# MINUTES OF THE SENATE COMMITTEE ON HEALTH AND HUMAN SERVICES

# Seventy-Eighth Session April 29, 2015

The Senate Committee on Health and Human Services was called to order by Vice Chair Ben Kieckhefer at 3:36 p.m. on Wednesday, April 29, 2015, in Room 2149 of the Legislative Building, Carson City, Nevada. The meeting was videoconferenced to Room 4412 of the Grant Sawyer State Office Building, 555 East Washington Avenue, Las Vegas, Nevada. <a href="Exhibit A">Exhibit A</a> is the Agenda. <a href="Exhibit B">Exhibit B</a> is the Attendance Roster. All exhibits are available and on file in the Research Library of the Legislative Counsel Bureau.

# **COMMITTEE MEMBERS PRESENT:**

Senator Joe P. Hardy, Chair Senator Ben Kieckhefer, Vice Chair Senator Mark A. Lipparelli Senator Joyce Woodhouse Senator Patricia Spearman

## **GUEST LEGISLATORS PRESENT:**

Assemblywoman Teresa Benitez-Thompson, Assembly District No. 27 Assemblywoman Michele Fiore, Assembly District No. 4 Assemblyman James Ohrenschall, Assembly District No. 12

# **STAFF MEMBERS PRESENT:**

Marsheilah Lyons, Policy Analyst Eric Robbins, Counsel Debra Carmichael, Committee Secretary

## OTHERS PRESENT:

Julie Kotchevar, Deputy Administrator, Aging and Disability Services Division, Department of Health and Human Services

Gary W. Olsen, through Kim Dawson, American Sign Language Interpreter David Daviton, through Kim Dawson, American Sign Language Interpreter Angela Greer, through Arthur Richmond, American Sign Language Interpreter Jeff Beardsley, through Arthur Richmond, American Sign Language Interpreter

Samuel S. Crano, Assistant Staff Counsel, Public Utilities Commission of Nevada

Mike Eifert, Executive Director, Nevada Telecommunications Association

J. Farrell Cafferata, President, Deaf and Hard of Hearing Advocacy Resource Center

Eli Schwartz

Herbert Randall, President, Nevada Silver Haired Legislative Forum

Heather Korbulic, State Long-Term Care Ombudsman, Aging and Disability Services Division, Department of Health and Human Services

Barry Gold, Director, AARP Nevada

Connie McMullen, Personal Care Association of Nevada

Janette Dean

Craig Handzlik, State Policy Coordinator, Goldwater Institute

Vicki Higgins

Cindy Brown

Mona Lisa Samuelson

Delphine Callahan

Wendy Simons

Chris McMullen, Senior Coalition of Washoe County

## Senator Kieckhefer:

I will open the hearing on Assembly Bill (A.B.) 200.

ASSEMBLY BILL 200 (1st Reprint): Revises provisions relating to persons with impaired speech or hearing. (BDR 38-419)

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

Concerns started to surface during the 77th Legislative Session around the Aging and Disability Service Division budget specific to the deaf and hard of hearing and their grantee the Deaf and Hard of Hearing Advocacy Resource Center (DHHARC). Senator William J. Raggio established the telecommunication device for the deaf (TDD) surcharge, which is Relay Nevada. When a deaf and hard of hearing person picks up a telephone, he or she can use this relay to communicate with others. In 2003, the Legislature added language to the statute regarding the DHHARCs. The DHHARCs are grantees of the Aging and Disability Services Division (ADSD). The Public Utilities Commission of Nevada (PUCN), which is the collection entity, passes the money on to the ADSD, who in turn passes the money to the grantees, which are the DHHARCs. The surcharge is collected on all landlines and wireless telephones. Data collected

since 2002 shows the TDD rate between 3 and 8 cents per month. The amounts collected are used to support the deaf and hard of hearing.

There was a lawsuit over the interim and questions were asked about how the funds were being used and how they could be used, and the ADSD prevailed. Assembly Bill 200 is consensus language supported by the Nevada Telecommunications Association, the deaf and hard of hearing community and the aging and disabled community.

Section 1 of <u>A.B. 200</u> creates the Subcommittee on Communication Services for Persons Who are Deaf or Hard of Hearing and Persons with Speech Disabilities of the Nevada Commission on Services for Persons with Disabilities. Proposed Amendment 6893 to <u>A.B. 200</u> (<u>Exhibit C</u>) changes the voting structure of the board. The intent of the board is to be a place where the members of the community can talk about their needs without having voting members like the Nevada Telecommunications Association present. Section 2 changes the oversight of the funds from the PUCN to the legislative budgeting process. The reason for the lawsuit was statute that stated Nevada Legislators set and approved a budget and the PUCN approved what was set. The PUCN requested to remove it from the oversight process. With this bill, the Legislators will have the approval and oversight on the budgets for the ADSD.

There is a need for available interpreters for the State to use. The ADSD is responsible for creating a pool of highly qualified interpreters but the language was placed under the deaf and hard of hearing centers as if the centers were responsible for the interpreter pool creation. The proposed amendment corrects the language and places responsibility for the interpreter pool creation with the ADSD as it has the regulatory oversight. The surcharge rate of not more than 8 cents per month is imposed; however, the ADSD budget for this biennium has placed it at 3 cents. We have had conversations with the Nevada Telecommunications Association about making sure the ratepayers had a measure of security about how high this rate could go. Contemporary technology language has been added as emerging technology has changed since 2002 when this bill was originally passed.

# Julie Kotchevar (Deputy Administrator, Aging and Disability Services Division, Department of Health and Human Services):

It is not typical for the ADSD to be a voting member on boards and commissions which we support. It is a conflict because we represent everyone.

We would prefer to be a nonvoting member. The proposed amendment adds the Subcommittee will provide advice and recommendations on how the surcharge should be spent. Section 2, subsection 2, paragraphs (a) through (e) of <a href="Exhibit C">Exhibit C</a> itemize what services should be offered by the deaf and hard of hearing centers. The deaf communities have requested access to highly qualified interpreters who have an understanding of the context of discussions. Many interpreters have no background in the areas of conversation such as complex health issues or service systems.

Our budget has decreased because fewer people are using Relay Nevada as they are not using telephones in the same way. Texting and smart phones have become popular and there are no provisions in the law to accommodate this type of technology.

The ADSD is working with the Legislative Counsel Bureau, as a technical adjustment to the budget will be required concerning the pool of interpreters. The pool of interpreters was not included in the budget and the ADSD will need an increase in budget authority.

## Senator Spearman:

Does <u>A.B. 200</u> cover any type of subtext or closed captioning with respect to meetings?

## Ms. Kotchevar:

The Communication Access Realtime Translation (CART) is included as part of the services that are offered when it is useful. The CART is not always accessible to all members of the deaf community as not all members are fully literate. Sign language is the primary language for many so CART would not be helpful.

# Gary W. Olsen (through Kim Dawson, American Sign Language Interpreter):

I am a member and advocate of the deaf community. <u>Assembly Bill 200</u> is a champion bill and will make the lives of deaf and hard of hearing better. I have submitted my written testimony (<u>Exhibit D</u>).

## David Daviton (through Kim Dawson, American Sign Language Interpreter):

We have been working a long time on a bill for the deaf and hard of hearing. We have worked with Senator Raggio and over time there have been significant changes. Assembly Bill 200 is a positive step and improvement in the right

direction. I appreciate that everyone has worked together to make this bill successful. I believe it will benefit the State in the long run. I support this bill and ask that you do the same.

# Angela Greer (through Arthur Richmond, American Sign Language Interpreter):

I support <u>A.B. 200</u> and see this as a positive thing. It will be very successful for members of the deaf and hard of hearing community. These changes are necessary because of the frustrations of the past where no one would listen to us. People are finally listening to what we want and hearing our voices.

Jeff Beardsley (through Arthur Richmond, American Sign Language Interpreter): I support A.B. 200 as it will hugely impact the lives of future deaf and hard of hearing generations.

# Samuel S. Crano (Assistant Staff Counsel, Public Utilities Commission of Nevada):

The Public Utilities Commission of Nevada is in favor of <u>A.B. 200</u> as presented today.

## Mike Eifert (Executive Director, Nevada Telecommunications Association):

The Nevada Telecommunications Association (NTA) and its members worked diligently with Assemblywoman Benitez-Thompson on A.B. 200. The consensus language is a compromise that the deaf, hard of hearing and speech-impaired communities will continue to be funded. It addresses the concerns of the Nevada ratepayers. In regard to the voting aspect of the bill, my position has been moved to nonvoting and I do not have any issues with the change. What the Subcommittee attempts to do and has done has been a benefit to the community. The NTA has never voted against an action. I understand wanting to keep the voting within its community. That only makes sense. The NTA is in full support of A.B. 200.

# Farrell Cafferata-Jenkins (President, Deaf and Hard of Hearing Advocacy Resource Center):

The Deaf and Hard of Hearing Advocacy Resource Center is one of the grantees that receive funds from the surcharge. I urge you to support <u>A.B. 200</u> because it will provide the services we have been looking for over the last year.

#### Eli Schwartz:

I am part of the hard of hearing community in Las Vegas. This bill not only helps the deaf community but the hard of hearing community as well. I support A.B. 200.

## Senator Kieckhefer:

I will close the hearing on A.B. 200 and open the hearing on A.B. 28.

ASSEMBLY BILL 28: Revises the duties of the State Long-Term Care Ombudsman. (BDR 38-415)

## Herbert Randall (President, Nevada Silver Haired Legislative Forum):

I have provided my written testimony to the Committee (Exhibit E).

## Senator Spearman:

Section 1, subsection 2, paragraph (b) addresses developing a course for training. Are you working in conjunction with anyone concerning best practices as the curriculum is developed?

# Heather Korbulic (State Long-Term Care Ombudsman, Aging and Disability Services Division, Department of Health and Human Services):

There is a national movement in the philosophy about culture change which establishes the theory and philosophy that long-term care centers should be homes and people should be treated as individuals. Our staff has received training on this philosophy. We are working with national representatives and have gone to conferences specifically about culture change initiatives. We have developed training about person-centered care as it relates to best practices.

## Senator Kieckhefer:

Is there any off-the-shelf training course that has been developed by the national organization that could just be implemented and we would not be required to purchase it?

#### Ms. Korbulic:

There is nothing available off-the-shelf. We have already developed quite a few of the training courses and made them specific to Nevada. They line up with the Nevada regulations.

## Barry Gold (Director, AARP Nevada):

Anything we can do to improve the quality of care for our residents in long-term care facilities is a positive step. I urge this Committee to pass A.B. 28.

# Connie McMullen (Personal Care Association of Nevada):

I am a Nevada Commission on Aging member. I worked on the integration plan for the Aging and Disability Services Division. Person-centered care is how we all want to be treated. It is a great initiative and will be a part of the new waiver process from the center for Medicare and Medicaid Services that will be adopted in the next 4 years. I support A.B. 28.

### Senator Kieckhefer:

I will close the hearing on A.B. 28 and open the hearing on A.B. 164.

ASSEMBLY BILL 164 (2nd Reprint): Revises provisions relating to access by patients to certain investigational drugs, biological products and devices. (BDR 40-125)

# Assemblyman James Ohrenschall (Assembly District No. 12):

A little over a year ago, I was contacted by a constituent who had lost his father to a terminal illness. The constituent read about the push for the "Right to Try" legislation across the United States and asked me to sponsor a bill. Assembly Bill 164 allows a person with a terminal condition who wants to try a medication that is being studied by the U. S Food and Drug Administration (FDA) but the medication has not made it through the entire process to try the medication. During the research process on this bill, I learned there are opportunities for patients across the Country to try medications. Medications that have gone through the first phase of trials guarantees the medication will not make a person worse than the underlying condition but there are no guarantees the medication will cure a person. Patients in larger cities with bigger medical centers or teaching hospitals have a greater opportunity to participate in clinical trials. Another avenue for patients is the FDA offers a compassionate use exception which dates back to the 1980s. This exception was used for patients with AIDS who were interested in trying different medications like azidothymidine (AZT), which was not yet on the market. Last year, 6,000 compassionate use exceptions were granted, but there were millions of cancer diagnoses and millions of deaths. Prior to a change a couple of months ago in FDA policy, a U.S. Government Accountability Office study estimated it would take the patient and doctor 100 hours to complete the

paperwork. Since the Right to Try legislation has passed in 15 states, the FDA has streamlined the compassionate use exception form and it now takes approximately 45 minutes to complete. The passage of the Right to Try legislation has helped to shape and change federal policy. The disadvantage for our constituents, up until now, is it is time-consuming, laborious and difficult especially when fighting a terminal illness to apply for a compassionate use exception. Clinical trials have been few and far between in Nevada.

When the Assembly Committee on Health and Human Services considered this legislation, we heard testimony in Las Vegas from a woman whose father has a form of incurable blood cancer. He is frail and it is difficult for him to travel. There is a medication that might help him but it is not offered in Nevada and he is not strong enough to travel to where it is offered. She testified in support of A.B. 164. She was not able to testify today but wanted me to put it on the record. Assembly Bill 164 will give patients an opportunity to try investigational drugs. With the groundswell across the Country of states passing this legislation, pharmaceutical companies will start offering investigational medications. The law is very new and it does not appear this has happened yet, but change has happened at the federal level.

## Assemblywoman Michele Fiore (Assembly District No. 4):

Assembly Bill 164 will help change Nevada into a medical tourism state. I have had personal experiences with patients in Nevada who have travelled to Italy and Germany to work on alternative measures. One individual, a casino owner in Clark County, with liver cancer and on the liver transplant list received the diagnosis to put his affairs in order. He fought and sought alternative medicine. He is off the liver transplant list because of the Right to Try legislation and travelled to Italy and Germany for alternative medications. The Right to Try is not alternative medicine. The diagnostic centers for blood work did not believe his test results and had him do them over. The chemically engineered medicines are alternative because before we evolved to where we are today, we used vitamins and plants for remedies. Once a person receives the news to get his or her affairs in order it is up to that person to choose what to do.

## **Assemblyman Ohrenschall:**

When I put in the bill draft request I was contacted by Assemblyman Jim Wheeler and Senator Woodhouse, and we worked together to get this bill where it is today.

# Senator Lipparelli:

What is the likelihood that medical doctors (MD) and doctors of osteopathic (DO) medicine would recommend patients try investigational medicines?

# **Assemblyman Ohrenschall:**

There was testimony in the Assembly Committee on Health and Human Services meeting and on the Assembly Floor from our physician Legislator, Assemblywoman Robin L. Titus recounting during the 1980s she sent some of her patients to Canada to purchase medications she knew would help them. These medications were not FDA approved at that time. I believe physicians are recommending their patients try investigational medicines. The medical association had concerns with the original bill. Those concerns have been addressed. I am optimistic we will get buy-in from the MDs and the DOs who are the only ones who can help. I am more concerned about the pharmaceutical companies. There are 15 states that have this legislation and I hope Nevada will be the sixteenth. The Board of Medical Examiners did vote to support A.B. 164. Liability has been addressed in the bill as it takes a willing patient, a willing doctor and a willing pharmaceutical company. It does not force anyone to do anything. The informed consent portion makes sure everyone's eyes are wide open.

## Janette Dean:

Section 2 of <u>A.B. 164</u> removes the misdemeanor that might have been applied to a physician who prescribes or recommends an investigational medicine.

# Craig Handzlik (State Policy Coordinator, Goldwater Institute):

The Goldwater Institute originated the language a couple of years ago and has assisted lawmakers in the 15 states that have passed this legislation. We have worked with the other 20 legislatures that are now considering it. Once it has been established that a patient has a terminal condition, the physician could recommend a medication that is past the first phase of the FDA's three phases of clinical trials. The first phase establishes whether a medication is toxic to patients. The medication is determined nontoxic but the underlying condition of the patient is terminal. The intent of the bill is to allow the patient one last arrow in his or her quiver in the battle to fight the terminal illness. Terminally ill patients, 97 percent of the time, are not permitted access to the FDA's clinical trials because they are too sick or not sick enough. Assembly Bill 164 opens the door to the medications, which have been proven to be nontoxic by the FDA and still are being investigated, to permit terminally ill patients to have access to

them. It is important to note the bill does not mandate physicians have to recommend it, or that insurance companies have to pay for it or manufacturers have to give out the medications and it certainly does not mandate a patient has to participate in Right to Try. Through the informed consent the patient is explained what the adverse effects could be; financially, physically and the potential benefits the medications have shown other patients.

In Arizona, the face of Proposition 303, which was our Right to Try measure, was a child named Diego Morris. When he was 11 years old, he received a terminal diagnosis of osteosarcoma in his leg. He visited St. Jude Children's Research Hospital in Tennessee. The many oncologists and specialists did not have any good options for Diego to beat his illness. His parents were told to take him home and enjoy what little time they had with him and there was nothing more that could be done. Diego's parents, being resourceful, intelligent and proactive parents, continued researching solutions for Diego. They discovered a medication that was available, approved and given a gold star in the United Kingdom for treatment of osteosarcoma in youth patients. The parents discussed using this medication with the doctors at St. Jude Children's Research Hospital and were told that seemed much better than the current option, which was doing nothing. Doctors at St. Jude Children's Research Hospital recommended if they had the resources and the ability to move to the United Kingdom they should do so for Diego to receive the treatment. Diego's family moved from Phoenix, Arizona, to London where Diego continued chemotherapy treatment and received 48 doses of medication, which sent his cancer into remission. They returned to Arizona and Diego has undergone several surgeries to repair the damage the cancer did to his leg. I saw him a couple of weeks ago and he is running for class president at his school, he is a 14-year-old kid who has, for all intents and purposes, a normal life. The medication that was used to save his life still has not made it through the FDA clinical trials process.

We live in the most medically advanced country in the world. Many of the medications being approved in other countries are not available for use here by people who cannot gain access to clinical trials and do not have the time to wait for the bureaucratic process of going through the compassionate use process. When faced with a terminal illness the battle goes on daily. It is tough to tell a terminally ill patient in addition to battling for his or her own life, he or she also has to battle our government. I urge you to adopt the Right to Try in Nevada as over 1,500 other legislators around the Country have voted in favor of it.

#### Senator Kieckhefer:

How many pharmaceutical companies are releasing the medications to patients upon request?

# Mr. Handzlik:

This is a new law. The first Right to Try law was passed in Colorado in May 2014. With this law, we are taking a step to remove barriers for physicians to give the care they were trained to give. It is like turning an aircraft carrier around with the regulations that have been set up by the FDA for the last 50 years. It will take time for pharmaceutical companies to release medications to patients. The Goldwater Institute is hearing from physicians, manufacturers and patients who want to get this right the first time.

## Senator Kieckhefer:

The language in the informed consent requires the patient to take on all fiscal liability, but there is no liability waiver for a physician. Have you talked to anyone who has engaged in conversation with insurance companies that write medical malpractice policies and how have they responded to something like this? Would they prohibit their insured members from participating in a program like this?

## Mr. Handzlik:

The bill is designed to remove liability from physicians for adverse effects brought on by the investigational medication. There is no law in any state that would remove liability for malpractice operating outside the scope of practice or negligence. There is language in the bill that removes liability in the event of adverse effects and for recommending the medication in the first place.

## **Assemblyman Ohrenschall:**

Section 3, subsection 3 of <u>A.B. 164</u> states, "A physician is not subject to disciplinary action for prescribing or recommending an investigational drug, biological product or device when authorized to do so pursuant to subsection 1." Similar language is in section 8, subsection 3. There is no absolute shield from a tort action. The patient or state could not succeed in action based solely on the use of the investigational drug. Other malpractice is not addressed in this bill.

## Senator Spearman:

How long does it take to apply? How are patients notified of the option of clinical trial medications?

# Assemblyman Ohrenschall:

There have been changes to the compassionate use exception. The FDA streamlined the regulations and it is about 45 minutes of paperwork as opposed to 100 hours. There has been positive media coverage on this bill. If this does pass into law, the MDs and DOs will talk to their patients and let them know what is available. I am hopeful that by the end of summer there will be 30 states that have passed legislation like this. Then pharmaceutical companies will be willing to let the investigational medications that have passed phase 1 to be tried in states like Nevada.

## Mr. Handzlik:

The FDA has proposed a change to the 100 hours of the physician's paperwork, which is 8 hours a day for 2 1/2 weeks, to 45 minutes for the compassionate use exception. It has been opened up for a 60-day comment period; therefore the change has not been made yet. The manufacturer also has a burden of paperwork to fill out. Both sets of paperwork go to the FDA, which has 30 days to consider the applications. If the FDA has any questions on either paperwork, it goes back to the party for which they have questions. Once the questions have been answered, the 30-day clock starts all over again.

## Senator Lipparelli:

Is there a mechanism for the physician to report use of the investigational medication? It would be beneficial to know if people are engaging in investigational medication treatments.

## Mr. Handzlik:

The idea behind the Right to Try is to remove barriers for patients. In the compassionate use clinical trials, the reporting is done by the manufacturer. The manufacturer and the physician, through the informed consent agreement would decide the terms of how the manufacturer allows the physician and patient access to the investigational medications. Part of that could be reporting back to the manufacturer who could report it to the FDA.

## Senator Lipparelli:

We know the cost of end of life care skyrockets and I am concerned about the "snake oil" salesman who makes an industry out of being the experimental doctor. Is there a natural way that would be discovered?

## Mr. Handzlik:

The underlying premise of Right to Try is the medication must have been approved and passed through the first phase of the FDA clinical trials and still be ongoing. Just to get to the first phase of the clinical trial is a years long, hundreds of millions of dollars process. That in itself weeds out the snake oil salesman. If at any point during the clinical trials, the FDA pulls the medication it is no longer available through the Right to Try process.

## Senator Kieckhefer:

A clinical trial is a scientifically based allocation of patients meeting certain demographic criteria for a drug that is under trial with the FDA. The results of the outcomes of the patients using these drugs through the Right to Try process is not included in any data for the clinical trials because it could skew the results. Is that correct?

## **Assemblyman Ohrenschall:**

There was discussion in the Assembly whether we wanted to mandate the physician to report use and outcome of the investigational medication. We felt it was best to leave it to the individual physicians and not impose additional burdens on them.

## Mr. Handzlik:

There is no mandate that anyone has to report. The physician and manufacturer, through the informed consent agreement can decide whether they want to report it. Yes, this is outside of clinical trials.

## Ms. Dean:

It is more likely that pharmaceutical companies will allow terminal patients to participate if there is no reporting involved. It would skew the results. Not requiring the reporting will be more helpful to the patient to acquire the medication. It will allow physicians to provide options to the patients through the clinical trial phase 1 process.

## Vicki Higgins:

It is important to have investigational medication options. I suffered with an 8-year migraine headache. Before I had surgery, I was told the doctors were going to aim for quality of life for me. Quality of life is a life sentence. I wish having alternatives was available to my doctors at the time I was going through this. I ended up having surgery and bone removed from my brain. My travel would have been much easier had I been able to use the alternatives available. One concern is the definition of terminal condition which results in death within 1 year. I did not have a terminal condition but I was terminally in pain, chronically ill, unable to function, unable to move through life and barely able to raise my daughter. Had there been options for me I would have been willing to try them, even though I had not received an imminent death sentence. I received a sentence of quality of life. Fortunately, since then I have found alternatives and have gotten off many of the pharmaceuticals that have caused massive damage to my digestive system. I now have arthritis and fibromyalgia, which I am told is a result of the pharmaceuticals. I suggest the term "Terminal condition ... will result in death within 1 year" is reevaluated and changed to "quality of life." Clinical trial in the United States was discussed earlier. Why not work with the clinical trials in Israel, Sweden or Portugal? There is information worldwide on clinical trials and should be taken into consideration when it comes to implementing investigational medications in the United States. Are doctors going to be notified about the possibility of recommending investigational medications?

## Cindy Brown:

I support this bill and have provided my written testimony (Exhibit F).

## Mona Lisa Samuelson:

I am a 25-year resident of Nevada and I support this bill. I have provided my written testimony (Exhibit G).

## Mr. Handzlik:

While there are absolute uses for medical marijuana and various forms of treatment that help people in their quality of life, in the Right to Try process the medication has to have passed through the first phase of the FDA clinical trial and still be under investigation by the FDA. To my knowledge, medical marijuana has not been in any FDA clinical trials or passed the first phase. Unfortunately, despite the benefits it may exhibit to some patients, the Right to Try process and A.B. 164 does not apply to medical marijuana.

## **Delphine Callahan:**

The FDA is now officially practicing clinical trials for medical marijuana. I am a medical marijuana patient and I support this bill. I have tried many pharmaceuticals that have not helped my condition or quality of life. I do not think there is anyone here who if they saw a person suffering, in physical or mental pain would say to that person you do not have the right to do anything possible to save your life, take away your pain or function in society. I am not terminally ill but I would not be here today with my psychiatric conditions if it was not for nontraditional non-pharmaceutical medications.

# **Assemblyman Ohrenschall:**

Assembly Bill 164 is a states' rights issue and a patients' rights issue. With the 15 states that have enacted this type of legislation, we have seen change in federal policy and the proposal to streamline the FDA regulations on the compassionate use policy. Many clinical trials are not available in Nevada but we are making great strides with the medical centers and teaching hospitals coming to Las Vegas and Carson City. Many of the clinical trials that can help the terminally ill patient are offered in other states, but not in Nevada. Our constituents who are facing a terminal condition are at a disadvantage. Assembly Bill 164 will help them. This bill only applies to a patient whose MD or DO believes the patient has 12 months or less to live. That was not the language used originally. We use the definition of terminal condition found in Nevada Revised Statute 449.590, "an incurable and irreversible condition that, without the administration of life-sustaining treatment, will, in the opinion of the attending physician, result in death within a relatively short time." The original language gave more latitude to the physician. There were concerns about it being open-ended and as part of a compromise, the Assembly committee chose 12 months.

## Senator Kieckhefer:

I will close the hearing on A.B. 164 and open the hearing on A.B. 222.

ASSEMBLY BILL 222: Revises provisions governing the imposition of administrative sanctions against facilities for the dependent. (BDR 40-645)

### Ms. McMullen:

I am in favor of <u>A.B. 222</u> because it would impose a fine on personal care agencies and other facilities for the dependent that fail to obtain licenses to do business with the Bureau of Health Care Quality and Compliance. I have provided my written testimony (Exhibit H).

#### Senator Kieckhefer:

We have penalties in statute for operating a residential facility for groups or a home for individual residential care without a license. Does it capture the two facilities types just mentioned when using the term facility for the dependent?

## Ms. McMullen:

There are seven altogether and it captures all seven facility types.

# Mr. Gold:

The AARP supports <u>A.B. 222</u>. Any oversight and protection we can give to our mothers, fathers, grandparents or people who live in long-term facilities are very important. Having an incentive for getting facilities licensed is important.

## Wendy Simons:

I support this bill. When I was serving in the capacity as bureau chief we would have some providers who would license one facility but would operate two or three other unlicensed facilities. They would purport to be a licensed facility when they marketed to certain entities. That is when A.B. No. 50 of the 76th Legislative Session created the \$10,000 fine incentive for securing a license. We had a number of personal care agencies that were not licensed and the industry brought it to my attention. We did not have the enforcement capability to encourage the facilities to operate with licenses. In the personal care agency world employees break away from the parent company and recruit four or five friends and market themselves as personal care agency entities without the criminal history background checks and the criteria for training. While it is entrepreneurial in nature for those individuals, it does not meet the intent of protecting our frail elders and people in a vulnerable capacity. Especially in the arena of one-on-one care in the home where there is no direct supervision other than periodic site visits. This bill will motivate people to be accountable business people.

Senate Committee on Health and Human Service April 29, 2015 Page 17	ees			
Chris McMullen (Senior Coalition of Washoe County): The Senior Coalition of Washoe County supports A.B. 222.				
Senator Kieckhefer: Seeing no more business before us, I adjourn the meeting at 5:04 p.m.				
	RESPECTFULLY SUBMITTED:			
	Debra Carmichael, Committee Secretary			
APPROVED BY:				
Senator Ben Kieckhefer, Vice Chair	_			

DATE:

EXHIBIT SUMMARY				
Bill	Exhibit / # of pages		Witness / Entity	Description
	Α	1		Agenda
	В	4		Attendance Roster
A.B. 200	С	6	Assemblywoman Benitez- Thompson	Proposed Amendment 6893
A.B. 200	D	1	Gary W. Olsen	Written testimony
A.B. 28	Е	2	Herbert E. Randall/Nevada Silver Haired Legislative Forum	Written testimony
A.B. 164	F	1	Cindy Brown	Written testimony
A.B. 164	G	1	Mona Lisa Samuelson	Written testimony
A.B. 222	Н	2	Connie McMullen/Personal Care Association of Nevada	Written testimony