who read the form or have it read to them, will not understand what it means.

I assume that the proponents of this bill, and those whom they consulted who have knowledge about the level of functioning of people with intellectual disabilities, have tested this form on test groups of such individuals. Perhaps they have used the form on a sample cohort of this population and questioned them about it two hours later or a day later.

This is such a significant departure from current law – implicating capacity to contract and to give informed medical consent – that such an analysis should have been done prior to introducing this bill into the Legislature. If it were done, I would be surprised if many people in the test group could explain what they signed or why they signed it – other than perhaps to say they signed it because they were asked or told to do so.

Of course, the Legislature could require an agency other than the proponents to use this new form with test groups of people with intellectual disabilities prior to proceeding with committee votes on the bill. The bill could be held, or reintroduced with modifications, after such testing has been done. However, if legislators are not concerned about the ability of people who sign this new form to understand what it means or the implications of what they are doing, then pre-testing would not be necessary. Tests should include up to what IQ level principals can demonstrate an understanding of the concepts and consequences of transferring medical decision making authority. Tests may show that almost no one below a certain IQ level can do so. This would inform whether a bill such as AB 128 is realistic.

I am familiar with the growing trend to require new programs or practices to be "evidence based." Implementing AB 128 without "evidence based" information about whether people with intellectual disabilities will understand what the form means or the consequences of signing it would run contrary to this trend. AB 128 should not be a grand experiment on a vulnerable population.

Sound Mind

A witness who signs the new form authorized by AB 128 must declare, under penalty of perjury, that at the time the document is signed, the principal "appears to be of sound mind." A notary must also attest that the principal "appears to be of sound mind."

The requirements that the witness and the notary attest that the principal appears to be of sound mind is consistent with the requirements of current law and the existing statutory medical power of attorney form. That form requires a witness and a notary to make the same assertion.

Blacks Law Dictionary (online) defines "sound mind" to mean "having the ability to think, understand and reason for oneself." The lawyers at Legalzoom, an online legal service, say that under Nevada law the term "sound mind" means "capable of reasoning and making decisions."

If someone is not of "sound mind," they are considered to be incapacitated and cannot enter into contracts or execute a valid will. According to 132.175, "incapacitated" means "a person who is impaired by reason of mental illness, mental deficiency, advanced age, disease, weakness of mind or any other cause except minority, to the extent of lacking sufficient understanding or capacity to make or communicate responsible decisions."

Since AB 128, like current law, requires certification by a witness and a notary that the principal who signed the medical power of attorney "appears to be of sound mind," it is reasonable to conclude that

the bill contemplates that the person with an intellectual disability understands the meaning of the words in the document and has the capacity to make responsible decisions.

Disability Rights Ohio has an explanation of the term "sound mind" and its applicability to medical powers of attorney. Their website tells people with disabilities that in order to have a durable power of attorney for health care, "you must be at least 18 years old; you must be of sound mind; and you must not be under or subject to duress, fraud, or undue influence in executing the agreement."

The website further explains that under Ohio law, "A person of sound mind must have the ability to understand and to communicate the decision to execute a durable power of attorney and the effect of the document." Putting it another way, the website states that a working definition "of sound mind" would be: "at the time you execute the durable power of attorney for health care, you have the capacity to make informed health care decisions for yourself; and you understand the basic purpose of the document you are signing, and the consequences of signing the document."

Assuming this explanation would apply to any state – since capacity to contract and capacity to give informed medical consent are universal legal concepts regardless of jurisdiction – my concerns about AB 128 are amplified.

Most people with an IQ under 70, and the vast majority with an IQ under 60, are <u>not</u> capable of making informed medical decisions for themselves. As a result, they lack capacity to make a huge medical decision of delegating complete medical authority over them to another person. No medical decision is greater than that. Further, in my opinion, the overwhelming majority of people with an IQ under 70 would not understand the consequences of signing a medical power of attorney. Therefore, according to Disability Rights Ohio, people with such a low IQ would not have the legal capacity to execute a power of attorney, the AB 128 type included.

Capacity to Make Decisions

Further discussion is appropriate on the question of whether people with an IQ of 70 or less have the capacity to enter into a contract or to make an informed medical decision such as delegating medical decision making power to another person. If a person does not understand what a "decision" is in general, or what a particular decision means, or the consequences of a particular decision, then they should be considered to lack the capacity to make that decision.

Some people with an IQ of 70 may understand what a decision is in a general sense. Some may even understand the result of giving power to another person to make decisions for them. However, due to passivity that may be associated with their particular type of disability, they may think that a decision is doing something that they are told to do. Many people with intellectual disabilities believe that they must obey adults. They do not truly understand that they have a right to say yes or no. Without an understanding that they have a right to say yes or no, without fear or punishment or disapproval – even saying no to a person in charge of them – then signing an AB 128 power of attorney is not an act of free will.

When the IQ level is 60 or lower, the number of individuals who would have the capacity to make rational decisions, exercise free will, and understand the consequences of their decisions, becomes quite low.

From my decades-long clinical experience as a therapist for many people with intellectual disabilities, and from my professional experiences doing forensic capacity assessments, it is my opinion that most of the people affected by AB 128 will not be able to understand what they are signing or the consequences of signing it. Again, this is irrelevant if it is the intention of the Legislature to allow vulnerable people to sign legal documents without having capacity to understand what they are doing.

The alternative to AB 128, of course, is for a guardianship process to be initiated where a proper analysis of capacities would occur. AB 128 presumes capacity, but such a presumption is unwarranted for people with IQs that should trigger the opposite presumption. AB 128 provides no procedure for assessing capacity to contract or capacity to make informed medical decisions.

It is unclear whether NRS 162A.790 (certification of competency) applies to the new medical power of attorney authorized by AB 128. This statute requires that, in order for a power of attorney to be valid under current law, if the principal resides in a hospital, residential facility for groups, facility for skilled nursing, or a home for individual residential care, a medical doctor, psychologist, or psychiatrist must certify that the principal is competent to execute such an agreement.

Having someone with an IQ of 60 or lower sign a legal document giving someone else power over them raises so many red flags that it seems that NRS 162A.790 should be required before the AB 128 power of attorney is considered valid. Such a certification of competency should apply regardless of whether the principal lives in such residential facilities or lives with parents or other relatives. Even when they are well intentioned, parents often have undue influence over an adult child with an intellectual disability simply because of their position of power and the extreme vulnerability and often passivity of the adult child. I question the wisdom of AB 128 as it lacks the added protection of a certification of competency such as that required by NRS 162A.790.

If legislators are determined to move this bill through the legislative process, despite the legal concerns raised by the Disability and Guardianship Project, and despite the clinical concerns raised here, then the bill could have additional protections added.

A place should be added to list the names of several people who are close to the principal and who are willing to serve as an agent, from which the principal could select one. This insures that the principal is choosing the person they prefer. Giving only the names of a parent, for example, could be a subtle form of undue influence, especially if that parent is present when the document is signed.

Having a parent present and only listing the parent's name as the primary agent is not giving the principal a true choice. This would be like offering a person with an intellectual disability one menu choice for breakfast – eggs. A person who is really hungry, if given only one choice for breakfast, may think that they will have no breakfast if they decline the only choice given. People with intellectual disabilities at this level of IQ are concrete thinkers and do not easily think of options on their own as abstract thinkers may. They have also learned to obey people who are in charge of them, which is called compliance training. Not offering a choice from a list of options may result in unwanted consequences that they want to avoid. Therefore, it is essential to give them choices as to agents.

The process of explaining and signing the document is more important than the document itself. The process must have integrity and integrity requires due diligence – something that is lacking in the

current version of AB 128.

I have done extensive work over the years on abuse of people with intellectual disabilities. Studies have shown that by the time such a person reaches the age of 18, he or she has likely been a victim of abuse. Studies have also shown that most perpetrators are in the immediate circle of support of the person who has been victimized. That circle of support includes parents, siblings, close relatives, household members, caregivers, and direct service providers, among others. Having such people present during the signing of legal document such as this creates a serious risk of undue influence. Therefore, if the Legislature wants to minimize the risk of undue influence, a provision should be added that the document should not be signed in the present of such individuals. Having it explained and signed in the presence only of neutral parties, such as a case worker, social worker, or medical provider would be the appropriate method to bring integrity to the process.

Another clause could be added requiring that an AB 128 medical power of attorney must be executed in the presence of a doctor, psychologist, or psychiatrist. The doctor could see how someone explained the document to the principal and could question the principal to see whether he or she really understood what they were signing, why they were signing it, and the consequences of signing it. The clause could require the doctor to question the principal again one hour after it was signed to see if the principal understood these things. If so, the doctor could sign a paragraph on the power of attorney form to that effect. If not, the document would not be valid.

Having a licensed professional certify that the principal knew what they were doing would remove any doubt about the validity of the document. It would be an efficient process. It would not require a guardianship proceeding. The added procedure would be simple, low cost, and efficient.

Finally, it should be noted that people with intellectual disabilities have been receiving medical services for years. No evidence has been presented, to my knowledge, that unless AB 128 is passed, people will be deprived of medical care.

Under current law, people with intellectual disabilities can receive medical care if they are able to give informed consent to such procedures. They also can receive medical care if they have the capacity to sign the current power of attorney form. If they do not have the capacity to do either, medical decisions can be made by an appointed guardian.

With AB 128 as written, the population intended to sign these new forms is vulnerable to undue influence – about surrendering decision making authority as well as selection of an agent. At least in guardianship, there is an independent investigation as to whether the adult has been subject to abuse. There is, or should be, an interview of the adult outside of the presence of the parents to ascertain his or her true wishes, including as to who should be the guardian. Guardianship has built in protections to minimize risk. AB 128 does not. That is why the inclusion of such protections into the language of the bill is so important.

About the Author

Nora J. Baladerian is a clinical psychologist who has been working with people with developmental disabilities for several decades. She is the Executive Director of the Disability and Abuse Project of Spectrum Institute. Her clinical practice is located in Los Angeles. (www.norabaladerian.com)