

**MINUTES OF THE MEETING
OF THE
ASSEMBLY COMMITTEE ON HEALTH AND HUMAN SERVICES**

**Seventy-Fourth Session
March 21, 2007**

The Committee on Health and Human Services was called to order by Chair Sheila Leslie at 1:34 p.m., on Wednesday, March 21, 2007, in Room 3138 of the Legislative Building, 401 South Carson Street, Carson City, 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/74th/committees/. In addition, copies of the audio record may be purchased through the Legislative Counsel Bureau's Publications Office (email: publications@lcb.state.nv.us; telephone: 775-684-6835).

COMMITTEE MEMBERS PRESENT:

Assemblywoman Sheila Leslie, Chair
Assemblywoman Susan I. Gerhardt, Vice Chair
Assemblyman Bob L. Beers
Assemblyman Joseph P. (Joe) Hardy
Assemblywoman Ellen Koivisto
Assemblywoman Kathy McClain
Assemblywoman Bonnie Parnell
Assemblywoman Peggy Pierce
Assemblyman Lynn D. Stewart
Assemblywoman Valerie E. Weber
Assemblywoman RoseMary Womack

GUEST LEGISLATORS PRESENT:

Assemblyman Garn Mabey, Clark County Assembly District No. 2
Assemblyman David P. Bobzien, Washoe County Assembly District
No. 24
Assemblyman Ty Cobb, Washoe County Assembly District No. 26



STAFF MEMBERS PRESENT:

Sarah J. Lutter, Committee Policy Analyst
Katrina Zach, Committee Secretary
Olivia Lloyd, Committee Assistant

OTHERS PRESENT:

Dr. Luana Ritch, Chief, Health Division, Department of Health and Human Services, Carson City, Nevada
Dr. Barbara Thornton, Founder, Nevada Center for Ethics and Health Policy, University of Nevada, Reno
Dr. Noel Tiano, Director, Nevada Center for Ethics and Health Policy, University of Nevada, Reno
Sally Hardwick, Long Term Care Facility Outreach, Nevada Center for Ethics and Health Policy, University of Nevada, Reno
Nicole Lambole, Chief Deputy, Office of the Secretary of State, Carson City, Nevada
Bobbie Gang, Private Citizen, Carson City, Nevada
Jon Sasser, Attorney, Washoe Legal Services, Reno, Nevada
Jan Gilbert, Private Citizen, Reno, Nevada
Pastor Thomas Beck, Private Citizen, Reno, Nevada
Patricia Glenn, President, Nevada Right to Life, Reno
Melissa Clement, Private Citizen, Reno, Nevada
Don Nelson, President, Nevada Life, Sparks
Janine Hansen, President, Nevada Eagle Forum, Elko
Mary Wherry, Deputy Administrator, Department of Human Resources, Division of Health Care Financing and Policy, Carson City, Nevada
Peter Burns, Attorney, Burns & Associates, Phoenix, Arizona

Chair Leslie:

The Committee will come to order, please. [Roll called.] We have two Committee introductions.

BDR 39-1376—Revises provisions governing the sealing of records concerning a person's admission to a hospital or mental health facility under certain circumstances. (Later introduced as [Assembly Bill 490](#).)

ASSEMBLYWOMAN WOMACK MOVED TO INTRODUCE
BDR 39-1376.

ASSEMBLYMAN STEWART SECONDED THE MOTION.

THE MOTION PASSED UNANIMOUSLY.

BDR 54-1339—Makes various changes concerning the clinical education of a student in a school of nursing. (Later introduced as [Assembly Bill 491](#).)

ASSEMBLYMAN STEWART MOVED TO INTRODUCE
BDR 54-1339.

ASSEMBLYMAN BEERS SECONDED THE MOTION.

THE MOTION PASSED UNANIMOUSLY.

Chair Leslie:

We have three bills today: [Assembly Bill 388](#), [Assembly Bill 158](#), and [Assembly Bill 390](#). Committee, we have four bills on our work session, and it is my hope we will get to those today. Right now we will hear [Assembly Bill 388](#) from Dr. Mabey.

[Assembly Bill 388](#): Requires the State Plan for Medicaid to include a provision authorizing pregnant women to obtain certain health care services from any provider of health care of their choice in certain circumstances. (BDR 38-1104)

Assemblyman Garn Mabey, Clark County Assembly District No. 2:

I asked the Chair to withdraw the bill for now. A few years ago, the Health Management Organizations (HMO) in Nevada took over the care of all the obstetric patients. I was concerned that the patients could not get access to obstetricians quickly enough. I met with Charles Duarte and Mary Wherry. I also learned that [Assembly Bill 388](#) might cause a number of unintended consequences. For those reasons, I have asked the Chair not to consider the bill. She can use it if there is a need.

Chair Leslie:

Thank you. We do miss your expertise on this Committee. We will do the honor of not indefinitely postponing it in case we need it. I appreciate your willingness for the Committee to hold onto the bill, but it is not my intention to process the bill. Are there any questions for Dr. Mabey? [There is no

response.] We will close the hearing on Assembly Bill 388. We will move to Assembly Bill 158.

Assembly Bill 158: Requires the Secretary of State to establish and maintain the Registry of Advance Directives for Health Care on his Internet website. (BDR 40-927)

Assemblyman David P. Bobzien, Washoe County Assembly District No. 24:

Before I begin the presentation, I have a disclosure. I would like to disclose, pursuant to *Nevada Revised Statutes* (NRS) 281.501, that I am employed by the University of Nevada, Reno (UNR), which is an agency of the state government. I hold the position of campus webmaster. In that capacity, I direct the planning, development, and maintenance of UNR's website. It is my understanding that the Nevada Center for Ethics and Health Policy of UNR is a proponent of Assembly Bill 158. The benefit or detriment accruing to UNR as the result of a passage of this bill is not greater than that accruing to any of the various other schools within the Nevada System of Higher Education, or any other group advocating for the creation of a voluntary repository for advance directives. I am required to make this disclosure, but I am not required to abstain from voting on this bill.

Assembly Bill 158 creates an online repository for living wills or advance directives on the Secretary of State's website that will be accessible to registrants and their health care providers. As you may know, this legislation produced a great amount of interest, and I am very heartened to know that many people consider this an important issue here in the state of Nevada.

This legislation will create a voluntary registry for families of patients and health care professionals for the storage and retrieval of living wills, ensuring that the end-of-life decisions of patients are honored. It would help alleviate cases in which living wills are lost or cannot be retrieved quickly in times of medical emergency. Overall, I believe it will help reduce suffering to individuals and their families.

This is truly an issue of life and death, and as such, it is very understandable that there are numerous opinions about this legislation. This bill will not change the way advance directives are implemented or defined. It will not allow health care professionals to deny medical services or basic necessities to a patient. It will not charge the Secretary of State with making decisions regarding living wills or their implementation. It will not make the living will registry a public record; only registrants and a registrant's health care provider will have access. It will not expand or limit any liability on the part of health care providers when it comes to the implementation of living wills.

In summary, my intention is to provide a value neutral option to individuals and their families to make sure their end-of-life decisions are honored. There are certainly a number of sides to the debate about end-of-life issues and it is not my intention to enter that discussion, but only to empower those who wish to take advantage of this voluntary service.

I would like to go over some exhibits. First, *The New York Times* opinion editorial ([Exhibit C](#)) is about the Terri Schiavo situation and why it is a good idea to consider an advance directive. Second, there is a memorandum ([Exhibit D](#)) from the Research Division of the Legislative Counsel Bureau regarding the implementation of advance directive repositories in other states. The researcher found that a number of states are already doing this, so Nevada is not necessarily breaking new ground. Third, there is a print-out ([Exhibit E](#)) from the Arizona Secretary of State website. Today, you will hear issues regarding the implementation of an advance directive registry and it will be worked out following the passage of Assembly Bill 158. Whatever you read here, do not take that as what the situation will be in Nevada. Finally, there is a letter ([Exhibit F](#)) of support from trial attorney Mr. Jim Crockett, and he provides an analysis of Assembly Bill 158.

Barbara Thornton, Noel Tiano, and Sally Hardwick from the Nevada Center for Ethics and Health Policy are with me today. They will provide more background on this proposal. Nicole Lamboley from the Nevada Secretary of State's Office is here and she can provide research on how to implement this program. Bobbie Gang will provide an illuminating story on why we need this legislation. I recently communicated with Patricia Glenn of Nevada Right to Life about possible amendments that she will be bringing to the table.

There is concern about Section 6 of Assembly Bill 158, which explains how the registry will work. Section 6 states, ". . . accessible portion of the website, the name of each registrant. . . ." After that, it states a member of the public cannot access the secure part of the website. There is a concern that names should not appear in the public portion of the website, and it is our belief that we do not necessarily need those names there. We are supportive of Patricia Glenn's first amendment, but I am not sure if the other amendments are consistent with the scope of this legislation.

Chair Leslie:

Regarding the Arizona Secretary of State website ([Exhibit E](#)), it looks like it is up to you to give your registry password to a loved one, a doctor, or whoever. Is that what is envisioned in Assembly Bill 158?

Assemblyman Bobzien:

Yes.

Chair Leslie:

As I understand it, it is completely voluntary. If any resident of Nevada does not want to do it, they do not have to do it.

Assemblyman Bobzien:

Correct. To reiterate my approach, matters of conscience and end-of-life decisions are intensely personal. The State, I believe, has no business in those decisions. This service would exist as a voluntary service. You can take advantage of it if you choose.

Chair Leslie:

Through your amendment, my name will not show up anywhere. The only way you could find out is if you have the password.

Assemblyman Bobzien:

That is correct.

Chair Leslie:

It protects a person's privacy.

Assemblywoman Womack:

How would the registry help the hospital or medical facility?

Assemblyman Bobzien:

For example, your relative has an advance directive located at the Secretary of State's registry. In the event of a medical emergency you could inform the health provider that your relative has an advance directive on file with the registry, and the health care provider would have exclusive access to the registry. This is the situation we are trying to alleviate. When someone executes an advance directive it goes into a drawer or safe deposit box or stays with the attorney. In the event of a medical emergency, no one can find it. That is the problem we are trying to alleviate.

Assemblywoman Womack:

What about the elderly living in nursing homes who have advance directives? My mother had an advance directive but they could not find it during an emergency, so she was resuscitated three times on the way to the hospital. Maybe access could be reassigned to the nursing home rather than just to an individual.

Assemblyman Bobzien:

In that situation, you are talking about a health care provider.

Assemblywoman Koivisto:

What if someone executed an advance directive prior to having serious surgery, what would happen to the advance directive? Would it stay with the hospital? Would it expire at a given time?

Assemblyman Bobzien:

I envision the service as a supplement to the existing situation on advance directives. If you executed an advance directive at a hospital prior to surgery, I am guessing you do not have time to file it with the registry. Your advance directive that was just executed is the advance directive. For instance, if a subsequent advance directive was filed and you changed your mind, but you have an existing one in the Secretary of State's office, the subsequent advance directive still holds the power. Again, it is not our intent to tinker with advance directives, only to provide a service that would act as a supplement.

Assemblywoman Pierce:

When you have surgery, your advance directive is put under the gurney and you tell somebody it is there. Then they give it back to you after the surgery and you take it home. When I need surgery, it takes 45 minutes to find my advance directive. I would be very happy if someone else would take that responsibility off my hands.

Assemblyman Beers:

A number of us have received numerous emails on this issue. A section of Assembly 158 mentions withdrawing food and water. I did some research and found NRS 449.624, which allows the withdrawal of food and water only with informed consent or by a previously authorized representative, both of which are forms of advance directives. As a form of disclosure, I have a relative who is slowly passing away. She is not here mentally, just physically. I have support for this bill now.

Assemblyman Bobzien:

Thank you very much for sharing that perspective, and for reminding us this is a very important matter. Thank you for your diligence in reviewing those statutes. Again, it is my intent to merely provide reference to what is already in statute so we can discuss advance directives and how they are executed rather than revising them.

Assemblyman Hardy:

Anyone that electively goes to a hospital is asked if they have an advance directive. If the patient does not have one, they are asked if they would want one. Problems occur in emergency rooms, or as Ms. Womack alluded to, problems also occur in ambulances. People should be able to print their advance directives from the website so people like Ms. Pierce will not have to spend a lot of time looking for it. I did not find the primary form for advance directives. I am curious to see your information.

Assemblyman Bobzien:

I will defer that concern to the folks from the Nevada Center for Ethics and Health Policy. I will make the disclosure that I have not filled out my own advance directive. When I first met with the people from the Nevada Center for Ethics and Health Policy, they all pulled their advance directives from their wallets. I realize I am behind the times, but I will let them answer your questions.

Assemblyman Hardy:

I am concerned about the updates. One challenge of the public access of advance directives is the implication that everyone on the website does not want medical intervention in case of an emergency. In reality, the form provides choices of what you want done. A problem could occur if someone assumes you did not want intervention when you requested the opposite. According to the bill, they are not liable. How long does it take to update the advance directive form? Who is responsible? What is the timeline? I have patients who have changed their mind. We have to ensure that the person who says he does not want medical intervention actually wants that.

Assemblyman Bobzien:

I will refer both those issues to Nicole Lambole. Again, this is merely a supplement to a properly executed advance directive. If you decide you want to change your advance directive and you properly execute the change, clearly you have the document you need. It is the document that will be used. The Secretary of State's office will have to decide how long it takes to submit a change to an advance directive.

Assemblyman Hardy:

This raises more questions than answers. If a person has a document in their possession, it takes priority over the one on the website. Medical professionals must honor the most recent document whether it is on the website or written down. Is that correct?

Assemblyman Bobzien:

That would be my understanding.

Chair Leslie:

In an emergency, no one is going to stop and search for paperwork. It is usually after the fact.

Assemblyman Hardy:

In an emergency situation, we do code. We start medical treatment and we do not ask the patient if she has something in her wallet. We do not wait for paperwork. We are deferring to life at the expense of the wishes of the patient who may not want that.

Chair Leslie:

I think it is important to clarify that. We need to look at every possibility.

Assemblyman Hardy:

In Boulder City, for instance, there is a fire department that has a registry of people who do not want medical intervention. A person can file a report with the Boulder City fire department and it is good for 90 days. You need to renew the report every 90 days. If the report is not renewed, and the fire department is called to your home, what do they do? The bill will help that situation. The person who is frantically looking for a loved one's advance directive will be able to go to the website, print it out, and give it to the fireman. It helps paramedics as well as physicians. While you do want to treat the patient, you also do not want to go against the wishes of someone who may not want medical intervention.

Assemblywoman Weber:

Section 9 of Assembly Bill 158 talks about the removal of advance directives. Can you walk us through Section 9? I do not know how registration is done, or what happens when a person is removed from the registry or when mistakes are made. It says an advance directive can be removed every five years. When they compare it to the vital statistics, some information needs to match so we know that it is the right person. I do not know if that is stated in the bill. Is there a notice sent to the next of kin to verify the individual's situation?

Assemblyman Bobzien:

I am not familiar with the procedures of the Office of Vital Records. I am not sure if I can comment on that, but we have someone who can.

Dr. Luana Ritch, Chief, State of Nevada Department of Health and Human Services, Health Division:

In compliance with Section 9, the Office of Vital Records would provide the Secretary of State with read only access to the Nevada Electronic Death Registration System for verification of advance directives, which may be removed from the registry. This activity will not have fiscal impact on the Office of Vital Records, and would give the Secretary of State the ability to conduct direct searches of the death registry. The Secretary of State would need to have enough individual identifiers to be able to match the advance directive individual to the death certificate. If they are able to make a full match, then they know there is a certifiable death certificate in the system.

Assemblywoman Weber:

Maybe we could leave people in the registry and just show the date of death instead of removing them from the system. It may give some reassurance that there will not be any mistakes. If there is a mistake, then it could be fixed through both divisions.

Assemblyman Hardy:

Can I print out information from the website if it is read only access?

Luana Ritch:

Read only access means you cannot go in and change information in the death certificate file. You can see the information, but you cannot make any changes.

Chair Leslie:

I think they are completely different. Mr. Bobzien, the intent is that people can download a copy of the advance directive.

Assemblyman Bobzien:

That is correct. In regards to Ms. Weber's suggestion, I will talk it over with some folks. I will have to do more investigation on that.

Dr. Barbara Thornton, Founder, Nevada Center for Ethics and Health Policy, University of Nevada, Reno:

[Submitted ([Exhibit G](#)).] I have been doing end-of-life and ethics work for 30 years. I would like to make it very clear that the Nevada Center for Ethics and Health Policy does not take positions on issues. We are here to discuss a process we think is important to all Nevadans, but you will not see us take positions on vital issues such as euthanasia or physician-assisted suicide. We are a state-funded organization.

Assembly Bill 158 is a very simple bill if we do not allow it to become complicated. The bill simply allows Nevadans to put a copy of their advance directive on file. It is no more and no less. We are not asking to discuss or change advance directives but only to set up a process for how those advance directives can be accessed. I have done end-of-life work for years and I have had to deal with people who cannot find their advance directives. My most poignant case deals with a doctor's wife. The doctor died and no one could find a living will for his wife. Eight months after the wife passed away, they found the advance directive. That is one of the most extreme cases that I have seen. We educate people on this process at the Nevada Center for Ethics and Health Policy. We need to make advance directives very accessible and we need to make sure Assembly Bill 158 does not get complicated with what should or should not be in an advance directive.

Nevada has strict provisions on how advance directives should be done. Places like our center will issue forms for advance directives. Sometimes advance directives are misunderstood. With advance directives, you can ask for all the care in the world you want. A section of the bill focused too much on how a person can withdraw treatment, but we are just as concerned about people who want to have extensive treatment. We just want people's wishes known.

It is important for us to work with people on all sides of this issue. Years ago, Frankie Sue del Papa and I co-chaired a task force for Death With Dignity. We made sure that people of all political persuasions, religious denominations, and views on end-of-life were included. Patricia Glenn, who will present a few amendments today, was a member of that task force. She was also a speaker at my ethics class. It is important that people on all sides are included when we discuss ethical issues.

Assemblywoman McClain:

When you were talking about other states doing this, I realized this is a good thing if you are on a vacation in another state and something happens to you. Out-of-state medical facilities may have access to the registry. Is that correct?

Barbara Thornton:

It is one of the important points we want to bring up. Dr. Noel Tiano will present what other states do.

Dr. Noel Tiano, Director, Nevada Center for Ethics and Health Policy, University of Nevada, Reno:

We support Assembly Bill 158 because the service will provide consumers and health care providers faster and more accurate access to treatment, wishes, and decision-making. Assembly Bill 158 is strictly voluntary and assures the

registry's safeguards and confidentiality. Moreover, the bill does not introduce new language to advance directives that are currently written. Arizona, North Carolina, Idaho, Louisiana, Montana, Vermont, and Washington use advance directive registries, and Connecticut and Pennsylvania are likely to follow. We believe in promoting conversations within families and communities regarding their wishes and values of care at the end-of-life. This will prevent another Terri Schiavo case. There are private registries such as MedicAlert. They are important in informing providers regarding advance directives. The service is available 24 hours a day, seven days a week. The downside of MedicAlert is that they charge an annual fee.

Sally Hardwick, Long-Term Care Facility Outreach, Nevada Center for Ethics and Health Policy, University of Nevada, Reno:

I am here to represent my husband, Dr. Wayne Hardwick, the president of the Nevada State Medical Association. He wrote a letter ([Exhibit H](#)) that supports Assembly Bill 158 and provides his personal experiences. He has been an emergency physician in Washoe County for 30 years, and has seen many people coming to the emergency room without their advance directives. You have heard testimony about the trauma and anxiety family members endure, but health care providers also endure trauma and anxiety. My husband expresses support for this bill. As a health care provider, he finds it extremely helpful in directing desired care for patients. Families are often unsure of the treatment their loved one wants and it removes that decision-making from them. It is a quick process and that is very helpful in an emergency.

Chair Leslie:

Thank you. We have the letter from Dr. Hardwick.

Nicole Lamboley, Chief Deputy, Office of the Secretary of State of Nevada:

Secretary of State Ross Miller met with Mr. Bobzien and he supports Assembly Bill 158, which would establish the registry within our office. We believe this registry will provide citizens with a secure and accessible place to file advance directives. It would become an electronic lockbox for people who would like to establish an advance directive. We provided an analysis to the Committee of how much it would take our office to establish and maintain the registry. The fiscal note is designed to ensure the integrity of the system, maintain its constant accessibility, and make sure it is secure and tamperproof for registrants.

Our staff did some preliminary research on programs administered by other states as a basis for determining how we would administer such a program. We believe that most of the administration of the registry could be absorbed by current staffing levels in our office; however, the significant cost to establishing

such registry comes from the technology that is required in developing not only the program, but the hardware and software. We propose a small filing fee to help offset the costs of administering and operating this system. It would be our desire, however, to find additional funding.

This will not be online. You cannot register by clicking on the Secretary of State's website, going to the advance directive registry, and filling out an online form. No state that we researched allowed such an activity because there is the issue of verifying that the person submitting the information is who he or she says they are. That would not be the purpose. We would require a physical copy of a form or a notarized legal document so we can scan it into the system and have an electronic record of it. The individual would still maintain an original copy of the advance directive. The legislation provides us the opportunity to establish procedures and regulations. We would go through a public process to determine the best way to design a form. If you are an elderly person, you may not have access to a notary.

To answer Assemblywoman Weber's question, we already maintain a good working relationship with the Office of Vital Records through the voter file. We have unique identifiers, and we would look into doing something like that to ensure the information is accurate. This is an issue we are willing to take on, but there is a significant fiscal impact.

Chair Leslie:

Thank you. We do not deal with fiscal notes, but I think the fiscal note is quite reasonable.

Assemblywoman Weber:

Did other states use the Secretary of State's office as an agency for this registry?

Nicole Lamboley:

It varies. Some states used the attorney general's office. The state of Arizona used the Secretary of State's office. Others use the Department of Human Resources. We use the Office of the Secretary of State because we accept and file documents.

Assemblywoman Weber:

I am concerned people will not think to go to the Secretary of State's website and will go to a health-related website instead.

Chair Leslie:

We can look at every health website, and it is a public education issue.

Assemblyman Stewart:

I got 25 emails from people who were concerned about mistakes. Were there cases in other states where mistakes were made? Were there any lawsuits? Are you confident very few mistakes will be made?

Nicole Lamboley:

We have not looked at it from that standpoint. We wondered if it would make sense for the Secretary of State to house such a registry and how much it would cost to maintain one. I cannot say how many mistakes were made, but it would be our intent to make sure there are very few mistakes. We are dealing with very sensitive information and that would be a part of the public process in determining the procedures and policies in accepting forms. We want to make sure people's wishes are honored with the most current and accurate information.

Chair Leslie:

If there is anyone who supports this bill, please tell us. We would also like to give the opponents of the bill the opportunity to speak.

Bobbie Gang, Private Citizen, Las Vegas, Nevada:

As I was driving to Carson City today, I was thinking about Assembly Bill 158 and I realized my husband is in Las Vegas. If I got in an accident, my husband would not have access to my advance directive. If he got in an accident, my inclination would be to get on an airplane headed to Las Vegas. I am not going to spend 45 minutes looking for his advance directive. My mother-in-law was healthy at 91 years old. I got a call from her caregiver saying they were on the way to the hospital. When I arrived at the hospital, her doctor asked for a copy of her advance directive. I knew her advance directive requested no medical intervention but I had no idea if we had a copy. By the time my husband found it two hours later, my mother-in-law had been given oxygen and she was stabilized. At that point, it was extremely stressful not knowing the location of the advance directive and not being able to tell the doctor her wishes. If we could have accessed the advance directive, it would have saved a lot of trauma for me and her doctor.

Chair Leslie:

More importantly, her wishes would have been carried out.

Bobbie Gang:

Yes. Fortunately, they did not have to do anything.

Jon Sasser, Attorney, Washoe Legal Services:

The Washoe County Senior Law Project helps clients draft advance directives. The project gets many calls from health care providers asking questions about advance directives, and they believe the registry is a terrific concept. There are concerns about details of Assembly Bill 158. Who is the personal representative that can access the advance directive? What happens when you do not give your health care provider the password to the website? I assume these concerns will be looked at in an open and public process.

Assemblyman Hardy:

Anybody can be the representative of the patient. In other words, the password to the website can be given to more than one person. It can be given to the doctor or the hospital.

John Sasser:

I certainly understand. Our question refers to when a password is not given. Section 8 says, "Access to the advance directive is requested by the registrant or his personal representative." It also states, "The Secretary of State determines that providing access to the advance directive is in the best interest of the registrant." These are the areas that I believe need to be fleshed out.

Assemblyman Hardy:

I misspoke when I said the hospital can accept the password. Regulations of the Health Insurance Portability and Accountability Act (HIPAA) must be considered when determining who is allowed to access the password. I do not know how to solve that problem.

Chair Leslie:

We need to make sure the intent of the law is understood by everybody. I think the regulatory process is very important.

Jan Gilbert, Private Citizen:

I strongly support Assembly Bill 158. I helped a woman with her advance directive and I delivered the document to all her doctors. It is complicated and difficult to make sure that emergency personnel see the advance directive. The advance directive is quite long. The Nevada Center for Ethics and Health Policy helped us fill out the forms. The woman did not want medical intervention in the event of an emergency, and hospice workers told us we needed to get a form from the Health Division. Emergency personnel must know what to do immediately. They are required to resuscitate. I think the website is fantastic, and I believe it will help.

Pastor Thomas Beck, Private Citizen:

I believe the registry is a tool that could be very helpful. I talked with my colleagues about advance directives and what happens when it gets lost or is not available. We have seen families go through that. There are questions on how the registry will be implemented but we trust that will be taken care of in a suitable fashion.

Chair Leslie:

Thank you. Let us hear from the opponents.

Patricia Glenn, President, Nevada Right to Life:

[Submitted ([Exhibit I](#)), ([Exhibit J](#)), and ([Exhibit K](#)).] I am against Assembly Bill 158 but I am not against everything that is in the bill. We have some concerns about the bill. I do not remember being invited to be on the task force chaired by Barbara Thornton but my memory is not what it used to be.

[Read ([Exhibit I](#)).]

Chair Leslie:

Thank you for your testimony. This is the best presentation of amendments I have seen all session. In the last two amendments, it sounds like you are suggesting we change existing law to make it much broader than Assembly Bill 158.

Patricia Glenn:

You are correct. My only concern is that Assembly Bill 158 does rely on the definitions in NRS 449.

Chair Leslie:

You are asking us to change those. We cannot just change it for . . .

Patricia Glenn:

I realize that it would probably require an actual bill addressing that concern.

Chair Leslie:

It is a lot more complicated.

Patricia Glenn:

Yes, it is more complicated, but Assembly Bill 158 does talk about that.

Chair Leslie:

Yes it does. I just want to make sure I completely understand.

Patricia Glenn:

I understand; it is a very complex issue.

Melissa Clement, Private Citizen:

I was in an end-of-life situation. In the past year, my mother-in-law passed away from a very aggressive form of esophageal cancer. During the Terri Schiavo controversy, my mother-in-law said she did not want to be on a feeding tube. She said, "I do not want to live that way and that is not what I want to do." I told her I should not be her decision maker because I cannot be the person who deprives her of food or hydration. She understood that.

Unfortunately, she was diagnosed with esophageal cancer at 65 years old. In June 2006, her doctors wanted to put a feeding tube in, and she said, "I cannot do that." We all think about these issues in terms of the worst case scenarios. I told her this is a chance for her to live a little longer. After much discussion, she decided to get a surgically installed feeding tube. It allowed her to live for four and a half more months. Four and a half months does not seem like a lot of time but in those four and a half months, she had the opportunity to take her three grandchildren to Oregon and experience the same kind of summer vacation she remembered with her grandmother. She had the opportunity to get all her affairs in order.

I certainly understand what Assembly Bill 158 is trying to do because these end-of-life issues are important and so difficult for all of us. These end-of-life issues mean something different when it happens to you than when it appears in a newspaper. She changed 180 degrees. Although it was difficult to watch those four and a half months, it was such a blessing for all of us, including her. I am asking the Committee to consider these situations.

Chair Leslie:

We appreciate your testimony. We will, as you have seen today, take this issue very seriously.

Don Nelson, President, Nevada Life:

[Submitted ([Exhibit L](#)).] We do not favor Assembly Bill 158 for a couple reasons. Advice for the registry would come strictly from the Nevada Center for Ethics and Health Policy. As we read the bill, we thought they were behind Senate Bill No. 206 of the 73rd Legislative Session. It was suggested that "Artificial nutrition and hydration would not be withheld from people without an effective advance directive." If that were taken out we are afraid that will happen again. We are afraid of it because dying by dehydration is very painful. We thought that part was going to be removed, and we thought they were behind it. We thought, "Wow, they are the people giving advice to the

Committee.” This causes concerns. We think advice should be from a broader group of people.

Secondly, we support the use of advance directives. They are necessary in the current culture of medicine and bioethics. There is a belief that some lives are no longer worth living and do not warrant the expenditure of resources. This belief has led to the practice of hospitals and other health care providers withholding treatment even though it would help the patient and is wanted by the patient’s family. The facility does not think that the patient’s life is worth the resources. We are afraid of a culture that believes death is a health care benefit in some instances and that living is not in ones interest. In this culture, an advance directive is the best way to make sure a person’s wishes are followed and not left to the subjective assessment of the care provider about the patient’s so-called quality of life. Advance directives are a good idea but we are concerned about safety and privacy.

We suggest providing an education packet to people on different kinds of advance directives. Assemblyman Bobzien mentioned living will and advance directive in the same sentence. There are different kinds. Because life is so precious, people ought to know exactly what they are signing.

Janine Hansen, President, Nevada Eagle Forum:

I support Patricia Glenn’s amendments to Assembly Bill 158. One of the sponsors of the bill said he wants it to be value neutral. The bill is not value-neutral because of the way it is written. If you read Section 3 and Section 11, the definition of advance directive only includes withholding or withdrawal of life sustaining treatment. It is a very limited definition.

Several years ago, my father was in the hospital. Because of the information on hydration and nutrition that Patricia Glenn gave to me, we specifically requested hydration and nutrition in his living will. After he had been in intensive care for 16 days, we knew there was not a chance for him. We made sure he still had hydration and nutrition because that was his desire. We would not have known about that if had not been for Patricia Glenn. The information available for people usually does not identify that this option is available. They do not even think about hydration and nutrition as medical care. Because Assembly Bill 158 does not note that, the bill is not value-neutral.

Dr. Hardy said that if you have an advance directive, there is an assumption that you do not want care. It is very important to people like my father and my 91 year old mother to have specifics on things like nutrition and hydration. It is very important that the care they want, not just the care they do not want, is noted. It is important to honor that. The Nevada Center for Ethics and Health

Policy wants us to have all the care in the world that we want. It is my concern that the focus of the bill is on withdrawing care.

The summary of Assembly Bill 158 mentions an interim study by the Secretary of State. It seems to be in the statute on page 5. I do not know if there will be another interim study or if there was an interim study. I do not know the answer and I am wondering if that could be resolved.

Chair Leslie:

I do not know. We are looking for that. That is a good thing to point out. Dr. Hardy's point was the opposite of what you said. He made the point that advance directives are not just about withholding treatment.

Janine Hansen:

Yes, I agree with him.

Chair Leslie:

I just want to make sure the record is clear.

Janine Hansen:

I would like to make sure that is the case. I hope it is very clear so that people are able to have a choice. I was not in disagreement with him at all. Thank you for that clarification.

Chair Leslie:

Thank you. Is there anyone that would like to testify for or against Assembly Bill 158? [There was no response.] We will work with Mr. Bobzien on some potential amendments. We will close the hearing on this bill, and open the hearing on Assembly Bill 390.

Assembly Bill 390: Requires that the State Plan for Medicaid provide for allowing recipients of Medicaid greater control and flexibility in administering personal assistance services. (BDR 38-1113)

Assemblyman Ty Cobb, Washoe County Assembly District No. 26:

Today, I am introducing Assembly Bill 390 that was written in conjunction with the State of Nevada Department on Health and Human Services. This bill allows Medicaid recipients to have more control over how they purchase personal care and related services. This was allowed through the Deficit Reduction Act of 2005 by the United States Congress. It eliminates the potential liability to the State for care giving. It has no fiscal note attached. With that, I would like to turn it over to Mary Wherry.

Chair Leslie:

Can you explain what the bill does? I am still confused.

Assemblyman Cobb:

There are Medicaid recipients who are restricted to spend their benefit funds in certain ways because of a provision in the Deficit Reduction Act of 2005. The bill allows the states to establish a program that would provide a greater leeway on how they spend some of their Medicaid benefits.

Chair Leslie:

Does this codify the new federal law under the Deficit Reduction Act?

Assemblyman Cobb:

This was a provision that allowed the states to change their programs to establish a state program that would allow greater leeway in how Medicaid recipients spend their funds.

Mary Wherry, Deputy Administrator, Department of Human Resources, Division of Health Care Financing and Policy:

[Submitted ([Exhibit M](#)) and ([Exhibit N](#)).] This bill is the result of the Deficit Reduction Act. It is another state plan option. Does it require states to implement this program? No, this is a state plan optional benefit. The Division started working on 1915(j) which is the same as 1396(nj). The Committee has a copy of Section 6087 of the Deficit Reduction Act ([Exhibit N](#)), which is the same as 1915(j) of the Social Security Act and 42 U.S.C. that is referenced in Assembly Bill 390.

The bill creates two more options under our existing state plan personal care program. We allow recipients to use a provider service agency where the agency does the staffing for personal care. They can also use an Intermediary Service Organization (ISO) where the ISO receives whoever the recipient has hired to provide their personal care. The ISO hires the personal care worker, does the payroll for the personal care worker, files the claims for the direct care provider, and acts as an intermediary for the recipient and the direct care provider.

We have another option under our physically disabled waiver which is the independent contractor. We allow the recipient to hire and fire a personal care worker. The direct care provider bills directly to Medicaid, not to the ISO.

The Attorney General advised that, in this case, we are the employer of record. Our intent for adopting 1915(j) is to eliminate the independent contractor option. We would create two options using 1915(j) under the ISO model. We

would allow a recipient to have a budget created, and they could allow the ISO to manage the budget for them so that they do not have to hire somebody.

The third option would allow the recipient to become the employer. They have to get a federal tax identification number and work with the ISO. According to federal requirements, we would still have financial management oversight. The recipient would become the employer of record. They would have to follow all the Internal Revenue Service (IRS) requirements and other requirements in statute for worker's compensation or liability insurance.

Under both options, whether the ISO manages the budget or whether the recipient manages the budget, it benefits the recipients as they are allowed to purchase more than just direct personal care hours. We develop that dollar amount by looking at the hours that are allocated through the functional assessment. For example, if they have 42.5 hours under the state plan, we would multiply 42.5 with the current hourly reimbursement rate, which is \$18.50 per hour. The recipient would have that much money per week to put into a budget. They are able to hire somebody at \$10 or \$8 per hour instead of \$18.50, and they can save that reserve, minus an administrative portion, to pay for the ISO budgeting process. They would be able to use that reserve to purchase a microwave for meal preparation, or other related personal care services.

Under 1915(j), states are allowed to elect the option of recipients being able to hire legally liable adults. Assembly Bill 390 would direct us to not elect that authority under our state plan. Currently, we allow families to be paid personal care services. The federal law restrictions state we cannot pay for legally responsible adults, which equates to spouses, adult parents of minor children, or guardians of adult children. Under 1915(j), the state would be allowed to elect that option, and Assembly Bill 390 would allow us to not select that option.

Chair Leslie:

Did this come up in the interim study on disabilities? The Committee heard a lot of testimony from people who want the ability to hire an independent contractor. According to your testimony, that would no longer be an option?

Mary Wherry:

We would no longer be the employer of record. The bill would allow the recipient to become the employer of record. They would still be allowed to hire whoever they want, but the state is no longer responsible to directly pay the direct care provider. The Attorney General believes we are at risk. What if a recipient was harmed? If we are paying the bill for personal care, one could argue we are the employer of record and liable for the consequences.

Chair Leslie:

Under this scenario, you are transferring the responsibility to them.

Mary Wherry:

Exactly.

Chair Leslie:

Did they discuss this in the interim study?

Mary Wherry:

I was not aware that this was a topic of discussion. The Deficit Reduction Act made clear what all these things meant. Some states implemented this kind of cash and counseling program. Arkansas, Florida, and New Jersey used the demonstration waivers. It was through these demonstration waivers when it was decided that it was a great deal. Let us allow recipients or states to place this in the state plan. Some states used 1915(c) waivers where recipients would have an individual budget as a service option.

Assemblywoman McClain:

We have talked a lot about it in the senior committees. I am sure other committees, like the disabilities committee, have discussed it as well.

Assemblywoman Gerhardt:

I understood the part about releasing the Division from liability, but you said that you will still be assessing some type of administrative fee even though you are assuming liability.

Mary Wherry:

The federal government requires a very accurate account of how these dollars are spent. There is a lot of concern from payers and public policy makers. If we give recipients cash, will they spend it on personal care related things? The federal government included language that states we have to be responsible for assuring the dollars are being spent on appropriate items. Our goal is to use the ISO to oversee the development and administration of that budget. The federal government will be auditing these books to make sure that their dollars are being spent appropriately.

Instead of hiring a financial management company to oversee this particular state plan benefit, we simply want to use the ISO. That is an administrative function; it is not a service. We do not have a mechanism to pay for that administrative function. We only have a mechanism to pay for the service.

The plan takes money out of the recipient's budget to cover the administrative costs. Some states may have a flat \$10 per month fee or some states may take 3 to 4 percent of the person's budget. We have not gotten to the point of figuring out what we would need to take from the person's budget.

Assemblywoman Gerhardt:

How much is the administrative fee?

Mary Wherry:

It would depend on the size of the person's budget. For example, if we did a flat \$10 fee per month, then \$10 would be taken from the monthly sum of the person's budget. If it was a percentage, then it would be based on how many hours the person receives in personal care.

Assemblywoman Gerhardt:

Which is it? Is it a flat fee?

Mary Wherry:

We have not made a decision yet. When we develop our public policy, we get a rough draft of our regulations and hold a public workshop. We find out how providers and recipients perceive these proposed regulations. After that, we create a final draft and hold a public hearing. Public hearings are used to affirm that we are going to adopt these regulations and codify them for Medicaid.

Assemblywoman Gerhardt:

The perfect scenario would be if the recipient could hire an assistant at an economical rate. What if a recipient gets involved with an individual who takes advantage of the recipient and charges them more than the going rate? Would you intervene? How much autonomy does the disabled person have?

Mary Wherry:

That could exist. Under the ISO model or the provider service agency model, these services are provided in a client's home. There is not a lot of oversight and recipients can be taken advantage of. Our regulations require that the agencies have a reporting process. If a recipient or family member reports that someone is being taken advantage of, the agencies should report that to us and intervene. The ISO model educates and trains the recipient in what it means to be the employer. If you make the decision to have people come to your home, there are things you need to be mindful about. The ISO must provide reports to us if something happens to a recipient. All providers must comply with all recipient abuse or neglect reporting requirements.

Assemblywoman Womack:

What happens in cases of extreme disabilities or mental incapacitations?

Mary Wherry:

Our regulations allow a legally responsible adult to direct their care for them. The adult parent of a person who is mentally incapacitated could be the one directing care. They could hire or fire personal care workers, create the budget, or act on behalf of the individual.

Jon Sasser:

I am neutral on Assembly Bill 390. We should explore the self-directed care option. To be clear, you do not need legislation to do this. This is a state plan option under Medicaid. They have done this on a regulatory basis and it had a financial impact. We can do all the things Ms. Wherry talked about without passing a bill. I look forward to the public hearing where we can work out some of the details.

Chair Leslie:

Is there anyone that will like to testify on Assembly Bill 390?
[There was no response.]

Peter Burns, Attorney, Burns & Associates:

We assisted the Committee on formulating a strategic health care plan for Nevada in fulfillment of Assembly Bill No. 342 of the 73rd Legislative Session. We produced a report that talks about health care in Nevada and made 39 recommendations in 6 or 7 subject areas.

[Read ([Exhibit O](#)).]

Chair Leslie:

Are there any questions about the report? It is good work, but we have heard it, and we will move on to our work session. Thank you. We appreciate your work. Ms. Pierce, we will hold your bill until the next work session because of time constraints. We will go to Assembly Bill 149.

Sarah J. Lutter, Committee Policy Analyst:

[Read Assembly Bill 149 of ([Exhibit P](#)).]

Chair Leslie:

Thank you. This bill has a concurrent referral.

Assembly Bill 149: Makes an appropriation to the Division of Mental Health and Developmental Services in the Department of Health and Human Services for the prevention of the abuse of methamphetamine. (BDR S-1038)

ASSEMBLYMAN HARDY MOVED TO AMEND AND DO PASS
ASSEMBLY BILL 149.

ASSEMBLYWOMAN PARNELL SECONDED THE MOTION.

THE MOTION PASSED UNANIMOUSLY.

Chair Leslie:

Let us go ahead with Assembly Bill 168.

Assemblywoman Pierce:

This is a disclosure regarding Assembly Bill 168. I would like to disclose that I have a personal relationship with Jon Sasser, a registered lobbyist for Washoe Legal Services, Washoe County Senior Law Project, and Nevada Legal Services. These legal service organizations advocate on behalf of low income residents of Nevada. The provisions of Assembly Bill 168 affect the clients of these legal service organizations. The benefit accruing to these clients is the result of the passage of Assembly Bill 168 is not greater to than that accruing to any other resident of Nevada. Although I am required to make this disclosure, I am not required to abstain from voting on this bill.

Sarah J. Lutter:

[Read Assembly Bill 168 from ([Exhibit P](#)).]

Chair Leslie:

A math mistake was detected from a version of the bill that was circulated, so another bill circulated. Apparently Assemblyman Marvel could not be found to get his signature. He asked if we could do him the courtesy of adding his name to the bill. I hope the members will agree to that. The third amendment is the request of the Nevada Association of Counties and everyone agreed to that amendment.

Assembly Bill 168: Makes various changes concerning expanding health insurance to make health insurance available to more residents of Nevada. (BDR 38-1144)

ASSEMBLYWOMAN PARNELL MOVED TO AMEND AND DO PASS
ASSEMBLY BILL 168.

ASSEMBLYWOMAN GERHARDT SECONDED THE MOTION.

THE MOTION PASSED UNANIMOUSLY.

Chair Leslie:

We will have to take the other bills on Monday. It was our intent to do it today, but it just did not get done. This meeting is adjourned. [3:31 p.m.]

[Assembly Bill 113 and Assembly Bill 247 was not heard.]

RESPECTFULLY SUBMITTED:

Katrina Zach
Committee Secretary

APPROVED BY:

Assemblywoman Sheila Leslie, Chair

DATE: _____

<u>EXHIBITS</u>			
Committee Name: <u>Committee on Health and Human Services</u>			
Date: <u>March 21, 2007</u>		Time of Meeting: <u>1:34 p.m.</u>	
Bill	Exhibit	Witness / Agency	
	A	Committee on Health and Human Services	Agenda
	B	Committee on Health and Human Services	Attendance Roster
AB 158	C	Assemblyman David P. Bobzien	<i>The Best Way to Keep Control Is to Leave Instructions</i>
AB 158	D	Assemblyman David P. Bobzien	Memorandum
AB 158	E	Assemblyman David P. Bobzien	<i>Arizona Advance Directive Registry</i>
AB 158	F	Assemblyman David P. Bobzien	Letter from Jim Crockett to Assemblyman Bobzien
AB 158	G	Dr. Barbara Thornton, Dr. Noel Tiano, and Sally Hardwick, Nevada Center for Ethics and Health Policy	Letters to Assemblywoman Leslie.
AB 158	H	Sally Hardwick, Nevada Center for Ethics and Health Policy	Letter from Dr. Wayne Hardwick to Assemblywoman Leslie
AB 158	I	Patricia Glenn, Nevada Right to Life	Prepared Testimony
AB 158	J	Patricia Glenn, Nevada Right to Life	Proposed Amendments
AB 158	K	Patricia Glenn, Nevada Right to Life	Proposal Robert Powell Center for Medical Ethics
AB 158	L	Don Nelson, Nevada Life	Prepared Testimony
AB 390	M	Mary Wherry, Department on Human Resources	Prepared Testimony
AB 390	N	Mary Wherry, Department on Human Resources	Section 6087: Optional Choice of Self-Directed Personal Assistance
AB 390	O	Peter Burns, Burns & Associates	<i>Nevada Strategic Health Plan</i>
AB 113 149 168 247	P	Sarah J. Lutter, Committee Policy Analyst	Work Session Document

