# MINUTES OF THE MEETING OF THE ASSEMBLY COMMITTEE ON JUDICIARY

# Seventy-Eighth Session February 23, 2015

The Committee on Judiciary was called to order by Chairman Ira Hansen at 8:59 a.m. on Monday, February 23, 2015, in Room 3138 of the Legislative Building, 401 South Carson St., Carson City, Nevada. The meeting was videoconferenced to Room 4406 of the Grant Sawyer State Office Building, 555 East Washington Avenue, Las Vegas, Nevada. Copies of the minutes, including the Agenda (Exhibit A), the Attendance Roster (Exhibit B), and other substantive exhibits, are available and on file in the Research Library of the Legislative Counsel Bureau and on the Nevada Legislature's website at www.leg.state.nv.us/App/NELIS/REL/78th2015. In addition, copies of the audio or video of the meeting may be purchased, for personal use only, through Legislative Bureau's **Publications** the Counsel Office (email: publications@lcb.state.nv.us; telephone: 775-684-6835).

### **COMMITTEE MEMBERS PRESENT:**

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

#### **COMMITTEE MEMBERS ABSENT:**

None

# **GUEST LEGISLATORS PRESENT:**

Assemblywoman Teresa Benitez-Thompson, Assembly District No. 27



# **STAFF MEMBERS PRESENT:**

Diane Thornton, Committee Policy Analyst Brad Wilkinson, Committee Counsel Linda Whimple, Committee Secretary Jamie Tierney, Committee Assistant

### **OTHERS PRESENT:**

Mary Bryant, Vice Chair, Nevada Commission on Services for People with Disabilities

Jon Sasser, Statewide Advocacy Coordinator, Washoe Legal Services Sally Ramm, Elder Rights Attorney, Aging and Disability Services Division, Department of Health and Human Services

Jana Spoor, Private Citizen, Dayton, Nevada
Travis Mills, Private Citizen, Reno, Nevada
Nicole Schomberg, Private Citizen, Reno, Nevada
Brian Patchett, President/Chief Executive Officer, Easter Seals Nevada
Ed Guthrie, Chief Executive Officer, Opportunity Village
Theresa Grant, Private Citizen, Reno, Nevada

#### Chairman Hansen:

[Roll was called and protocol was explained.] Good morning, everyone. We are going to start with our work session, and then move on to <u>Assembly Bill 128</u>.

Mark Olson, Private Citizen, Henderson, Nevada

Assembly Bill 12: Provides for the continuation of the diversion program that allows certain probation violators to receive treatment for alcohol or drug abuse or mental illness in lieu of revocation of probation. (BDR 14-341)

#### Diane Thornton, Committee Policy Analyst:

Assembly Bill 12 was heard in Committee on February 2, 2015. This bill provides for the continuation of the diversion program that allows certain probation violators to receive treatment for alcohol or drug abuse or mental illness in lieu of revocation of probation. The bill establishes a permanent diversion program providing treatment for alcohol or drug abuse or mental illness to certain probation violators in lieu of revocation of probation by removing the expiration of authorization. The provisions authorizing the program expire by limitation on July 1, 2015. This bill removes the expiration (Exhibit C). There are no proposed amendments.

#### Chairman Hansen:

I will entertain a motion at this time.

ASSEMBLYMAN OHRENSCHALL MOVED TO DO PASS ASSEMBLY BILL 12.

ASSEMBLYMAN THOMPSON SECONDED THE MOTION.

Is there any further discussion on the bill at this time?

#### **Assemblyman Ohrenschall:**

I think that time and time again therapeutic programs have been shown to be very effective and obviously the 2011 Legislature wanted to sunset on this to see how it would work. It looks like the results have been very favorable, and I commend you for processing this bill so quickly.

#### Chairman Hansen:

Is there any further discussion? [There was none.]

THE MOTION PASSED UNANIMOUSLY.

Assemblyman Thompson will handle the floor statement.

We will now begin our hearing on <u>Assembly Bill 128</u>, which creates a power of attorney for health care decisions for adults with intellectual disabilities. Assemblywoman Benitez-Thompson is here to present the bill.

Assembly Bill 128: Creates a power of attorney for health care decisions for adults with intellectual disabilities. (BDR 13-418)

#### Assemblywoman Teresa Benitez-Thompson, Assembly District No. 27:

I have prepared comments which are uploaded to the Nevada Electronic Legislative Information System (NELIS), which I want to read to you (Exhibit D), and then I want to walk you through the different sections of Assembly Bill 128. I would then like to have Mary Bryant provide more context of the bill and additional rationale for why this would be good to embed within our statutes.

During the past year and a half, I have had the pleasure of serving as Chair of the Interim Legislative Committee on Senior Citizens, Veterans and Adults with Special Needs, established by Nevada Revised Statutes (NRS) 218E.750. Committee Appointed members of the were Senator Hutchison, Senator Assemblywoman Senator Spearman, Manendo, Spiegel, Assemblyman Wheeler. The Committee met four times and discussed important policy measures pertaining to these very important constituencies.

[Assemblywoman Benitez-Thompson continued to read from prepared text (Exhibit D).]

Section 1 of A.B. 128 references the chapter. Section 2 references the intellectual disability, which definition of an means someone with "significantly subaverage general intellectual functioning existing concurrently with deficits in adapted behavior and manifested during the developmental period." This definition was put into place in 2011 by Senate Bill No. 149 of the 76th Session, which Senator Cegavske championed. This changed the term from "mental retardation" to "intellectual disability" throughout NRS. I would encourage you to read it, because what that bill also did was set the framework for the policy in the state of Nevada that we ought to find a way to recognize the individual, not their disability, and try by all means to engage them in decision-making processes. I think this bill helps support that intent.

Section 3 is where we actually get into the language for the suggested health care power of attorney for individuals with an intellectual disability. We do have in statute now a health care power of attorney. If you look deeper into this chapter you will find it. It is a 9-page form, and the intent behind the traditional health care power of attorney is that someone can make decisions for individuals about their health care preferences should they not be able to make those decisions. It is really designed for people who are completely incapacitated. A good example might be someone who is in a coma or unconscious and they cannot make their own health care decisions. It then names an agent to make decisions for them. It assumes that at the time the form is signed that the person is completely understanding of that 9-page legal document.

The traditional health care power of attorney has a lot of legalese in it. For the average person, if you read it once and understand it, you are an above-average person. It takes about three or four readings to really understand and appreciate what is going on—there are a lot of nuances in it—it is something that can be very difficult to understand. We would say that it is not possible for people with intellectual disabilities to completely understand and comprehend. It is too complicated.

I also want to set the framework that there is a federal Health Insurance Portability and Accountability Act (HIPAA) form and this health care power of attorney form is different from the HIPAA form. The federal HIPAA form states that you give permission to someone to have knowledge of your health care information. This form is different in that it is about a codecision-making authority between someone with an intellectual disability and someone they name and trust to help them make health care decisions. The ultimate goal

of this—and a trend nationwide—is to try to keep a person as independent as possible with supported decision making so they do not have to go through guardianship proceedings. A lot of people—although this Committee might be more aware than most because you handle the chapter and the subject matter—do not realize that when a person goes under guardianship, they lose all of their rights and they do not get to speak for themselves. We want to help these people have a voice as long as we can.

You are going to hear some suggestions from people on how to make this language a more cosupported decision, and those are all going to be friendly suggestions.

On page 3 of section 3, you will see that the language is simpler and easier for a person to understand. There is a signature line where they sign and date, that they understand they are naming someone as their agent to help them make decisions in a health care setting. Starting on line 17 you will also see where the agent will sign. You will notice that this also includes language on lines 23 through 28 that says "a physician, health care facility or other provider of health care that in good faith accepts an acknowledged power of attorney for health care is not subject to civil or criminal liability or discipline for unprofessional conduct for giving effect to a declaration contained...."

There are two ways to make this a valid document. One is to have it notarized, or you can have two witnesses sign it. That standard is what you see in the traditional health care power of attorney form. If you have it notarized, then there is a simple process where you have the notary sign. If you choose witnesses, you will see there are qualifications as to who can and cannot serve as a witness. You need two witnesses, and none of the witnesses are able to be providers of health care, employees of health care, an operator of a health care facility, or an employee of a health care facility. That is a really good check and balance which is already built into the traditional power of attorney.

The other one is that the actual person being designated as the agent cannot be a signee, which is another check and balance. At least one of the two people signing cannot be related to the principal by blood, marriage, or adoption, and they are not a person who would stand to inherit from the estate of the principal.

As you read through section 3, my hope is that you will appreciate that what we are trying to get at is a very simple form that is in as plain and simple English as we can possibly get so that people with an intellectual disability can participate in their own health care decision-making process. They can have

someone they know and trust to help support them in that decision-making process, so we can keep these people as independent for as long as we can.

I will open it up for questions, or have Mary Bryant testify and then have both of us available for questions if you would like.

#### Chairman Hansen:

I prefer to have Mrs. Bryant come up.

# Mary Bryant, Vice Chair, Nevada Commission on Services for People with Disabilities:

I am the vice chair of the Nevada Commission on Services for People with Disabilities but more importantly, I am a mom to Kailin, who is 20 years old and has Down syndrome. She is very bright and competent. She has worked her dream job at Bully's, and she went out and got it by herself. She owns a small business called KK Glass, where she makes beautiful fused glass pendants. She just got engaged, so she is planning a full life for herself. She will be getting married. While she is very competent, her brain works differently than other young women her age, and she usually makes good decisions, which might be unusual, too, for girls her age. She definitely knows her mind and she is often very sure of what she is doing. She was sure she did not want to get out of bed this morning to come down here. (Mary Bryant continued to read from prepared text (Exhibit E).]

As we were putting this together, we received some information from people who thought it could be made better, so we have really been looking at it and seeing if we could make some improvements to the verbiage and have people making more of the decisions as well as some safeguards in there.

# Jon Sasser, Statewide Advocacy Coordinator, Washoe Legal Services:

Today I am representing Washoe Legal Services; I am also the Legislative Chair for the Commission on Services for People with Disabilities. We think that A.B. 128 addresses an extremely important problem, which is the access to health care for adults with intellectual disabilities where they have had problems, as Ms. Bryant said, having a doctor either accepting their own consent to a medical procedure or accepting their consent on the current durable power of attorney form. Their concern is that the patient did not understand it. So putting that in simpler language for the adult with intellectual disabilities is a great idea and we support it fully.

Assemblywoman Benitez-Thompson asked me to review the language after it came out of the Legislative Counsel Bureau (LCB), and I think there are a couple of places where changes would help make the bill stronger in terms of the

supportive decision making. The current durable power of attorney has three sections. One is a long list of warnings, second is the body of the power of attorney, and third is a checklist of end-of-life decisions. I think the LCB has done a terrific job of putting that little section into layperson's language. I think there are a couple of important concepts in the early warnings that are not included that I think either need to be put into the document or addressed in another part of the chapter. The same for the end-of-life decisions—I do not think you want a person with this durable power of attorney making end-of-life decisions if there had not been any expression of what that person's intent was and explained to them. I would be glad to work with the bill sponsor and try to work those things out.

#### Chairman Hansen:

There are no amendments that I have seen on NELIS at this point, so any changes you have I will assume you will go directly to Assemblywoman Benitez-Thompson. Are there any questions?

### Assemblyman Gardner:

One of the concerns I have is I think there is a possibility for abuse in here. The way I read it is it exempts some areas such as health care workers, but it does not require it to be a relative. Most of the letters in support were "I want to do this for my son," "I want to do this for my daughter," "I want to do this for someone close to me." I do not know if we need to limit it to someone who is actually related, but I think there is a possibility for abuse.

Regarding competence assigned, you do not really explain the intellectual challenge of these people who have the powers of attorney, and the degradation on it. This person could basically be an average Joe and able to do everything to someone who is almost comatose and there really does not seem to be a difference on how this is going to happen. If you are an average Joe, then you are going to understand almost everything I tell you, but if you are on the other end of the spectrum, you may not understand anything I am telling you. I am a little concerned about that.

In the bill language, it is asking that the person with the disability be spoken to by the doctor and by the agent regarding health care issues they are planning on treating, even if that person is not understanding. I am wondering why that was included.

# **Assemblywoman Benitez-Thompson:**

I heard three points and I will go down them and I might ask a couple other people to chime in. One is consideration of making one of the signers a relative, if you use two witnesses, is something that we can consider. We did not want

to necessarily make this a document that could just be used for people who have intellectual disabilities that have very supportive families around them. Some people might have different types of support networks. I think the language does a good job of making sure that we keep out people who might have certain sets of conflicting interests; for example, people who are employees of health care facilities or work in the health care facilities. Perhaps there is a way, and a middle ground, to make sure that we have people who are close to them. We have the language that states that the two people have to be known to the person. In section 3, page 3, lines 37 through 39, it says "signed by at least two qualified witnesses who you know and who are present when you sign or acknowledge your signature." Would you look for something that better defines "to know a person"? Is that what you might suggest?

# **Assemblyman Gardner:**

Yes, I was thinking of something like that. Once again, these are people with intellectual disabilities. I apologize; I am an attorney, so that is why I am focusing on some of the details. I could argue and win on "I know you if I just met you." I could introduce two people to this person, and technically they can say they know the person. I am concerned if you leave it light, such as "Well, you know them." I could be trying to harm this person; I could get them to sign this form. By my reading, I could have those two people who just met be the signers, and that would be legal under this document. Maybe I am missing some language, but I am concerned about it. I do not think it is going to happen. I think there are a lot of safeguards in here, but I am concerned that what I just spoke of might be possible under this bill. I do not know the way to fix it, but I would be happy to work with you.

#### Assemblywoman Benitez-Thompson:

We will probably take you up on that offer to help define it. This is language taken from later in the section—the traditional power of attorney—but maybe we need more qualifiers in there for that protection part.

I am going to leave the discussion of the competency level for last because it is the hardest one, and I think has a bigger conversation. Your third point, which is within the language of section 3—I think we are looking at the second paragraph. I am looking at lines 19 through 21 where it states in part, "I would like the doctor to speak with my agent about my sickness or injury and whether I need any medicine or other treatment." Is that what you are referencing?

#### **Assemblyman Gardner:**

It is just below that on lines 29 through 32, where it says, "I would like the doctor at the hospital to speak with me about what care or treatment I should receive, even if I am unable to understand what is being said about me."

# **Assemblywoman Benitez-Thompson:**

I think the goal of this is to make sure the person is being acknowledged and spoken to directly as a person, keeping in line with the language we adopted in Senate Bill No. 149 of the 76th Session, which is that the person be treated like a person and not like a disability.

#### Mary Bryant:

Yes, I think it is really important to involve the person in the decision, even if they cannot completely understand all of the medical terms. I cannot understand all the medical terms, but I still want the doctor to talk to me. In this case, say it were my daughter, if the doctor was talking to both of us and she did not understand everything, then I could take what he said and put it in terms that she could understand and explain it to her better. I think it is really important that they still explain everything.

#### Assemblywoman Benitez-Thompson:

The second question was regarding competency level and how do we know that they are able to sign the form. That is a very good question. We made a decision not to put in hard metrics. An example would be that, technically, someone with an intellectual disability is a person with an intelligence quotient (IQ) at or below 70. There was conversation about whether we put it from 70 to 32, or how far down do we drop it. We realized that that hard metric number is not always in line with how a person presents and it is much more of a qualitative decision. I guess we could ask them to carry around a "this is my intellectual disability and this is my IQ level card" for when the person presents in the emergency room. I believe what we are looking for is that for the two people who know them and sign for them, they know what this person is capable of and they know it is a basic enough form that says, "I am asking for help when making these decisions."

#### Mary Bryant:

I think that is correct. I do not think we can put an IQ on it. I think it is going to be up to the person who wants assistance and their family to think this form will work for them. A lot of people it will not work for, but it will work for many.

#### **Assemblyman Gardner:**

You said that doctors were not accepting these forms. How do we know that if we change it to this the doctors will accept them?

# **Assemblywoman Benitez-Thompson:**

You are going to hear the families testify, and I think what has been Ms. Bryant's experience, is that the traditional health care power of attorney is complicated and high-level enough that many physicians assume that a person with any kind of intellectual disability cannot sign them at all because they are not competent to sign them. If we have a simpler form that is easy to understand, then their level of confidence in that competency of the form will go up.

# **Assemblyman Elliot T. Anderson:**

You have answered some of the questions that I was going to get into, such as capacity and tying down the definition. I would like to talk about the existing power of attorney that we have. I understand the concept and why you are trying to get the legalese out of it, because not everyone is an attorney. You have the Uniform Act specifying the power of attorney because doctors were having problems deciding what to accept and when to accept it, so the idea was to standardize it. Is there any way to try to rope in the existing power of attorney in trying to make it a little bit simpler without making a whole different one? I wonder about the health care providers in the state getting used to that power of attorney. We made it standardized so we would not run into those problems. Is there a way to do an attachment to it?

#### Assemblywoman Benitez-Thompson:

I think the point of this is to get away from the standardized language that is so complicated to understand. We see a trend nationwide to move towards simpler language to engage people who are intellectually disabled. The proposed language you see before you is what Michigan has accepted and used. We have not heard from the medical profession in Michigan that this was too hard, too complicated, or too confusing for them. Does that mean there does not need to be an educational component to this for the community and the physicians? No, I believe that it would be upon us as advocates to make sure that we are getting this form in front of the people so there is a higher comfort level with them. When something is new and different, there is going to be a discomfort level, a little bit of hesitancy, but we have seen this work well in other states and we hope that Nevada will follow suit.

# Assemblyman Elliot T. Anderson:

Following up on the capacity issue, would you anticipate that the people who would sign this form would have the capacity to sign different types of simple contracts?

# **Assemblywoman Benitez-Thompson:**

I am going to have Sally Ramm help me answer that because she is a lawyer. My understanding is that if a person can understand what they are signing, they are able to sign it, and the goal would be to make this form simple enough for a wider range of people to sign.

# Sally Ramm, Elder Rights Attorney, Aging and Disability Services Division, Department of Health and Human Services:

We run into this problem quite a lot with people with intellectual disabilities and with people who are older and in the beginning stages of some kind of dementia. Legally, if a person signs a contract and another person relies on that contract, it is actually deemed to be a valid contract. If someone challenges it, that is where the problem would come in. If someone challenges a contract that was signed by a person with intellectual disabilities and that person cannot then describe what they understand of that contract, and if the person who relied on the contract is sued for some reason, then there is a problem. The person who relied on the contract could be liable for some kind of damages or return of money or something. That happens in the retail area sometimes. But if a person can understand it, signs it, the person who relies on it can rely on the person understanding it unless someone challenges it. That is how the contract is. So if they can understand it when they sign it, it is a perfectly legal contract. If they are questioned on it, then the contract can hold.

#### **Assemblywoman Benitez-Thompson:**

Being a social worker in hospice, the health care power of attorney advance directives are forms that I often discuss with families. Having this form does not mean that there will not be potential disputes that come up. It is not uncommon for me to have a family where the dad has appointed a health care power of attorney and the siblings are suing each other over when he signed it and how he signed it. Within the traditional power of attorney framework there can be complications like that, but I do not think it should negate that form existing.

# **Assemblyman Nelson:**

I think this bill is a good idea. I have sat in my conference room with people many times trying to explain the power of attorney to them. These are people who probably have IQs over 100 and it takes forever; it is difficult language. However, I want to make the record clear that I am a little concerned by some

of the exhibits that give the impression that what this is doing is getting the person with the intellectual disability supported in the decision making. The way I read the bill, that is not really accurate. Some of the language, for example, from the Commission on Services for Persons with Disabilities is that "this increases the independence for persons with disabilities in Nevada." Another one that Ms. Bryant wrote is, "This new power of attorney form will help Nevadans with intellectual disabilities lead more self-determined lives by means of supported decision making." I think those are worthy goals but as I read the legislation, it says in there about seven times that the person with the power of attorney will be making the decision. Yes, I agree that this language is much more understandable for anyone to read and understand what they are getting into, but is it not true that the import of the bill is that the person with the power of attorney will make the ultimate decisions?

### **Assemblywoman Benitez-Thompson:**

What you speak about is one of the conversations we are having right now to adjust the language in section 3 to reflect more of a codecision-making ability, which is one of the amendments that you are going to see coming forward. There has been discussion that we add the phrase "and then discuss with me" after each place where we talk about when the agent receives information, there is the requirement for the agent to then turn around to discuss with the person what has been said and what the decisions available to them are. That is a very good point, because we want to move towards that goal and we realize that the language was not exactly reflective of that goal.

# **Assemblyman Nelson:**

That is a laudable goal, but the ultimate decision will need to be made by one person in case there is a disagreement. Is that correct?

# **Assemblywoman Benitez-Thompson:**

Yes. The goal in the supported decision making would be that we would have the person with the intellectual disabilities receiving the information, making the decision, and the agent would ultimately make the final decision, but we would still have a person who is not under a guardianship. Delaying those guardianship proceedings is one of the goals of this bill. I believe it is a step in the right direction to keeping that person's rights intact. Is there an exact way to slice decision making? Could we have codecision making and have both of them sign off? That might be more cumbersome but in the end, the goal is to help the person understand the decisions that are before them with someone that they trust and when that decision has to be made, it would be by the agent.

# **Mary Bryant:**

Thank you for that question because it is a ticklish one. I think one of the reasons that we have to have powers of attorney to start with is because the physicians will not take the word of, or do not think, the person with an intellectual disability is competent enough. By having another person who does not have an intellectual disability as the signer, I think it gives the physicians more confidence.

# **Assemblyman Ohrenschall:**

Thank you for bringing this bill. I have gone door-to-door, I knocked on doors, and some of those doors were adult group homes. I can see that this bill is badly needed. My question has to do with those people specifically—people who are living in the adult group homes. Could the owner of the group home or someone who works in the group home be the agent in order to take them to their doctor's appointments? What is happening now? Often, the people who are there do not have family close by. The people who run the group homes are the only caretakers they have.

#### Sally Ramm:

This document would not be appropriate for someone who is living in a group home for a couple of reasons. One reason would be that the document would not be valid unless there was a statement of competency attached because that is the law. The law now says that if you are in a group home, assisted living, or a long-term care facility of any kind, and if you sign a power of attorney, will, or any document like that, you have to have a statement of competency attached to it. In this situation, that would not work. I do not believe that these documents would be valid if they were signed in a group home.

Secondly, I do not believe that documents can be signed by an unrelated caregiver. The health care person or the operator of a health care facility, or someone like that, may not be specific enough to cover the group home operator, but I do not believe that the document would work within a group home setting.

### Assemblyman Ohrenschall:

My interpretation of lines 26 through 34, on page 4, was that the preclusion had to do with the witnessing—the preclusion of the provider of health care, not with actually being the agent. So I thought if someone lived in a group home, the owner or one of the representatives could be their agent if that was the only person they had. If I am misreading it, please explain.

# Sally Ramm:

There is another law in NRS Chapter 449 that precludes having long-term care facility operators or health care personnel be appointed as agents or inheritors.

#### Chairman Hansen:

Are there any other questions from the Committee? [There were none.] Is there anyone else in the audience who would like to speak in favor of A.B. 128?

# Jana Spoor, Private Citizen, Dayton, Nevada:

I have been a resident of Nevada for over 35 years. I am a deaf person and I help with my brother. He was born with developmental disabilities—cerebral palsy—he is a hydrocephalus baby, meaning water on the brain, and he had multiple surgeries on his brain from that. I am testifying on his behalf. He is currently in a hospital. He was a pedestrian that got hit by a car last month on South Virginia at the Meadowood Mall. This has been his area of living situation for 20 years. Ever since he was 18 years old he has lived on his own, and I am his representative payee for his social security. His social security check gets directly deposited to his account. He goes to the bank every month to verify his direct deposits, and then he pays his bills. He writes out his own checks, he goes to different utility companies to pay his bill in person, or he will mail his checks. He lives on his own in his own apartment and he works part-time at the Reno Target. His community is his apartment managers and the people who work there as well as the store members, his coworkers, and his bank, and they are his community-based support services. We have been alerted by the banks or the apartment manager that there are issues that we have to come in and address. There are people taking advantage of him, so they help us. He is not under a guardianship; we do not believe in that.

The power of attorney for health I can read right off the bat. Should he become incapacitated was a big issue for us because he is alert a lot of the times at the hospital. He is very, very self-sufficient, independent, and a wonderful, wonderful person. People do listen to him. I take him into Charter to get his bills reduced, and I will take him to AT&T and he speaks for himself. Watching him in health care, he speaks for himself. The doctors and nurses take advantage of him to a certain point with his disability because they are not notifying the family of issues.

My brother was struck by a car on January 23—it has been about four weeks. It was horrible. He has been in and out of the intensive care unit (ICU) twice. The second time he was in ICU was for pain that they failed to assess correctly. Of course, they blame it on his disabilities, but he is really easy to understand-he speaks for himself. When he is in pain along with other

symptoms, even I can see for myself that there is internal bleeding or there is an It was something that I had expected, and the nurses are really surprised that I am saying that. He was in a rehab hospital at that time. He had been in pain for eight hours, so he called a family member on his cell phone and said, "Please, please come help me. My back hurts." He is groaning and he clicks off. I got over there and I walked into his room. He was naked except for his underpants, and he was all crunched up in pain. When I walked in, it looked like a person in a mental health hospital. I am very sensitive to people with disabilities, and that really angers me that he was alone. His anxiety was through the roof. His eyes were rolling back, he was cold to the touch, and I had to yell for a nurse or a doctor to come. That was at 9:30 a.m. Apparently, at 9:20 a.m. they started the paperwork to get him transferred over. He missed his 7 a.m. appointment for therapy because he was in pain, and why they left him in pain for two more hours, I do not know. But the pain was from the bleeding in his stomach and in his pancreatic area. I do not know if anyone knows what that pain is like. He has high pain tolerance, and I can think of it as the equivalent of giving birth and the contraction of the muscle. That is how much pain my brother was in. It started at 1 a.m. They did not get him out of that facility until 9:30 that morning. If we had had more of the control in being his agent, that would have been avoided. I filed complaints with the state, with the nursing board, and with the medical examiner. I think having the document in place would have avoided all of that, and we would have had better communication between the doctors and nurses.

He was assigned a social worker, but I found that a social worker in a private setting is very different from a social worker in a governmental setting. I would ask the social worker about the regulations or the therapy, how many days, and I would be reading up on and finding information so that I am familiar with the services that my brother needs to be receiving. The social worker could not answer my questions. Out of the five different social workers assigned to him, one of them he had twice, but only one left me a business card, and the other three never did. If I asked the nurse something, she would say, "Well, the social worker will talk to Greg about that." That was the attitude I got from the nurse, and that is why I am in support of this bill. It is the answer to our questions. In obtaining an attorney for Greg to coordinate with the insurance company on medical bills, even he was surprised. "You do not have a guardianship?" I told him, "No, we do not believe in guardianships." There is a lot of education that still needs to be put out. My brother is very capable, but with the medical complexity of today, even taking him to the dentist I am going to need this form because he is going to need dentures, and we have that in place. Medical is very, very difficult. He is starting to tell people to talk to his sister.

#### **Assemblyman Wheeler:**

Are you saying that at your brother's level of disability, he will be able to understand this much more plain English form rather than the 9-page form that is currently in place?

# Jana Spoor:

I am glad you asked that; I was going to comment on it. Putting in the IQ levels or trying to put in a measure is going to be very difficult. I would not recommend it. My brother can read this new form. In fact, I was so excited when I read it. I love our *Nevada Revised Statutes*, and I read up on them quite frequently for my job and for personal use just to verify things. To see this for my brother, and my brother being able to read it, he will be able to say, "Yes, I want so-and-so," and he will be able to sign it. He can understand this document.

### Travis Mills, Private Citizen, Reno, Nevada:

I have an intellectual disability and my dad comes with me to my doctor appointments. He helps me explain what the doctor discusses for me. My mom and dad help me make my own health care decisions. The current power of attorney form is six pages long and it is very complicated for me to understand. So the new power of attorney form is much easier to understand. Please support A.B. 128. [Mr. Mills also submitted written testimony (Exhibit F).]

#### Chairman Hansen:

Thank you, Mr. Mills; well said.

#### Nicole Schomberg, Private Citizen, Reno, Nevada:

I am a member of the Nevada Commission on Services for Persons with Disabilities. I am also a parent of a young adult daughter with Down syndrome. I am here today to ask for your support in favor of A.B. 128. I believe A.B. 128 creates a new power of attorney form that can be used by people with intellectual disabilities for health care decisions.

My daughter, Heather, is a 26-year-old, very independent young adult. She graduated from Earl Wooster High School in 2008 where she was homecoming queen and modeled in the senior fashion show. She is currently employed as an independent contractor for Esprit Salon and Paul Mitchell Beauty School. Heather loves all facets of the fashion and beauty world. She collects handbags and has her nails done regularly. She is a super star dancer with The Note-Ables, which is where she met her boyfriend, Mike. Heather enjoys a full life and is her own legal guardian. She does, however, from time to time ask and require assistance from her parents and siblings to

help make decisions about home, career, community involvement, health, and social life. A power of attorney like the one proposed in <u>A.B. 128</u> preserves her rights as an independent adult. [Continued to read from prepared text (Exhibit G).]

I think that is where supported decision making and self-determination comes in—they are deciding that they want to use this form to help with their decision making. I think it helps my daughter preserve her independence and lets her maintain her own guardianship and her dream of getting married and living a full life. Thank you for your valuable time and consideration.

#### Assemblyman Araujo:

I wanted to take the time to thank all three of you for coming out here. I know it can be a little scary to testify, but it really hits home when we can hear these real-life scenarios and see how this bill would impact your lives. Thank you for being here today and testifying.

# **Assemblyman Elliot T. Anderson:**

I want to ditto Assemblyman Araujo and say that it is very helpful to get an idea of who this might help. It is very useful for all three of you to come here and tell your stories.

#### Chairman Hansen:

Thank you very much; very well done today.

# Brian Patchett, President/Chief Executive Officer, Easter Seals Nevada:

I am the CEO of Easter Seals Nevada and the Chair on the Commission on Services for People with Disabilities. I am also a person with a disability. I do not have much to add other than what has been said by my colleagues on the Commission. I am in support of A.B. 128. I believe this is a much-needed bill for the reasons that have been stated (Exhibit H). I am very happy to hear the willingness to work on tweaking some of that bill. I appreciate Assemblywoman Benitez-Thompson's efforts during the interim to put this together and work with our Commission, and I want to thank you all for the conversation that has taken place today. Again, I ask for support of this bill.

# Ed Guthrie, Chief Executive Officer, Opportunity Village:

Opportunity Village is a community rehabilitation program in southern Nevada that serves almost 2,000 individuals who have intellectual disabilities, and it can be youth or adults with the intellectual disabilities. I think one of the things that was brought up today which is important for the Committee to understand is that in medical procedures, there are really—this is a broad-brush generalization—two categories. There are life-threatening situations that

happen to an individual, and in those cases any medical professional can provide any service and it is okay. They are not going to stop doing something because of it. In the case of an abscessed tooth or other similar issue, it can be very painful. The medical professional is worried that if the individual does not understand the ramifications of what is happening to them, then that medical professional can be sued. I have had people whom we have served that had to wait hours if not days—and in some cases longer than that—to receive a service and to endure the pain while they were waiting for the service, so the medical professional can make sure there is a court order or document that makes them feel comfortable that they are not going to be sued when they are providing this service. I think it is really important that we somehow short-circuit that, and I think this bill allows us to do that so the individuals do not endure any more pain than the average individual would when having to get a procedure done.

The second thing that I want to make the Committee realize is that most individuals with intellectual disabilities—some of them have severe intellectual disabilities—do not have guardianship. They live with mom and dad, brother and sister, and these are the people who have been helping them with their decisions all of their life, especially up to age 18. They are making all of those decisions. Guardianships are a very complicated process, and many of the families do not choose to go through the guardianship process. If they are able to go through this process, it allows them to do the power of attorney rather than going through the guardianship process.

#### Chairman Hansen:

Are there any questions? [There were none.] Is there anyone in Las Vegas who would like to testify in favor of A.B. 128? [There was no one.] Is there anyone in Carson City who would like to testify in favor of A.B. 128?

#### Theresa Grant, Private Citizen, Reno, Nevada:

I brought my son, Elliott, with me. He is 17 years old and very active in the community. He is in his second year of Junior Reserved Officers' Training Corps at Reno High School. He works part-time at Trader Joe's. We do not plan to have guardianship over him as we do not want to limit the things he wants in his life, such as getting married, living on his own, owning a home, et cetera. When my family and I read this form together, we liked it. I want to have A.B. 128 to help my son. My 12-year-old said, "We need this form. Being in the hospital is very stressful." I totally agree with him. When I read this, I saw more into it. Many people seem to lump people with intellectual disabilities into one box, where there are many levels—they all have their strengths and weaknesses. Each individual is unique, whether they have a disability or not. I think sometimes in situations at the hospital, physicians do not even acknowledge individuals with intellectual disabilities. They do not

know what their level is. I know two occasions where parents of a child with an intellectual disability had to tell the doctor, "Please do all you can to help him. We love him. He is an important part of our lives and community." I think that is really sad that one even has to say that.

When I read this, I saw this as a way of treating people with intellectual disabilities with respect and dignity and acknowledging them as well as their agent. It says, "I would like the people who work at the hospital to try very hard to care for me." That is kind of sad, but that is reality. I do think this will give people with intellectual disabilities a little more respect and acknowledgement when they are being cared for in the hospital. That is another thing that I really like about this. [Submitted testimony (Exhibit I).]

#### Chairman Hansen:

Are there any questions at this time? [There were none.] Is there anyone else in Carson City who would like to testify in favor of A.B. 128? [There was no one.] Is there anyone in Las Vegas who would like to testify in favor of A.B. 128? [There was no one.] We will now open the testimony in opposition to A.B. 128. Is there anyone in Carson City who would like to testify against the bill? [There was no one.] Is there anyone in Las Vegas who would like to testify against the bill?

#### Mark Olson, Private Citizen, Henderson, Nevada:

On Friday, I submitted written testimony and expert analysis of the bill through the system and instructions at the bottom of the agenda (<u>Exhibit J</u>). I am not sure everyone has it, but I am more than happy to read the letter that covered the testimony that I sent in. I also have additional remarks that I prepared for today.

#### **Chairman Hansen:**

Mr. Olson, we have it on NELIS, so frankly we would prefer that you not read the entire thing. If you would like to do a synopsis of it that would be fine, and if you have additional comments, please proceed.

#### Mark Olson:

I am the father and legal guardian of my 19-year-old daughter, Lindsey, who has autism, some intellectual disability, epilepsy, and a condition called polycystic ovarian syndrome. She is also nonverbal. I am also an advocate for the human and civil rights of persons with disabilities, especially adults with autism and related developmental disabilities.

As I said in the documents I submitted, I believe guardianship and the power of attorney process in Nevada needs considerable change, and I think we need

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. Just as importantly, these changes need to be carefully considered and thoroughly evaluated. The law in many areas involving persons with disabilities is changing rapidly and dramatically. In other areas, medical decision making and the urgent needs of persons with disabilities and their families for access to services are running up against definitions of competency, fiducial liability, tort laws, and federal regulations.

I am here today to voice my opposition to <u>A.B. 128</u> as written and being considered by this Committee. I think the bill is certainly well-intentioned and I absolutely take to heart the comments of the people who have spoken in support of it. Curiously, I find myself in a very unusual situation today, opposing Mr. Guthrie and Mr. Patchett and other members here. I am typically on the same side with them, so it is a bit unusual for me. I believe the bill is well-intentioned, but I also believe that it is fatally flawed. It reduces or eliminates too many of the rights and protections afforded under state and federal laws for persons with disabilities. This bill is not supported decision making. It is substituted decision making. The flaws are detailed in the expert analysis that I have provided which has been uploaded to NELIS (Exhibit K).

This arrived to me last night and did not meet your deadline for Friday, but I have received a clinical analysis of <u>A.B. 128</u> separate from the legal analysis. It was prepared by Dr. Nora Baladerian of the Disability and Abuse Project (<u>Exhibit L</u>). She is a clinical psychologist with four years of experience working with people with disabilities, including intellectual disabilities. I am prepared to read that into the record now, or if you have it in your system, I am certainly happy to waive the reading of it.

#### **Chairman Hansen:**

You could do a brief synopsis. The analysis is in the record.

#### Mark Olson:

I believe the bill as written fails to respond to BDR 13-418 approved by the Interim Legislative Committee on Senior Citizens, Veterans and Adults with Special Needs on August 15, 2014. We are at a time of great change in the disability community. The good news is that we are creating many exciting opportunities and reducing the longstanding barriers to enabling persons with disabilities to live the lives they choose. Unfortunately, some of this change is also bringing the erosion of rights of persons with disabilities at state and federal levels and also, unfortunately, by people and agencies who are advocates for the rights of persons with disabilities. The problems this creates is that it divides our community and sends conflicting messages to people such

as yourself. Nevada should not rush into enacting flawed legislation but rather take the time to craft legislation for the Nevadans with intellectual disabilities.

#### Assemblyman Thompson:

I was listening to you talk and I appreciate your being very thorough with your comments. One thing really hit my mind when you were saying "as written." I am just wondering—because the beauty of this is that we are able to negotiate and try to amend—are you completely opposed to this, or are you able to see some other areas included to make it whole for you?

#### Mark Olson:

I was very specific in saying "as written" for the purpose that you identify. I am not a lawyer, and I have relied on the help of lawyers who are experts in this area. The conversation that we have had is that there are substantial defects to this bill in its current form. I am not saying that we could not work together and craft enough fixes to make it palatable, but the conversations that I have had with the people assisting me have been such that by the time you get done putting back in the rights and protections that are under the existing power of attorney, you essentially have the existing power of attorney form again.

What has been proposed to me, and certainly makes sense, is that Title III of the American with Disabilities Act provides for accommodation for individuals with disabilities to be able to understand policies, practices, systems, and other things. The simplifying of the language in this power of attorney form could just as easily have been in an accompanying document, a multimedia presentation, a booklet, or some other document that explains each section in whatever detail was necessary for the individual to be able to comprehend it without sacrificing the legal fences that are contained within the power of attorney. I volunteered to the Commission on Services for People with Disabilities and to Ms. Bryant, and I am more than happy to work with them to see if we could craft something in that area. Again, the people I have consulted with have indicated to me that the flaws are significant enough that the bill as written may not be salvageable in the sense they were returning to the current power of attorney form.

#### Chairman Hansen:

Thank you, Mr. Olson. Is there anyone else in Las Vegas who would like to testify in opposition to the bill at this time?

#### Mark Olson:

No.

#### Chairman Hansen:

Thank you very much; I appreciate your testimony this morning. Is there anyone in Carson City who would like to testify in opposition at this time? [There was no one.] Is there anyone in Carson City or Las Vegas who would like to testify in the neutral position on A.B. 128? [There was no one.] Assemblywoman Benitez-Thompson, if you would like to come and wrap it up. There was a lot of very interesting, emotional, and heartrendingly frank testimony today.

# **Assemblywoman Benitez-Thompson:**

Thank you for hearing this bill. It is an interesting conversation and an important public policy conversation to say that our current legal framework is "You make your own decisions or someone else makes them for you under guardianship." There is not a middle space by which supportive decision making is recognized in law, and I think we have to get away from that either/or to create a space for these very important people. I am very much interested in making sure that we have Nevada lawyers involved in this. I think they are going to be our best legal experts as to how we can make a law that fits right for the needs of Nevada.

I would like to mention for the record—because I think it is especially important—but it was not mentioned that Mr. Travis Mills, who testified, is administrative faculty at the University of Nevada, Reno. I just want to acknowledge his job with how far he has come and how accomplished he is.

There are additional comments that I believe were uploaded to NELIS, and I just want to reference them so that they are sure to be included as part of the minutes of this meeting. I look forward to working with advocates on making sure our language is the most reflective in section 3 that it can be supportive decision making. There are some elements to this that are tricky and really force us to think in a different way than we have thought before, and to acknowledge what individuals with intellectual disabilities are able to do, and to give them the support to make decisions so they can have as much autonomy as possible. Thank you so much for the time today and for the hearing. I appreciate it.

#### **Assemblyman Wheeler:**

I want to thank you. You did a good job on that committee. This bill was done in a very bipartisan way, and it absolutely includes a segment of our population that has not been included before. Thank you for bringing this forward; it is a good bill.

# **Assemblywoman Benitez-Thompson:**

Thank you, Assemblyman Wheeler. You were such an active participant in that committee, and I think we did good work as committee members, but I am biased.

### Chairman Hansen:

At this time I am going to close the hearing on A.B. 128 and open it up for public comment. Is there anyone who would like to have the floor to talk about anything they would like, either in Carson City or Las Vegas? [There was no one.] Seeing none, this meeting is adjourned [at 10:13 a.m.].

[All items submitted on NELIS but not discussed will become part of the record: (Exhibit M), (Exhibit N), (Exhibit O), (Exhibit P), and (Exhibit Q).]

	RESPECTFULLY SUBMITTED:	
	Linda Whimple	
	Committee Secretary	
APPROVED BY:		
Assemblyman Ira Hansen, Chairman		
DATE:		

# **EXHIBITS**

Committee Name: Committee on Judiciary

Date: February 23, 2015 Time of Meeting: 8:59 a.m.

Bill	Exhibit	Witness / Agency	Description
	Α		Agenda
	В		Attendance Roster
A.B. 12	С	Diane Thornton	Work Session Document
A.B. 128	D	Assemblywoman Teresa Benitez-Thompson	Testimony
A.B. 128	E	Mary Bryant, Nevada Commission on Services for People with Disabilities	Testimony
A.B. 128	F	Travis Mills	Testimony
A.B. 128	G	Nicole Schomberg	Testimony
A.B. 128	Н	Brian Patchett, President/CEO, Easter Seals Nevada	Testimony
A.B. 128	I	Theresa Grant	Testimony
A.B. 128	J	Mark Olson	Testimony
A.B. 128	K	Spectrum Institute	Clinical Analysis
A.B. 128	L	Spectrum Institute	Power of Attorney Liability Concerns
A.B. 128	М	Laura Jenkins	Testimony
A.B. 128	N	Richard and Kathy Mills	Testimony
A.B. 128	О	Janice John, Department of Employment, Training, and Rehabilitation	Testimony
A.B. 128	Р	Nevada's Governor's Council on Developmental Disabilities	Testimony
A.B. 128	Q	Spectrum Institute	Response to Testimony