

February 20, 2015

Assemblyman Ira Hansen, Committee Chair
Assemblyman Erven T. Nelson, Committee Vice Chair
Assemblywoman Michele Fiore
Assemblyman David M. Gardner
Assemblyman Brent A. Jones
Assemblyman P.K. O'Neill
Assemblywoman Victoria Seaman
Assemblyman Jim Wheeler
Assemblyman Elliot T. Anderson
Assemblyman Nelson Araujo
Assemblywoman Olivia Diaz
Assemblyman James Ohrenschall
Assemblyman Tyrone Thompson

Nevada Legislature

401 S. Carson Street
Carson City, NV 89701-4747

RE: Testimony Opposing AB128 As Written

Dear Committee Chair Hansen, Vice Chair Nelson and Committee Members:

Thank you for the opportunity to provide this letter and expert testimony on Assembly Bill 128 which proposes to create a power of attorney for health care decisions for adults with intellectual disabilities.

My name is Mark Olson. I am the only parent, father, and legal guardian of my 19yo daughter who is diagnosed with autism, intellectual disability, epilepsy and a pre-diabetic condition.

I am an advocate for the rights of persons with autism and intellectual and development disabilities (I/DD) on a state and national level. I presently chair the Adults and Aging Subcommittee for the Nevada Autism Commission and am an appointed member of the Governor's Task Force on Integrated Employment. I also am co-founder of the Coalition for Community Choice, a national collaboration defending the human and civil rights of persons with disabilities to choose the life they want to live.

I oppose AB128 for the reasons I will summarize below from myself and extensive expert analysis of the bill that I requested from Thomas F. Coleman, Executive Director of the Disability and Guardianship Project of Spectrum Institute. The full text of that analysis is attached to this letter. Mr. Coleman is an attorney with more than 40 years of experience advocating for the rights of populations subjected to discrimination, including people with disabilities.

The mission of the Disability and Guardianship Project is to improve guardianship procedures for persons with developmental disabilities and to promote viable alternatives.

I want to be clear...I believe the guardianship process in Nevada needs considerable change and creation of a range of viable, defensible options to meet the diverse needs of Nevadans with disabilities, and to comply with the person-centered standard of service required by the federal government.

Specifically, AB 128 should not advance because:

- 1) The bill is certainly well intentioned, but it is fatally flawed. It reduces or eliminates rights of and protections under current law for persons with intellectual disabilities. These flaws are detailed in the expert analysis from Thomas Coleman attached to this letter.
- 2) As introduced, AB 128 does not respond to BDR 13-418 approved by the Interim Legislative Committee on Senior Citizens, Veterans, and Adults with Special Needs on August 15, 2014.
- 3) The Durable Power of Attorney form created by AB 128 is not merely an attempt to provide disability accommodations to the person with ID by using language in the form that is more understandable to a person with an intellectual disability. It does not create a type of "supported decision-making" where the person with ID makes his or her own decisions with the help of a facilitator. Instead, it creates the same type of "substituted decision-making" inherent in the standard power of attorney form used by people who do not have an intellectual disability..
- 4) Title III of the Americans with Disabilities Act provides for the kinds of reasonable modifications in policies, practices, and procedures that facilitate equal access to goods and services including legal documents such as the current Nevada Durable Power of Attorney form.
- 5) The bill as written serves the convenience of parents while sacrificing existing rights and protections for persons with ID. This is a potential conflict of interest. It lumps persons with ID and parents under a "family" umbrella. A family is not a legal unit. It is made up of individuals, each of whom is a separate legal entity with distinct and separate rights and obligations.

Lastly, several states and advocacy groups have rushed to introduce legislation for supported decision-making, including for medical purposes, but much of it is as flawed or more flawed than this bill. Model legislation for medical supported decision making agreements is in the process of being formulated at a national level.

Nevada should not rush to enact flawed legislation, but rather take the time and make the effort to bring together a broad group of experts on this issue to take the model legislation and craft legislation worthy of Nevadans with intellectual disabilities.

Thank you for the opportunity to comment on AB 128.



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Enclosure: An Analysis of Nevada Assembly Bill 128: Passage of Bill Would Diminish the Rights of People with Intellectual Disabilities by Thomas F. Coleman



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An Analysis of Nevada Assembly Bill 128: Bill's Passage Would Diminish the Rights of People with Intellectual Disabilities

by Thomas F. Coleman
February 19, 2015

Assembly Bill 128 was introduced into the Nevada Legislature on February 6, 2015. The bill would create a power of attorney for health care decisions for people with intellectual disabilities.

The Disability and Guardianship Project of Spectrum Institute received a request to analyze this bill. The request was submitted on February 19, 2015. Because the bill is scheduled to be heard in committee next week, our analysis of the bill was given expedited status.

Our analysis of the bill has resulted in a conclusion that AB 128 has many serious deficiencies. It removes legal protections that are currently available to people with intellectual disabilities.

Background

The bill was developed in response to a Bill Draft Request (BDR) from the Legislative Committee on Senior Citizens, Veterans, and Adults with Special Needs. BDR 13-418 was approved by the committee at its final work session on August 15, 2014.

The committee [summarized](#) BDR 13-418 as follows: “Draft a bill to create a Power of Attorney for Health Care Decisions for persons with intellectual or developmental disabilities. This form would be different from the Power of Attorney for Health Care Decisions form set forth in *Nevada Revised Statutes* (NRS) 162A.860. The new form would enable adults over 18 years of age with intellectual or developmental disabilities to receive assistance in making medical decisions. (BDR 13–418)”

Substituted Versus Supported Decision Making

As introduced, AB 128 does not respond to BDR 13-148. AB 128 is a delegation of medical decision-making authority from the person with an intellectual disability (hereinafter described as “principal”) to an agent. The agent is not assisting the principal to make his or her own medical decisions. Rather, once the power of attorney form is signed by the principal, the agent makes the decisions. The form does call on the agent to explain things to the principal to the extent that is possible, but the agent makes the decisions and the medical personnel follow the directions given by the agent.

The way it is currently worded, the new form is not merely an attempt to provide disability accommodations to the principal by using language in the form that is more understandable to a person with an intellectual disability. It does not create a type of “supported decision making” where the principal makes his or her own decisions with help from a facilitator. Instead, it creates the same type of substituted decision making inherent in the standard power of attorney form used by people who do not have intellectual disabilities.

Current Medical Power of Attorney Form

Pursuant to NRS 162A.860, the Legislature authorized a standard form to be used as a medical durable power of attorney (DPA). By signing this form, the principal is delegating authority to an agent to make medical decisions under circumstances specified in the form.

This is a legal contract that creates a relationship between two people as principal and agent. By taking actions pursuant to the contract, the agent assumes a fiduciary relationship with the principal. This contract can have significant medical consequences to the principal since by delegating such authority, the agent can make irreversible and sometimes life and death decisions for the principal.

Capacity to Contract

The current medical DPA form, when signed by the principal and acted on by the agent, is an agency contract. Therefore, laws regarding contracts apply. Contracts are voidable if one of the parties lacked capacity to enter into it at the time it was signed. The principal may later challenge the contract on the ground that he or she lacked the capacity to contract. A subsequently appointed conservator or guardian may also challenge the contract for the same reasons.

Furthermore, if the principal dies, surviving family members or the estate of the principal can challenge the contract on the ground that the principal lacked capacity to enter into it at the time it was signed.

Incapacity is a legal defense to a contract that exists for the benefit of the principal. The right to challenge a contract on the ground of incapacity is an important provision of current law. It applies to medical powers of attorney executed under current law.

To have an enforceable contract, each party must be over the age of 18 and legally competent. Under NRS 159.019 “Incompetent means an adult person who, by reason of mental illness, mental deficiency, disease, weakness of mind or any other cause, is unable, without assistance, properly to manage and take care of himself or herself or his or her property, or both. The term includes a person who is mentally incapacitated.”

Certification of Competency

In addition to the general requirement of capacity to contract, NRS 162A.790 imposes an additional requirement if the principal resides in a hospital, residential facility for groups, facility for skilled nursing, or a home for individual residential care. Under any of those circumstances, the DPA agreement is only valid if it is accompanied by a certification of competency of the principal from a physician, psychologist, or psychiatrist.

Informed Consent

The current medical DPA form specifies that the authority of the agent to make medical decisions for the principal only exists if the principal is unable to give informed consent. If the principal can give informed consent, the agent has no authority and the medical provider must take direction only from the principal.

The requirement of informed consent is not only a matter of state law (giving the patient a right and giving the medical provider a duty), it is also a requirement of medical ethics. Furthermore, informed consent is required by federal law if the medical provider receives any federal funds for the medical services. A state law may not dispense with this federal requirement.

Informed consent requires disclosures by the medical provider to the patient about risks and benefits of the procedure in question. It requires that the patient understand what the procedure is, why it is being done, and what the risks and benefits are. The patient must have the ability to weigh the pros and cons and to make an informed decision on how to proceed.

Limitations on the Agent

Under current law, the DPA form gives the principal the right to impose limitations on the actions that may be taken by the agent. The current form specifically informs the principal of this right.

The current form provides options for the principal to select regarding end of life decisions. The principal can select from five options provided on the form, or the principal can add additional language regarding his or her desires for end-of-life treatment.

Termination of Authority

The current form tells the principal that he or she may terminate the authority of the agent at any time and for any reason. The form tells the principal that this is a durable power of attorney, which operates indefinitely unless it is terminated by the principal.

Witness Certification

A witness who signs the current form must declare, under penalty of perjury, that the principal “appears to be of sound mind.”

Proposed DPA Form Under AB 128

The proposed DPA form for people with intellectual disabilities may be well intentioned but it has many undesirable effects on the existing rights of the people AB 128 is intended to benefit.

Capacity to Contract

The proposed DPA form is a contract between the principal and agent. Therefore, general contract law applies to this new type of agreement. Such law requires parties to the contract to have capacity to understand the provisions of the agreement and their consequences.

Under current law, a contract is not actually formed until the agent asserts his or her authority pursuant to the DPA form. The agent does not sign the current form when it is executed. Therefore, the implied agreement of good faith and fair dealing does not spring into action until the agent accepts the delegation of authority by acting on it.

The new form, however, requires the agent to sign the form when it is signed by the principal. The contract is formed at the time the DPA form is executed. Therefore, the competency of the principal to form a contract would be tested as of the moment the form is signed and witnessed.

Certification of Competency

The question arises as to whether the new form is intended to bypass the legal protections in NRS 162A.790 imposing an additional requirement of competency certification if the principal resides in a hospital, residential facility for groups, facility for skilled nursing, or a home for individual residential care. If the intention is to bypass this protection, then AB 128 is removing existing legal protections for people with intellectual disabilities.

Informed Consent

Unlike the current DPA form, the proposed form fails to even mention the crucial topic of informed consent. The current form specifies that the agent may only make decisions, and the medical provider may only act on the agent's decisions, if the patient lacks the ability to give informed consent.

Current law is consistent with the requirements of medical ethics and the requirements of federal law. A medical provider can only perform services with the informed consent of the patient, unless the patient lacks the capacity to give informed consent and there is a guardian or an agent under a valid health care power of attorney.

Under the proposed form, the principal is transferring power to make medical decisions from the moment the DPA form is signed and witnessed. This is not supported decision making where the designated person is merely helping the principal to understand the procedures, choices, risks and benefits. This is substituted decision making where the agent assumes full responsibility from the inception of the DPA agreement.

The form states: "After my agent speaks with the doctor, I would like my agent to decide what care or treatment I should receive. . ." It also states: "I would like my agent to decide if I need to see a dentist and make decisions about what care or treatment I should receive . . ." There is no doubt. This is substituted decision making.

This new DPA form creates the opposite of supported decision making. This is also a major departure from the rights of patients and the obligations of medical providers under current law.

Limitations on the Agent

As mentioned above, the current DPA form gives the principal the right to impose limitations on the actions that may be taken by the agent. The current form specifically informs the principal of this right. Because the new form does not provide for such limitations, it is diminishing existing rights.

As mentioned above, the current form provides options for the principal to select regarding end of life decisions. The new form is silent about what occurs if the agent is presented with decisions regarding terminal illness. The current form allows the principal to select from five options provided on the form, or to add language regarding his or her desires for end-of-life treatment. Again, the current form is restricting options, not expanding them.

Proponents of AB 128 may argue that people with intellectual disabilities have a choice to use the current form or to use the new one. However, it is probably their parents or relatives who will be making that decision. Because of their intellectual disabilities, the proposed beneficiaries of AB 128 probably lack the ability to understand the differences between the current DPA form and the new one. Furthermore, if they lack the capacity to execute the current form they probably lack the capacity to execute the new form. They either have the capacity to contract or they do not.

Termination of Authority

As mentioned above, the current form tells the principal that he or she may terminate the authority of the agent at any time and for any reason. The form tells the principal that this is a durable power of attorney, which operates indefinitely unless it is terminated by the principal. The new form fails to inform them of the right to terminate the agreement or that it may last for years or decades unless terminated. The new form therefore is less informative than the current form.

Witness Certification

A witness who signs the current form must declare, under penalty of perjury, that the principal “appears to be of sound mind.” The same is true of the new form.

AB 128, by its own terms, can only be used by people with intellectual disabilities. Intellectual disability means significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period.

By this definition, the people who AB 128 is intended to benefit may very well be people who lack the capacity to contract or lack the capacity to give informed medical consent. Without the capacity to contract or to give informed medical consent, they lack the capacity to make an informed decision to delegate life-and-death medical decision making to another person.

Although written in another context, the Legislature has linked the issue of subaverage intelligence with the issue of capacity to contract. (NRS 159.0593)

A medical provider may be sued by the estate of a patient with an intellectual disability for negligence or wrongful death of the patient. The plaintiff may argue that the medical provider did not act in good faith in relying on the newly-authorized DPA form because the provider should have known that the patient lacked the capacity to delegate such authority at the time the form was signed. It would be hard for a provider to raise a “good faith” defense when the provider knows that the mental incapacity due to a developmental disability is something that is ongoing and not transient.

The medical provider may join into the lawsuit the witness who signed the certification that the patient was “of sound mind” at the time the DPA form was executed. The provider could argue that he or she relied on the certification by the witness that the patient was of sound mind as the basis for relying on the validity of the DPA form.

The question would then arise as to the factual basis for the certification. If the witness was not familiar with the details of the patient's mental competency, then the witness should not have made such an assertion under penalty of perjury. If the witness was familiar with the seriousness of the patient's mental incapacity, and signed the certification anyway, then the witness could be guilty of fraud or misrepresentation. Either way, a witness who signs a mental competency certification clause for a contract signed by a person with subaverage intellectual functioning and adaptive deficits runs a serious risk of liability to a medical provider who relies upon the certification.

Agent's Signature

The current DPA form does not require the agent to sign the form or to agree in writing to anything. Only the principal and witnesses sign the form. The agent later acts pursuant to the authority delegated by the principal and, by doing so, becomes a party to the contract.

At first it seems odd that the new DPA form would require the agent to sign it. However, once the language of the agreement made by the agent is read, it becomes apparent that the purpose of the agent's signature is to document that the agent is aware that the medical provider has no liability for accepting the document and for following the instructions of the agent.

The paragraph titled "agent signature" is really a release of liability form that would make it impossible for the agent (who is probably a parent or relative of the patient) to sue the medical provider for rendering services without the informed consent of the patient or pursuant to a DPA form that was invalid for other reasons. That clause should be titled "Agent Waiver of Liability."

Conclusions

AB 128 may be well intentioned but it is fatally flawed. It reduces or eliminates rights of and protections for people with intellectual disabilities under current law.

The DPA form created by AB 128 is not a form of supportive decision making. It is substituted decision making, but without traditional legal protections that do and that should apply to people who sign a form that places such tremendous power in the hands of another person.

It is important to emphasize that the core principle of "least restrictive alternative" should apply to any law affecting the rights of people with intellectual and developmental disabilities. AB 128 violates that principle. By using the new form created by AB 128, the adult is immediately surrendering authority to make his or her own medical decisions to another person.

The transfer of authority is immediate. It is unlike the current DPA form that requires the doctor to continue to get informed consent from the patient (if he or she has current capacity to do so), unless the doctor determines that the patient no longer can give informed consent. The current form dispenses with an individualized assessment by the doctor of the current capacity of the patient to make a particular decision. A patient, even though he or she has signed a DPA form, may very well have the capacity to give informed consent for low risk/high benefit procedures like a teeth cleaning.

In contrast, the patient may not be able to weight the cost-benefit analysis of general anesthesia. So under current law, doctors make a current and individualized determination of capacity before each procedure, notwithstanding the existence of a DPA form. AB 128, however, dispenses with this assessment. The adult signs a blank check for medical decisions and the agent fills in the blanks.

This violates the “least restrictive alternative” principle for those who can make some decisions.

Legislation should enhance and add to the rights of people with intellectual disabilities, not diminish or eliminate them. A bill could be drafted that would authorize a state agency to explain the current DPA agreement and make it more understandable to people with intellectual disabilities. An educational booklet, written at an educational level appropriate for such patients, would be consistent with the goals of supported decision making. That would be productive legislation.

Model legislation for medical supported decision making agreements is in the process of being formulated. Unfortunately, the current form of one model bill does not contain sufficient protections to reduce the risk of abuse or exploitation.

The Disability and Abuse Project brought those concerns to the attention of the those who are promoting that model bill. The primary attorney for that model bill promised to have it amended to alleviate those concerns. However, as to this writing, an amended bill has not been released for review. Therefore, we can only wait for a day in the near future when a model bill emerges with provisions sufficient to protect people with intellectual disabilities. When that day comes, the Nevada Legislature may decide to consider such a bill for passage. ◇◇◇

About the Author

Thomas F. Coleman is the Executive Director of the Disability and Guardianship Project of Spectrum Institute. Mr. Coleman is an attorney with more than 40 years of experience advocating for equal rights for populations subjected to discrimination, including people with disabilities. (www.tomcoleman.us)

About the Project

The mission of the Disability and Guardianship Project is to improve guardianship procedures for people with developmental disabilities and to promote viable alternatives. The mission of its companion project, known as the Disability and Abuse Project, is to identify ways to reduce the risk of abuse, to promote healing for victims, and to seek justice for those who have been victimized. Both projects are functions of Spectrum Institute. (www.spectruminstitute.org)

Resource Materials

The website of the Disability and Abuse Project contains essays, commentaries, and reports that analyze supported decision making. <http://disabilityandabuse.org/supported-decision-making.htm> Included in these materials is a critical analysis of the “model legislation” on medical supported decision making agreements, as well as a presentation of principles that would need to be included in responsible legislation on this topic.

The website of the Disability and Guardianship Project contains many essays and reports about the need for adult guardianship reform. <http://spectruminstitute.org/publications/>