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

Eightieth Session May 15, 2019

The Committee on Health and Human Services was called to order by Chairwoman Lesley E. Cohen at 1:15 p.m. on Wednesday, May 15, 2019, in Room 3138 of the Legislative Building, 401 South Carson Street, 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/80th2019.

COMMITTEE MEMBERS PRESENT:

Assemblywoman Lesley E. Cohen, Chairwoman Assemblyman Richard Carrillo, Vice Chairman Assemblyman Alex Assefa Assemblywoman Bea Duran Assemblywoman Michelle Gorelow Assemblyman Gregory T. Hafen II Assemblywoman Lisa Krasner Assemblywoman Connie Munk Assemblywoman Rochelle T. Nguyen Assemblywoman Robin L. Titus

COMMITTEE MEMBERS ABSENT:

Assemblyman John Hambrick (excused)

GUEST LEGISLATORS PRESENT:

Senator Pat Spearman, Senate District No. 1 Senator Ira Hansen, Senate District No. 14 Senator Joyce Woodhouse, Senate District No. 5



STAFF MEMBERS PRESENT:

Marsheilah Lyons, Committee Policy Analyst Karly O'Krent, Committee Counsel Christian Thauer, Committee Manager Terry Horgan, Committee Secretary Melissa Loomis, Committee Assistant

OTHERS PRESENT:

Barbara D. Richardson, Commissioner of Insurance, Division of Insurance, Department of Business and Industry

Dena Schmidt, Administrator, Aging and Disability Services Division, Department of Health and Human Services

Eli Schwartz, Chair, Nevada Commission For Persons Who Are Deaf, Hard of Hearing or Speech Impaired

Penni Echols, Private Citizen, Las Vegas, Nevada

Marie Sassman, Private Citizen, Henderson, Nevada

Evan Sassman, Private Citizen, Henderson, Nevada

Cindy Frank, Private Citizen, Carson City, Nevada

Eric Wilcox, Private Citizen, Reno, Nevada

David Boire, Policy Intern, Children's Advocacy Alliance

Beth Jones, Private Citizen, Las Vegas, Nevada

David Daviton, Private Citizen, Sparks, Nevada [through American Sign Language interpreter Kim Johnson]

Carolyn "Lina" Tanner, Private Citizen, Reno, Nevada

Jeff Beardsley, Private Citizen, Las Vegas, Nevada [through American Sign Language interpreter D. Scott]

Mike Eifert, Executive Director, Nevada Telecommunications Association

Margot Chappel, Deputy Administrator, Regulatory and Planning Services, Division of Public and Behavioral Health, Department of Health and Human Services

Michael Hackett, representing Nevada Academy of Nutrition and Dietetics; and Nevada Academy of Physician Assistants

Allison Schnitzer, State Policy Representative, Nevada Academy of Nutrition and Dietetics

Kristina LaBouff, Board Secretary, Nevada Academy of Nutrition and Dietetics

Tyre L. Gray, representing Nevada Hospital Association

Stephen Lencioni, representing Nevada State Medical Association

Dillon Martin, Private Citizen, Las Vegas, Nevada

Randy Robison, Owner, Plan B Ranch, Reno, Nevada

Nancy Ogan, Owner, Ogan Family Farm, Gardnerville, Nevada

Kelli Kelly, Private Citizen, Fallon, Nevada

Paul E. Quade, representing Kennedy Ranch; and The Farmer's Table at Girlfarm

Sue Kennedy, Owner, Kennedy Ranch, Lamoille, Nevada

Douglas Farris, Administrator, Animal Industry, State Department of Agriculture

Wendy Baroli, Owner, The Farmer's Table at Girlfarm, Reno, Nevada

Marc Arreola, Private Citizen, Las Vegas, Nevada

Pat Gerber, Private Citizen, Las Vegas, Nevada

Julie Pazina, Private Citizen, Las Vegas, Nevada

Sean P. McDonald, Administrator, Central Services and Records Division, Department of Motor Vehicles

Cari Herington, Executive Director, Nevada Cancer Coalition

Alexis Motarex, Private Citizen, Reno, Nevada

Shirley Folkins-Roberts, Executive Director, Northern Nevada Children's Cancer Foundation

Katie Roe Ryan, Director, Public Policy, Dignity Health-St. Rose Dominican Neighborhood Hospitals

Tom McCoy, Nevada Government Relations Director, Cancer Action Network, American Cancer Society

Chairwoman Cohen:

[Roll was taken. Committee rules and protocol were explained.] We are going to begin with our work session today, but first, we are going to roll <u>Senate Bill 477</u>, because someone has a proposed amendment that has not been addressed with the bill's sponsors. I want to give them a chance to work something out.

Senate Bill 477: Prohibits the release of a child to a parent or guardian in certain circumstances. (BDR 38-1005)

[This bill was not considered and will be rescheduled.]

Marsheilah Lyons will begin with our work session.

Marsheilah Lyons, Committee Policy Analyst:

We are starting with Senate Bill 364 for our work session today.

Senate Bill 364: Prohibits discrimination against and provides protection for persons who reside in or receive services from certain facilities. (BDR 40-757)

Marsheilah Lyons, Committee Policy Analyst:

[Marsheilah Lyons read from the work session document (Exhibit C).] Senate Bill 364 prohibits medical facilities, facilities for the dependent, and certain other facilities from discriminating against a person based on the actual or perceived race, color, religion, national origin, ancestry, age, gender, physical or mental disability, sexual orientation, gender identity or expression, or human immunodeficiency virus status of the person or a person with whom the person associates. The bill requires the records of such a facility to refer to a person using the gender identity, name, and pronouns preferred by the person, and it requires administrators and employees of such facilities to receive training concerning cultural competency and sensitivity to certain issues. The bill also requires these facilities to post prominently and include in marketing materials a statement that a person who is

discriminated against on prohibited grounds may file a complaint with the State Long-Term Care Ombudsman within the Aging and Disability Services Division of the Department of Health and Human Services (DHHS) and provide contact information for the ombudsman.

There is a conceptual amendment proposed for the bill attached to the work session document that would:

- 1. Allow the DHHS to promulgate regulations:
 - a. Specifying discriminatory practices that are prohibited in facilities;
 - b. Establishing the requirements for the development of policies and procedures to ensure that patients and residents in facilities are referred to by their preferred name, gender identity, and pronoun preference; and
 - c. Mandating that certain records are adapted.
- 2. Clarify that a "person" is the patient or resident of the licensed facility;
- 3. Align the cultural competency training with the training required in Senate Bill 470;
- 4. Revise the requirements to list a specified statement on all marketing material; and
- 5. Specify that complaints may be filed with the Bureau of Health Care Quality and Compliance, Division of Public and Behavioral Health rather than the Long-Term Care Ombudsman.

Also, Assemblyman Carrillo has asked to be added as a cosponsor to this measure.

Chairwoman Cohen:

Are there any questions before we vote on this? [There was no response.]

ASSEMBLYWOMAN MUNK MADE A MOTION TO AMEND AND DO PASS SENATE BILL 364.

ASSEMBLYWOMAN NGUYEN SECONDED THE MOTION.

Is there any discussion?

Assemblywoman Titus:

Unfortunately, I am going to have to vote no on this bill. Although I understand the concerns and am sympathetic to the issues, I feel there will possibly be some problems with billing and unintended consequences related to this bill, so I will not be able to support it at this time.

THE MOTION PASSED. (ASSEMBLYMEN HAFEN, KRASNER, AND TITUS VOTED NO. ASSEMBLYMAN HAMBRICK WAS ABSENT FOR THE VOTE.)

Chairwoman Cohen:

The motion passed, and I will take the floor statement.

Marsheilah Lyons:

Senate Bill 33 (1st Reprint) is next.

Senate Bill 33 (1st Reprint): Revises provisions governing enforcement of child support obligations. (BDR 38-199)

Marsheilah Lyons, Committee Policy Analyst:

[Marsheilah Lyons read from the work session document (Exhibit D).] Senate Bill 33 (1st Reprint) requires certain insurers to exchange information with a program established by the Division of Welfare and Supportive Services (DWSS) of the Department of Health and Human Services (DHHS) to locate absent parents, establish paternity, and obtain and enforce child support not less than five days after opening certain bodily injury, wrongful death, workers' compensation, or life insurance claims for the purpose of verifying whether the claimant owes a debt for child support to the Division or to a person receiving services from the program. If a claimant owes child support, the insurer must withhold the amount specified and remit it to the appropriate entity within 30 days. However, priority must be given to any item, claim, or demand for attorney's fees or costs, medical expenses, or property damage over any amount remitted.

There is an amendment that was proposed by Nova Murray, Deputy Administrator, DWSS, DHHS, at the hearing on this bill and a draft of that amendment is attached on page 2 of the work session document (Exhibit D).

Chairwoman Cohen:

Are there any questions? [There was no response.]

ASSEMBLYMAN CARRILLO MADE A MOTION TO AMEND AND DO PASS <u>SENATE BILL 33 (1ST REPRINT)</u>.

ASSEMBLYWOMAN GORELOW SECONDED THE MOTION.

Are there any comments? [There was no response.]

THE MOTION PASSED. (ASSEMBLYMAN HAMBRICK WAS ABSENT FOR THE VOTE.)

I will ask Assemblyman Carrillo to take the floor statement.

Marsheilah Lyons:

Next is Senate Bill 258 (1st Reprint).

Senate Bill 258 (1st Reprint): Revises provisions relating to applied behavior analysis. (BDR 39-248)

Marsheilah Lyons, Committee Policy Analyst:

[Marsheilah Lyons read from the work session document (<u>Exhibit E</u>).] <u>Senate Bill 258</u> (<u>1st Reprint</u>) makes various changes related to applied behavior analysis (ABA). Specifically, the bill:

- Removes certification as a state certified behavior interventionist from *Nevada Revised Statutes*;
- Transfers certain responsibilities related to licensure for certain ABA providers from the Aging and Disability Services Division of the Department of Health and Human Services to the Board of Applied Behavior Analysis;
- Requires continuing education prescribed by the Board for behavior analysts or assistant behavior analysts to be consistent with nationally recognized standards; and
- Authorizes applicants for registration as registered behavior technicians to forego the required background check if they submit verification of having passed a criminal background check within the immediately preceding six months.

There is an amendment from Senator Seevers Gansert that was presented at the hearing, and it is included.

Chairwoman Cohen:

Are there any questions? [There was no response.]

ASSEMBLYWOMAN TITUS MADE A MOTION TO AMEND AND DO PASS SENATE BILL 258 (1ST REPRINT).

ASSEMBLYMAN HAFEN SECONDED THE MOTION.

Is there any discussion on the motion? [There was no reply.]

THE MOTION PASSED. (ASSEMBLYMAN HAMBRICK WAS ABSENT FOR THE VOTE.)

Assemblywoman Titus, please take the floor statement.

Marsheilah Lyons:

We will move on to Senate Bill 262.

Senate Bill 262: Makes various changes to provide for tracking and reporting of information concerning the pricing of prescription drugs for treating asthma. (BDR 40-55)

Marsheilah Lyons, Committee Policy Analyst:

[Marsheilah Lyons read a description of the bill from the work session document ($\underbrace{Exhibit F}$).] Senate Bill 262 makes various changes to provide for the tracking and reporting of information concerning the pricing of prescription drugs for treating asthma. Specifically, the bill adds asthma drugs to:

- The list of essential prescription drugs that the Department of Health and Human Services must compile and add to the list of such drugs that have been subject to a significant price increase in the immediately preceding two calendar years;
- Certain reports that must be submitted by a manufacturer of such prescription drugs or a pharmacy benefit manager; and
- The report the Department must compile concerning the reasons for and the effect of the pricing of essential asthma drugs.

In addition, the bill authorizes the Department to use the money collected from administrative penalties for failure to submit certain required reports, and to establish and carry out programs to provide education concerning asthma and to prevent asthma. There are no amendments in the work session document for this measure.

Chairwoman Cohen:

Are there any questions? [There was no response.] I am looking for a motion to do pass.

ASSEMBLYWOMAN NGUYEN MADE A MOTION TO DO PASS SENATE BILL 262.

ASSEMBLYWOMAN DURAN SECONDED THE MOTION.

Is there any discussion on the motion?

Assemblywoman Titus:

Although I understand that asthma is a serious illness and that medications can be expensive, I think this bill will not solve any of those problems. It can become a slippery slope when we start managing the cost of drugs, so this bill is not something I can support.

THE MOTION PASSED. (ASSEMBLYMEN HAFEN, KRASNER, AND TITUS VOTED NO. ASSEMBLYMAN HAMBRICK WAS ABSENT FOR THE VOTE.)

Assemblywoman Nguyen will take the floor statement.

Marsheilah Lyons:

Next is Senate Bill 270 (1st Reprint).

Senate Bill 270 (1st Reprint): Requires the Department of Health and Human Services to establish and administer the Nevada Housing Crisis Response System. (BDR 38-792)

Marsheilah Lyons, Committee Policy Analyst:

[Marsheilah Lyons read from the work session document (Exhibit G).] Senate Bill 270 (1st Reprint) requires the Department of Health and Human Services, to the extent that money is available, to establish and administer the Nevada Housing Crisis Response System to prevent and address homelessness in the state by:

- Coordinating with local governments and nonprofit organizations;
- Providing a system to respond to crises 24 hours per day, 7 days per week;
- Developing prevention and assistance programs; and
- Generally assisting people who are transient, at imminent risk of homelessness, or homeless.

The Department may adopt regulations to carry out the provisions of the bill, including regulations that require a person or entity that accepts money from the Department to participate in the Nevada Housing Crisis Response System. Finally, the Department must submit an annual report to the Legislature concerning activities and services to prevent homelessness in the state. There were no amendments in the work session document for this measure.

Chairwoman Cohen:

Are there any questions about this measure? [There was no response.] I am looking for a motion to do pass.

ASSEMBLYWOMAN MUNK MOVED TO DO PASS <u>SENATE BILL 270</u> (<u>1ST REPRINT</u>).

ASSEMBLYWOMAN NGUYEN SECONDED THE MOTION.

Is there any discussion on the motion?

Assemblywoman Titus:

Although this is a good idea, I think we need to look at other ways and other possible funding. I have some huge concerns about cost although the funding was not addressed; but, ultimately, it will have to be. As a result, I will vote no on this bill at this time.

THE MOTION PASSED. (ASSEMBLYMEN HAFEN AND TITUS VOTED NO. ASSEMBLYMAN HAMBRICK WAS ABSENT FOR THE VOTE.)

Assemblywoman Munk will take the floor statement.

Marsheilah Lyons:

We will move on now to Senate Bill 362 (1st Reprint).

Senate Bill 362 (1st Reprint): Revises provisions concerning the placement of persons with dementia in a residential facility for groups. (BDR 40-611)

Marsheilah Lyons, Committee Policy Analyst:

[Marsheilah Lyons read from the work session document (Exhibit H).] Senate Bill 362 (1st Reprint) requires regulations adopted by the State Board of Health governing the licensing of adult day care facilities and residential facilities for groups that provide care to people with Alzheimer's disease to also apply to facilities that provide care to people with other severe dementias. It requires the administrator of a residential facility for groups to annually:

- Cause a physician to conduct a physical examination of each resident of the facility; and
- Conduct an assessment of the history of each resident.

If the physical examination, assessment, or observations of certain persons indicate that a resident requires a secure facility or a facility with a high staff-to-resident ratio, the bill requires the administrator to cause a physician to conduct an assessment of the condition and needs of the resident. If the physician determines the resident suffers from dementia to an extent that he or she may be a danger to himself or herself or others if not placed in a secure unit or a facility with a high staff-to-resident ratio, then the residential facility in which the residential placed must meet the regulatory requirements prescribed by the Board for group residential facilities that provide care to persons with Alzheimer's disease or other severe dementia.

There is an amendment in the work session document for this measure. The amendment makes the following revisions in section 1:

- The measure refers more broadly on line 4 and line 10 to "medical provider" rather than "physician;"
- In addition to family, it allows for friends or individuals who have a relationship with the resident to provide their observations regarding a resident (line 17); and
- On line 18, adds language recognizing that a resident may meet those criteria or "has had a change of condition."

Chairwoman Cohen:

Are there any questions? [There was no response.] I am looking for a motion to amend and do pass.

ASSEMBLYWOMAN GORELOW MADE A MOTION TO AMEND AND DO PASS SENATE BILL 362 (1ST REPRINT).

ASSEMBLYWOMAN TITUS SECONDED THE MOTION.

Is there any discussion on the motion?

THE MOTION PASSED. (ASSEMBLYMAN HAMBRICK WAS ABSENT FOR THE VOTE.)

Assemblywoman Gorelow will take the floor statement.

Marsheilah Lyons:

Next is Senate Bill 470 (1st Reprint).

Senate Bill 470 (1st Reprint): Revises provisions relating to health care. (BDR 40-785)

Marsheilah Lyons, Committee Policy Analyst:

[Marsheilah Lyons read from the work session document (Exhibit I).] Senate Bill 470 (1st Reprint) requires the State Board of Health to establish regulations requiring a medical facility to conduct training related to cultural competency for any employee that provides direct care to a patient. The bill requires the Department of Health and Human Services to approve the medical facility's cultural competency course or program.

There is an amendment to this measure in the work session document. In addition to the medical facilities currently in <u>S.B. 470 (R1)</u>, the bill would be amended to require the employees who provide direct care in all of the facilities included in <u>Senate Bill 364</u> to develop and conduct the required cultural competency training. <u>Senate Bill 364</u> includes a medical facility, facility for the dependent, or facility which is otherwise required by regulations adopted by the Board pursuant to *Nevada Revised Statutes* (NRS) 449.0303 to be licensed. Pursuant to NRS 449.0045, "facility for the dependent" includes:

- A facility for the treatment of abuse of alcohol or drugs;
- A halfway house for recovering alcohol and drug abusers;
- A facility for the care of adults during the day;
- A residential facility for groups;
- An agency to provide personal care services in the home;
- A facility for transitional living for released offenders;
- A home for individual residential care;
- A peer support recovery organization; and
- A community health worker pool.

Chairwoman Cohen:

Are there any questions about the bill? [There was no response.] I am looking for a motion to amend and do pass.

ASSEMBLYWOMAN NGUYEN MADE A MOTION TO AMEND AND DO PASS SENATE BILL 470 (1ST REPRINT).

ASSEMBLYMAN CARRILLO SECONDED THE MOTION.

Is there any discussion on the motion?

Assemblywoman Titus:

I think we need to be sensitive to all groups. Setting out certain groups and excluding others is not something we should be doing at all, so I cannot support the bill as written.

THE MOTION PASSED. (ASSEMBLYMEN HAFEN, KRASNER, AND TITUS VOTED NO. ASSEMBLYMAN HAMBRICK WAS ABSENT FOR THE VOTE.)

Assemblywoman Duran will take the floor statement.

We will close our work session and move to the hearing on Senate Bill 203 (1st Reprint).

Senate Bill 203 (1st Reprint): Revises provisions governing programs for children who are blind, visually impaired, deaf or hard of hearing. (BDR 38-77)

Senator Pat Spearman, Senate District No. 1:

According to the 2014 Gallaudet University study, an estimated 38,000 individuals who are deaf and hard of hearing live in Nevada, and according to the National Federation of the Blind, more than 100,000 Nevadans are blind or visually impaired. Children who are blind, visually impaired, deaf, or hard of hearing deserve an education equal to that provided to other children. They deserve systems and services that ensure they can participate equally in society and develop language and literacy skills at an early age, access to the assistive technology and interpreters they need to succeed, and the opportunity to attend schools that are designed around and cater to their needs. This is what the bill does. The bill addresses four broad areas that will help ensure children in Nevada who are blind, visually impaired, deaf, or hard of hearing have access to assistive technology and are served by systems that are designed to work for them.

<u>Senate Bill 203 (1st Reprint)</u> authorizes the establishment of a program to negotiate discounts and rebates for hearing devices and related costs for certain children in Nevada. It requires the development of a program to help certain children under 13 years of age who are hard of hearing to apply for hearing aids at no charge. It creates an advisory committee charged with recommending criteria to evaluate language and literacy skills for children who are blind, visually impaired, deaf, or hard of hearing. Finally, it requires the creation of an interim

committee to study the possibility of establishing a public school for young people who are blind, visually impaired, deaf, or hard of hearing here in Nevada.

Specifically, section 3.2 authorizes the Director of the Department of Health and Human Services (DHHS) to establish a program to negotiate discounts and rebates for hearing devices and other related costs—such as ear molds and batteries—for children in Nevada who are deaf or hard of hearing on behalf of public and private insurers, residents, and other entities that provide health coverage for the purchase of hearing devices for these children.

Section 3.3 of the bill requires that the Aging and Disability Services Division (ADSD) develop and administer a program through which certain children who are less than 13 years of age may apply for hearing aids at no charge. Such children must be hard of hearing, live in a home with a household income at or below 400 percent of the federal poverty level, and not have other insurance coverage for hearing aids. The Division must establish regulations outlining how a person can apply for hearing aids through this program, and must report certain information each year.

Section 3.8 addresses funding for this program and requires ADSD, in consultation with the Public Utilities Commission of Nevada (PUC), to designate each year the amount of money in the Account for Services for Persons With Impaired Speech or Hearing that ADSD must use during the calendar year to cover the cost of the program to provide assistive technology and interpreters. They must use the remaining money in the Account for certain other purposes including paying the cost of the program to provide hearing aids to low-income children.

Section 9 of the bill requires the Superintendent of Public Instruction to establish the Advisory Committee on Language Development for Children Who Are Deaf, Hard of Hearing, Blind or Visually Impaired which must include members who specialize in teaching or providing services to children who are blind, visually impaired, deaf, or hard of hearing. This must include children who are both deaf and blind and their parents and students who perform research in a field relating to such children. The Committee's duties are outlined in section 10 and include making recommendations regarding the criteria used to evaluate the development of language and literacy skills by children who are less than six years of age and are blind, visually impaired, deaf, or hard of hearing, among other things.

Section 11 requires the State Board of Education to: (1) make any necessary revisions so that the criteria recommended by the Advisory Committee meet certain requirements; (2) adopt those criteria; and (3) develop a resource for use by the parents or guardians to evaluate the development of language and literacy skills by children who are less than six years of age and are deaf, hard of hearing, blind, or visually impaired. In addition, sections 3 and 14 require the teams to develop an individualized education program prescribing special education or individualized family service plan prescribing early intervention services for a child with a hearing or visual impairment or both to use the criteria adopted by the State Board of Health to evaluate the child's language and literacy development.

Section 13 of the bill requires the Department of Education and ADSD to publish an annual report that includes aggregated data comparing the development of language and literacy skills by children who are less than six years of age who are blind, visually impaired, deaf, or hard of hearing with development of these skills with children of the same age who do not have this disability.

Finally, section 15 requires the Legislative Commission to appoint a committee to conduct an interim study concerning the feasibility of establishing a public school for pupils who are blind, visually impaired, deaf, or hard of hearing. The committee must consult with and solicit input from appropriate individuals and organizations and consider potential sources of funding for such a school and submit a report of the results of the study and its recommendations to the Legislature.

Last session we established a commission for those who are deaf and hard of hearing. At that time, I made a commitment to look and see how we might be able to establish a school for children who are differently-abled like this. I think we should be ashamed of the fact that here in Nevada we do not have a dedicated school for the deaf, hard of hearing, blind, or visually impaired. There is a school making a small beginning in southern Nevada, but it has limited resources.

I know we talk a lot about day care and its cost—if your child is blind, visually impaired, deaf, or hard of hearing, do you know they cannot go to day care? That is just one challenge parents of these children experience. Some parents in single-parent households have to juggle the special needs of their children with either trying to keep a job or do other things to get income so they can take care of their children. At this time, most insurance plans do not cover hearing aids, nor does Medicare.

This bill is designed to give us a step in the right direction. It is wrong for parents and children who have these challenges not to have the same foundation and the same start to success as their peer groups who do not have to contend with these challenges. Some people say they should be mainstreamed, but without the basic foundation of language and literacy skills, and without programs that help parents understand how to do this, what most parents do is try to figure it out. Some have aid from some 501(c)(3) organizations that try to help. This bill just says that we are asking the Committee to help families who face these challenges as we do for those families who do not. Children deserve a fresh start and a start at success that is equal regardless of their ability or lack thereof.

I have an amendment that will remove the fiscal note on the bill. The needed language for changes discussed today that will ensure coverage of children between 250 percent and 400 percent with high deductible plans is as follows:

Section 3.3, subsection 1, paragraph (b): Does not have the affordable access coverage for hearing aids. This change will allow the Division to adopt regulations defining "affordable," as it will differ based on plan types.

Section 3.2, subsection 2, paragraph (c): An admitted insurer licensed pursuant to Title 57 of NRS. This change was recommended by the Insurance Commissioner to better define the insurers who may participate.

Chairwoman Cohen:

For the sake of clarity, when you say amendment, do you mean what became the reprint? We do not have any document to refer to.

Senator Spearman:

This is the language that will be in a mock-up.

Barbara D. Richardson, Commissioner of Insurance, Division of Insurance, Department of Business and Industry:

I am here primarily to answer questions.

Chairwoman Cohen:

Are there any questions?

Assemblywoman Titus:

Thank you, Senator Spearman. This is an issue that absolutely needs to be addressed, and I appreciate your championing it. I also appreciate your comment about mainstreaming, because there has been a mindset for a long time that children with unique needs needed to be part of the mainstream of education. That is what we all pushed for so those children would not be identified as "special" education children. In medicine, sometimes the pendulum can swing and ideas can change. Perhaps we miss some things with that philosophy.

For clarity, my question on the bill concerns section 3.3 where the age of a child is 13 and then you address the needs of children younger than 6. We know they have unique needs because of development, but I am wondering why you chose those ages. How do we address children who become deaf later due to things such as infections after an illness, et cetera? Early intervention is critical for communication and writing skills. It is not just teaching them sign language. If they do not hear the words it is not like they can learn phonics to write, so there are these unique challenges to the development of language and writing skills. Can you address the different ages you have aligned in this bill?

Senator Spearman:

In 2003 there was a bill passed that required all children from birth to age 3 to be tested for hearing loss. Between the ages of 3 and 6, there is a gap. The age of 13 was actually a compromise, because what I really wanted to do was get coverage for all children 18 and under. This is a start.

Assemblywoman Titus:

What would happen to those 13-year-olds? Suddenly we are assisting them, and then when they hit 13 they no longer get assistance yet they do not qualify as adults. Could you clarify what would happen then?

Dena Schmidt, Administrator, Aging and Disability Services Division, Department of Health and Human Services:

Unfortunately, depending on their circumstances, if they did not have access to other coverage by that time, at 13 they would not be eligible for this program.

Assemblywoman Titus:

That is not acceptable, but thank you for the information.

Assemblyman Carrillo:

My question concerns section 3.3. Is it only for hearing aids, or would this bill also apply to cochlear implants?

Senator Spearman:

We started out with hearing aids, but I think what the Director wants to do is use the money as we have it to address the hearing challenges of children. That may or may not include cochlear implants; however, I am hopeful that it will. Keep in mind that the way we are going to fund this is through the provisions of <u>Senate Bill 400 of the 79th Session</u>, which is now codified in NRS Chapter 232.3601. They will request grants and other funding and while the money lasts, we will be able to provide these services for children. I believe it is incumbent upon us as legislators and policy makers to figure this out so that parents and children who have these challenges are not left behind.

Assemblyman Carrillo:

How did you come up with the age of 13 to put that limit there?

Senator Spearman:

Age 18 and under was first, but if we could at least get the children through middle school, it would give them a pretty good foundation, and that is how we arrived at the age of 13. To Assemblywoman Titus's point, it is not that I am saying mainstreaming is not worthwhile; but you cannot mainstream a child who has not had the basic fundamentals of language development and literacy and skills and those sorts of things. You cannot throw a child who is deaf, hard of hearing, blind, or visually impaired into kindergarten and tell them to go play. They have to have a foundation. We are going to try to get them through middle school, and it is my hope that we, as a body, will commit to figuring this out next session for all children 18 and under.

Assemblyman Carrillo:

Will this cover the cost of the hearing aids?

Dena Schmidt:

Yes, it would, as well as the ancillary services needed to have the hearing aids made.

Assemblyman Hafen:

Senator, thank you for bringing this bill. I think it is a very good bill. I, too, have a concern about the children between the ages of 13 and 18, as do my colleagues. My question relates to the 400 percent of household income related to the federal poverty level. A lot of other legislation uses a 300 percent threshold. Where did the 400 percent threshold come from, and if you used 300 percent, could we cover the gap between 13 and 18?

Dena Schmidt:

Four hundred percent of the federal poverty level is in alignment with the health insurance exchange subsidy program, so we aligned it with that. Those folks between 250 and 400 percent, while they may have an insurance plan, they do not have the copays and deductibles and they may have a very high deductible plan which would not allow them to access hearing aids. That is one reason we aligned it with the health insurance exchange.

Chairwoman Cohen:

I have a question about section 9 and the Advisory Committee and its makeup. I was a little confused by that. It is 13 parents of pupils who are deaf, hard of hearing, blind, or visually impaired as well as pupils, and then there are an additional 7 members. Can you break that down again for me?

Senator Spearman:

The general idea for that was to make sure we had people who are affected by these challenges be part of the Advisory Committee. We tried to cover just about every possible category. We thought it was important to have parents and some students. I got that idea from Eli Schwartz who is Chair of the Nevada Commission for Persons who are Deaf, Hard of Hearing or Speech Impaired. It was important to him that we have people who are affected by these challenges. It may seem a little confusing, but we were trying to capture all the various categories, or the bulk of them, that would be impacted.

Chairwoman Cohen:

I appreciate that and understand where the idea came from, but what is the total number of people who will be on the Advisory Commission?

Senator Spearman:

Thirteen members, and that language is on page 11 at the top, "who are the parents of pupils who are deaf, hard of hearing, blind or visually impaired, including, without limitation, pupils who are both deaf and blind, specialize in teaching or providing services to such children." That is the criteria for the makeup of the 13. There may be various ways to get there, but optimally, we would really like to have that makeup.

Chairwoman Cohen:

Seeing no other questions, we will invite people up for testimony in support. We will have to stick to two minutes per testimony.

Eli Schwartz, Chair, Nevada Commission for Persons who are Deaf, Hard of Hearing or Speech Impaired:

The Commission is tasked with making recommendations to the State of Nevada concerning the establishment and operation of programs for people who are deaf, hard of hearing, or speech impaired. Hearing loss can affect a child's ability to develop speech, language, and social skills. The earlier a child who is hard of hearing can start getting services like hearing aids, the more likely a child's speech, language, and social skills will reach their full potential. The human brain is programmed to learn language during the first 6 years of life, with the first 3 1/2 years being the most critical. The early weeks and months following the identification are the times when parents and caregivers should be weighing different options, opportunities, and situations that would be a good fit for the child and family.

Children need to develop English literacy skills based on their individual abilities and potential to ensure academic success. If a child learns American Sign Language, we should find continuing educational opportunities as described in S.B. 203 (R1) for the student to develop his or her academic American Sign Language just as typical peers develop academic English skills. Therefore, the Nevada Commission for Persons who are Deaf, Hard of Hearing or Speech Impaired supports this bill, S.B. 203 (R1).

I would like to speak now as a private individual and give you a little background on my upbringing. I am deaf and I am wearing a cochlear implant, but I was identified at age three as having hearing loss. My parents immediately put me in a school for the deaf, and after the first three years in that school, I was able to mainstream to a public school. As I mentioned earlier, identification is very important, and getting the right education is good. Thankfully, through my parents, I am able to be what I am today.

Penni Echols, Private Citizen, Las Vegas, Nevada:

[Penni Echols spoke from prepared text (Exhibit J).] I am the mother of a deaf-blind child. I would like to thank Senator Spearman for drafting and advocating so passionately for S.B. 203 (R1). This bill has great power to improve the lives of children in Nevada who, like my daughter, need additional assistance in understanding and interacting with the world around them. Martha is four years old. She was born with CHARGE syndrome. For her, this means that she is deaf-blind. She wears hearing aids and cannot see out of her right eye. Her left eye does all the work. She attends a Clark County School District preschool, and she is thriving. She loves to go to school, and she is learning to speak. She signs fluently, and she is beginning to learn how to read. In her classroom, three of the students have only Spanish spoken in their homes. When they come to school, English and American Sign Language (ASL) are spoken simultaneously. Two students in her class hear both Spanish and English at home and sign language and English in class. Martha is the only student in her class who, I think, gets sufficient sign language support at home.

Deaf Centers of Nevada promised us programs like ASL classes, deaf mentorship, and SKI-HI curriculums that go through age five to teach parents at home how to communicate with their children. Those programs are no longer offered. Promises that have been made to us have been broken time and time again, so I am asking you today to pass this bill. The language acquisition measures in sections 9 through 14 and in section 16 are extremely important because they give children the right to develop language which they currently do not have. Now, if we have complaints about our individualized education programs (IEPs), we file due process under the Individuals with Disabilities Education Act, but there are no state laws that back us up on that. It is hands off. We need additional rights for our children.

Chairwoman Cohen:

I am very sorry, Ms. Echols, but we are going to have to cut you off at your two minutes. I see you have written testimony. If anyone has written testimony, please drop it off with staff so we will have a copy of it. Also, thank you, Ms. Echols, for sharing with us about your daughter, Martha.

Marie Sassman, Private Citizen, Henderson, Nevada:

Shortly after my son Evan's birth, I found myself sitting in an audiologist's office trying to get answers about exactly why he had failed his infant hearing screening. I can remember sitting in the waiting room of this office holding him in my arms and looking up at a poster on the wall. That moment changed my life. The poster featured a quote from Helen Keller that read as follows: "Blindness separates us from things but deafness separates us from people." I played that last bit over in my mind: deafness separates people from people. I wanted so much to refute that quote and tell myself that she was wrong. Surely this could not be true. I sat there in grief, fear, and with a broken heart. I decided right then that my son would never be separated from people, never be isolated, and never be alone. I told myself I would do absolutely anything to ensure he gets what he needs to live a fulfilled life.

Here I am, six years later, addressing all of you in this fine state of Nevada, not only for my son, Evan, who sits with me today, but also for many more. I spent nearly a decade teaching in the Clark County School District. I hold my undergraduate and master's degrees in the field of education, and as both a parent and educator, I understand the absolute importance of education bridging that gap to equality. Senate Bill 203 (1st Reprint) has so many great aspects that will contribute to the education of all the children we have spoken about today.

Being able to communicate is a basic human right. Without it, we are, as Helen Keller suggested, forced to live in isolation. With my background in language acquisition, I can tell you with assurance how critical it is for children to master a native language before the age of five and particularly critical by age three. Yet 90 percent of deaf and hard-of-hearing children are born to parents who are hearing. I myself would have loved to have immersed my son in ASL and spoken language from the start, but I did not have the resources to be proficient in ASL to teach him. I was, however, one of the families that was lucky enough to be able to afford to get my son hearing aids, but that is not the case for all our families, and that is unacceptable. No child or family should be denied access to spoken language based on monetary circumstances.

Evan Sassman, Private Citizen, Henderson, Nevada:

I am six years old. I am very fast and I have run over 100 miles this year. I love soccer and I am hard of hearing. I love having my hearing aids, and if I did not have my hearing aids I would feel sad. This bill is very important because it will help kids pay for hearing aids. If my family could not afford hearing aids, I could not hear anything, and that is pretty sad because I like to talk and I could not hear my friends and family. Thank you so much to everyone for writing this bill. Please help me and other deaf kids by voting yes on S.B. 203 (R1).

Chairwoman Cohen:

Thank you for coming to visit us, Evan, and for your testimony.

Cindy Frank, Private Citizen, Carson City, Nevada:

I am a college professor, a language specialist here in the Carson City School District; and, most importantly, I am a member of the deaf community. I am third-generation deaf. I was lucky. I had ASL and English while growing up in my house, but most kids do not have that. What you decide today and over the next few weeks is going to decide if deaf children are disabled or deaf children are language-different. What does that mean? If we do our jobs well and we develop the synapses in their brains while they are growing as we do with hearing kids, they will be fine. They could be President of the United States. But if we do not take advantage of this time period, the synapses will not grow. If those synapses do not grow, those kids will be permanently disabled. I know; I work with them every morning. I am still teaching an 11-year-old who is in fourth grade. It is not cool. We have to stop this, please. You talk about mainstreaming. How would you like it if I poked your ears out and put you in the middle of Japan and then put you in a school and said, "Get to work"? That is what mainstreaming is for deaf kids. I beg of you, please, please, honor the soul of the child—both blind and deaf.

Eric Wilcox, Private Citizen, Reno, Nevada:

I am the parent of a deaf child. I also volunteer as the president of Nevada Hands and Voices—a statewide nonprofit support and advocacy group for parents of deaf and hard-of-hearing kids. I also represent parents on the Nevada Commission for Persons Who are Deaf, Hard of Hearing and Speech Impaired. In my remarks today, I am representing myself and voicing my support for this critically important bill.

Most recent data from the federal government indicates that the typical deaf child reaches high school graduation with only a fourth-grade literacy level. From my experience raising a now-six-year-old girl who was born severely deaf, even with hard work and engaging the best educators and speech language pathologists we could find, our daughter struggled with language and entered preschool with a significant language delay. What I also learned from working on family outreach throughout the state is that not every deaf or hard-of-hearing child is receiving services from early interventionists and teachers with specific training in language acquisition in deaf children and how to measure it.

This bill calls for the establishment of language benchmarks to improve the school readiness of these children. This provision in the law is essential because parents need to know if their children are making progress toward being ready for kindergarten, and early interventionists and those working with preschool-aged kids need to help families gauge that progress. Without the force of law, these tools and access to this level of expertise is not available to every deaf and hard-of-hearing child in Nevada. The establishment of these language benchmarks is not costly to the state and will align Nevada with a movement toward best practices in states across the nation.

In six years, my family has purchased two sets of hearing aids for our daughter costing a total of \$7,000. It is important for this Committee to understand that, when receiving news that their child has been diagnosed with a hearing loss, parents are typically told that they must provide their child with a hearing device as soon as possible or risk losing valuable auditory stimulus to the child's brain during the crucial early months and years of early language development. Every month, several children are born in Nevada who will be diagnosed at an early age as deaf or hard of hearing. Every month, there are parents in the state who are confronted with thousands of dollars in unexpected costs they could not have anticipated or prepared for. The programs for hearing devices provided in this bill will help alleviate this unfair burden for families that do not have the resources to provide the devices that the medical and educational establishment tells them they must. Thank you again for considering these critical needs and for the opportunity for all of us to share our stories.

David Boire, Policy Intern, Children's Advocacy Alliance:

Hearing loss is the most common congenital condition present at birth in the United States. Approximately two or three out of every one thousand children in the United States are born deaf or with some degree of hearing loss, and more lose their hearing later during childhood. As a child learns his or her first language, it is not taught like a school subject, rather, it is caught as a child picks up on words through continuous exposure to spoken language through listening. If hearing loss is left undetected and untreated, a child's spoken speech and language acquisition, academic achievement, and social and emotional development can be harmed. It is critical that a child with hearing loss receive appropriate hearing devices and access to early intervention services as early as possible. According to the American Speech-Language-Hearing Association, hearing aids represent relatively inexpensive intervention for the amount of benefit gained, especially when calculating the long-term benefits of early intervention to children and society.

When infants with hearing loss have access to hearing devices and start intervention by six months of age, they are often able to have the same language abilities as their peers when they enter kindergarten. Nevada Medicaid—which covers 61 percent of Nevada's children—and Nevada Check Up cover hearing tests, hearing devices, batteries for hearing devices, and speech therapy. However, many commercial insurance plans in Nevada do not fully cover hearing devices, leaving many families unable to afford to obtain these necessary and life-changing devices. Families struggle to pay bills amounting to several thousands of dollars for hearing devices in addition to the cost of ear molds, batteries, hearing-assisted technology, other supplies, and additional necessary maintenance.

<u>Senate Bill 203 (1st Reprint)</u> looks to address this high cost for families. As such, we are very supportive and urge your passage of this matter. We want to thank Senator Spearman for her hard work on this bill.

Beth Jones, Private Citizen, Las Vegas, Nevada:

I am a mom of three children, two of whom are deaf or hard of hearing. This week, they turned 8 and 12 years old, and currently they are successful at their mainstream neighborhood school only after years of intervention and deaf and hard-of-hearing services in self-contained rooms.

The aspect I want to talk about today refers to having a deaf and hard-of-hearing school here in Nevada. It could serve as a place to provide extracurricular activities such as sports, music and theater, summer camps, leadership opportunities, as well as being an overall deaf education resource center for our state.

My family has traveled to two other states multiple times in the first two years after my kids were diagnosed to gain resources and services from other schools on deaf education and language acquisition in the absence of a school in Nevada. This included attending a three-week deaf and hard-of-hearing parent and child education program where we lived in the dorms at the University of Southern California. We had to leave our then-five-year-old son at home in Nevada because they did not offer any program for him.

My husband and I needed help and our kids needed help and Nevada could not provide that. Now that my kids are in elementary and middle schools, their extracurricular activities are especially important to them, and there is often a struggle to gain equal access, especially with assistive technology. Because of this, we are again trying to get help out of state and we are traveling to the Georgia School for the Deaf this summer to allow my daughter to attend a soccer camp led by the U.S. Deaf Women's National Soccer Team, which has been a dream of hers for years.

Having a school in our state that could support our kids' educational and extracurricular needs means new opportunities for other deaf-centered experiences and events from throughout the country and would expose our kids to so much more than we can do presently.

David Daviton, Private Citizen, Sparks, Nevada [through American Sign Language interpreter Kim Johnson]:

Hello, Chairwoman and Committee members. I am in support of this bill; in some regards I am in a neutral position as well. There are some places in this bill where it is vague and would need some clarification. I agree with Assemblywoman Titus that the age cap should not be at 13; what about zero to age 100? We, as citizens, pay for these services and we need that access to communication as equally as anybody else, and that is key. It should not only apply to deaf individuals, it should apply to everyone.

Regarding establishing a school for the deaf, that is definitely a possibility, but it is important that that program is established to create success. There are other states with schools for the deaf, so we do not need to recreate the wheel in that regard. We can bring these deaf students together and copy other states' models. With that, if this bill does not pass, as was mentioned earlier, that critical age of 6 years of age, it will change their lives forever and that will end up costing the state more in the future. So the key is to provide these services for these children early on so that the cost will be less for the state later on.

Chairwoman Cohen:

I invite you to reach out to Senator Spearman if you have any concerns to address.

Carolyn "Lina" Tanner, Private Citizen, Reno, Nevada:

I am a lobbyist working in natural resources and energy, and it is an anomaly that I am here in this Committee today. I did not know about this bill, but I sat through the hearing and thought I would say something based upon my personal experience.

I had a son who died about ten years ago from retinoblastoma. He did not have vision in his first eye when he was seven weeks old. He lost his second eye when he was three. It is odd to say that your child was kicked out of preschool, but it is true. We struggled; he was in remission; but he did get kicked out of preschool. We were lucky and found an in-home day care to help him and we had early intervention services, but it was a thought in our heads that had we taken both his eyes out as a baby, he would still be alive. That said, every day that your child has vision is a day when that child learns more. It was very difficult. When we got through with chemotherapy and radiation, we had to deal with the blindness, which created a whole different set of scenarios. I have to say that there were people in worse situations than ours, but it was a struggle.

I certainly have mixed feelings about mainstreaming, because my child did not have any other issues. He was not deaf and blind, but I think it is really important for people to have choices. Other states offer those opportunities but we do not in Nevada. It would be something to give families that choice.

Chairwoman Cohen:

Thank you for sharing your story.

Jeff Beardsley, Private Citizen, Las Vegas, Nevada [through American Sign Language interpreter D. Scott]:

I am strongly in favor of <u>S.B. 203 (R1)</u>. I think it is important. As Senator Spearman pointed out, language acquisition is the key for children to have equality. The goal is setting up a school for the deaf, hard of hearing, deaf/blind where they have experts who are professors themselves who may be deaf or hearing, are teaching in ASL, and encouraging them in their language acquisition—and then they see them as role models. I can be a professor, I can be a teacher. Keep in mind, we want these deaf and hard-of-hearing children to feel that they have someone to look up to. Language acquisition, of course, provides

better education and they can then go into many different fields. I hope you take this into consideration and support S.B. 203 (R1).

Chairwoman Cohen:

Is there anyone else in support in Las Vegas or Carson City? [There was no response.] We will now move to opposition. Is there anyone in opposition in Las Vegas or Carson City?

Mike Eifert, Executive Director, Nevada Telecommunications Association:

As Senator Spearman said, this bill has four broad areas. We take no position on three areas we are discussing: the school for the deaf; establishment of criteria and literacy skills; and the development of resources for measurement and development for parents and guardians to understand where their children are.

<u>Senate Bill 203 (1st Reprint)</u> proposes to use the telecommunications device for the deaf (TDD) surcharge for purposes not intended when the program was last litigated. The Nevada Telecommunications Association (NTA) opposes the diversion of TDD revenues for any purpose other than those codified into law in <u>Assembly Bill 200 of the 78th Session</u>, which the NTA supported. Further, this bill appears to be missing a fiscal note for the development and administration of the new hearing aid program within the Aging and Disability Services Division (ADSD) of the Department of Health and Human Services (DHHS).

As background, on May 31, 2013, the Public Utilities Commission of Nevada filed an order in Docket No. 12-11027 in response to the Aging and Disability Services Division's request for approval of the state fiscal year 2014 TDD budget. In the order, the Commission found NRS 427A.797 should be interpreted to provide TDD surcharge monies only to programs that directly relate to TDD equipment, equipment use training, equipment use outreach, and the relay system, along with the duties to regulate interpreters and real-time captioning providers consistent with NRS Chapter 656A. This order led to the ADSD suing the Public Utilities Commission of Nevada in the First Judicial District Court of the State of Nevada. The First Judicial District Court upheld the PUCN order, believing a plain interpretation of the NRS restricts what the surcharge may be used for.

Subsequent to that ruling, the ADSD appealed the lower court ruling to the Supreme Court of Nevada. On March 2, 2015, the Nevada Supreme Court issued an Order of Reversal and Remand stating that ADSD is not limited in using the surcharge money at the deaf and hard-of-hearing centers to fund services with a nexus to telecommunication devices and the relay system. As a result, A.B. 200 of the 78th Session changed NRS 427A.750 and NRS 427A.797, codifying the Supreme Court order removing the PUCN's approval of the annual ADSD budget, establishing the Legislature as the sole oversight body for the program to provide assistance to persons with impaired hearing and speech, and capping the surcharge at eight cents per access line per month.

As such, consistent with the Supreme Court order, a new program diverting TDD surcharge funds for hearing aids is not allowable under law. Additionally, this bill as amended appears to overlook the cost associated with developing and administering any state program. Earlier

in this session, <u>Senate Bill 222</u> proposed to establish a program to provide hearing aids at no charge to certain children who reside in low-income households and required the use of the TDD surcharge to cover the cost of the new program and the hearing aids. <u>Senate Bill 222</u> did not make the first committee deadline this session due in part to a fiscal note from ADSD outlining the cost to develop and administer the new hearing aid program. If you compare <u>S.B. 222</u> with the amended <u>S.B. 203 (R1)</u> before you, the language in the bills' scope and funding of the new hearing aid program is nearly identical, the notable difference being ADSD submitted a fiscal note for the development and administration of a new hearing aid program in <u>S.B. 222</u> but has not filed a fiscal note for the same hearing aid program proposed in <u>S.B. 203 (R1)</u>.

Chairwoman Cohen:

Sir, I allowed you to speak for well over two minutes because you are the only person in opposition, but would you please wrap it up and then provide us with any additional testimony in writing?

Mike Eifert:

The most notable difference between these two bills is that ADSD has put in a fiscal note on <u>S.B. 222</u> but not on <u>S.B. 203 (R1)</u>. For the record, the fiscal note on <u>S.B. 222</u> was \$6.3 million for the first biennia and \$8.1 million for future biennia to develop and administer the program. It is our belief that a fiscal note has not been filed on <u>S.B. 203 (R1)</u> that would account for the cost to develop and administer a new hearing aid program, and logic tells us there is a cost and, in full disclosure, a fiscal note should be added to the bill that describes not only the fiscal impact but also the funding source.

Chairwoman Cohen:

I invite you to reach out to Senator Spearman to discuss that further. Is there anyone else in opposition in Las Vegas or Carson City? [There was no response.] Is there anyone neutral in Las Vegas or Carson City?

Dena Schmidt:

I just wanted to clarify some information regarding the fiscal note. The language in this bill does allow the Division to provide for these hearing aids as funding is available. There is currently a budget built annually for this program, so those funds would be used as available. That is why there is no fiscal note; the bill is not asking for additional funds.

Chairwoman Cohen:

Thank you, Ms. Schmidt, and I will direct the Committee to section 3.3, subsection 2, which does mention "to the extent money is available."

With no one else wishing to speak in neutral, I will invite the Senator back for any closing remarks. Before you begin, there are members of the Committee who would like to sign on as cosponsors. To save time, and as you are indicating that it is all right with you, I am letting Committee members know that if you would like to sign on as cosponsors, please

contact our Committee Counsel, Karly O'Krent, as soon as possible. Because there is already an amendment, additional cosponsors can just be added to that amendment.

Senator Spearman:

The previous gentlemen mentioned that the language in another bill was similar, and he was correct. Senator Hardy and I had similar bills. We both wanted to do something to help children who are deaf, hard of hearing, blind, and speech impaired. In a bipartisan fashion, this bill was crafted. The fact of the matter is, I do not think there is any excuse for us not to be using every tool available to us to help these children. If you have your full capacity, it is very easy to criticize it, but if you are the parent of a child with these challenges and you hear people criticize using money to make sure we mitigate those challenges, it is very difficult to hear.

Chairwoman Cohen:

Before I close the hearing, I want to especially thank our interpreters and the closed-captioning system. [(Exhibit K) was submitted but not discussed and is included as an exhibit for this meeting.] With that, I will close the hearing on S.B. 203 (R1) and open up the hearing on Senate Bill 95 (1st Reprint).

Senate Bill 95 (1st Reprint): Revises provisions governing diets that are ordered or prescribed for patients. (BDR 40-445)

Senator Pat Spearman, Senate District No. 1:

I am here to present <u>Senate Bill 95 (1st Reprint)</u> for your consideration on behalf of the interim Legislative Committee on Health Care, which I chaired during the 2017-2018 Interim. <u>Senate Bill 95 (1st Reprint)</u> takes a step toward improving patient outcomes, reducing the cost of health care, and shortening the length of stay in hospitals. It was proposed at the request of representatives of the Nevada Academy of Nutrition and Dietetics, and the bill enables licensed dietitians to independently order special diets. It requires medical facilities to provide diets as ordered or prescribed and authorizes hospitals to grant clinical privileges to licensed dietitians for certain purposes.

Specifically, <u>S.B. 95 (R1)</u> requires medical facilities to take any action necessary to adhere to a diet ordered or prescribed by a licensed dietitian, physician, physician assistant, dentist, advanced practice nurse, or podiatrist. Such facilities must maintain documentation demonstrating compliance with these requirements and provide it to the Division of Public and Behavioral Health within the Department of Health and Human Services (DHHS) upon request. In addition, the bill authorizes hospitals to grant clinical privileges to licensed dietitians for the purpose of ordering special diets for patients, ordering laboratory tests to monitor the effectiveness of the special diet or dietary plans, and modifying special diets or other dietary plans based on the results of such tests.

This deficiency first came to my attention when my sister, who is now in Stage 4 kidney failure, was in a rehabilitation center. The doctor prescribed a specific diet for her, and the facility did not have the resources or the food. She was not supposed to have processed meat

or brown bread, her sugar intake was limited, et cetera. For three days straight, they brought her bacon and whole wheat toast. There was not a whole lot the dietitian on duty could do because she could not change the diet to accommodate the food they had in that facility. In talking with some other people who were in that rehabilitation hospital with her, they were all in the same boat. I had about a three-hour conversation with the dietitians there. I was told that when this happens, their hands are tied and there is really nothing that can be done. That was the genesis for this bill. We fixed things for my sister by bringing her food she could eat so she would not be hungry.

Chairwoman Cohen:

Are there any questions for Senator Spearman?

Assemblywoman Titus:

This is a great idea, but I have some concerns. As a physician and head of a long-term care medical unit, I frequently will order a diet. We have a dietitian whom I refer to and turn to for guidance such as proper calories and ways to achieve a goal for patient care. My question involves section 1, subsection 3. When a hospital grants privileges to the dietitian, would that be as an independent practitioner? I am concerned that the dietitian might order a diet that perhaps conflicts with a medication I might prescribe or something like that, so I just worry about them being independent in that way and not having to communicate with the provider who may be looking at certain medications. Yes, I use dietitians; yes, they are critically important; yes, they are a very important component of the health care delivery team. But I am worried about any conflict and making sure they would not be independent practitioners without having some need to be sure everyone is on the same page regarding the patient.

Margot Chappel, Deputy Administrator, Regulatory and Planning Services, Division of Public and Behavioral Health, Department of Health and Human Services:

This is the perfect time to read you a bit from the *Federal Register*. This is from Volume 78, Number 26, [page 9222] published on Thursday, February 7, 2013, which indicated:

A review of the literature [Kinn TJ. Clinical order writing privileges. Support Line. 2011; 33; 4; 3-10] supports that, in addition to providing safe patient care with improved outcomes, RDs [registered dietitians] with ordering privileges contribute to decreased patient lengths of stay and provide nutrition services more efficiently, resulting in lower costs for hospitals.

In terms of how it benefits, research indicates that the benefits definitely outweigh the concerns.

Michael Hackett, representing Nevada Academy of Nutrition and Dietetics; and Nevada Academy of Physician Assistants:

We are very grateful to Senator Spearman, to the Department of Health and Human Services, and to Director [Richard] Whitley for their efforts to bring this legislation before you. Without their support, this would have been impossible.

One thing this bill proposes to do is align state law with the Centers for Medicare and Medicaid Services (CMS) rule issued in 2014 that does exactly what this bill is proposing to do. We also appreciate the amendment on this bill that was added in the Senate which would allow hospitals to grant privileges to licensed dietitians to be able to go ahead and provide the services described in this bill.

Someone from our organization is in Las Vegas, and she can speak more specifically to the particular benefits this legislation will provide for the Academy's members.

I also represent the Nevada Academy of Physician Assistants, and we would like to be on record in support of this bill as well.

Allison Schnitzer, State Policy Representative, Nevada Academy of Nutrition and Dietetics:

[Allison Schnitzer spoke from prepared text (Exhibit L).] We represent about 600 registered dietitians here in Nevada. This bill would bring Nevada into alignment with CMS. The amendment from the Senate Health and Human Services Committee would authorize hospitals to grant clinical privileges to dietitians.

Currently in hospitals in Nevada, dietitians give recommendations for patient therapeutic diets to a physician, then that physician places the order for the patient. This is an inefficient system. It costs the hospital time and money and it costs the patient quality of care because, as Senator Spearman pointed out, it can be days before a dietitian's recommendation is seen by a physician. That really influences patient care negatively. By granting registered dietitians hospital privileges to order therapeutic diets, <u>S.B. 95 (R1)</u> would allow us to practice to the full extent of our competencies.

I want to quickly address Assemblywoman Titus's concern. We are well trained to recognize any interactions between prescribed medications and food. That is well within our competencies. We really believe we are well trained and competent to have clinical privileges at hospitals to order therapeutic diets for patients, and this would help hospitals function more effectively, more efficiently, and greatly increase patient care.

Assemblywoman Titus:

Thank you for the information. As I said, I definitely use dietitians and greatly appreciate their information. Do you have National Provider Identifier (NPI) numbers, and are you able to bill for your services?

Allison Schnitzer:

I believe Kristina LaBouff, a clinical dietitian who is here with me, can answer your question more specifically.

Kristina LaBouff, Board Secretary, Nevada Academy of Nutrition and Dietetics:

I am a clinical dietitian at Mountain View Hospital. We are not currently diagnosing anything like malnutrition, so we are not billing for any services. The company I work for—Sodexo—is contracted through Mountain View Hospital, so I think all our fees are incorporated into the patient's hospital stay. We are not individually billing for anything currently at my hospital.

Chairwoman Cohen:

Before we continue with additional testimony, Ms. Chappel, should we list you as neutral or in support?

Margot Chappel:

Neutral, please.

Kristina LaBouff:

[Kristina LaBouff spoke from prepared text (Exhibit M).] I am a registered and licensed dietitian who has been working in the clinical field in Las Vegas for about five years. I am here today to voice my support for S.B. 95 (R1). As with all registered dietitians, I have completed the basic requirements of a bachelor's degree in nutrition science and a dietetic internship. In addition, I am also certified in providing nutrition support to patients. I have obtained my Certified Nutrition Support Clinician (CNSC) credential. The National Board of CNSC exam is offered to registered nurses, nurse practitioners, physicians, physician assistants, and pharmacists who have two years of experience in specialized nutrition who want to verify that they have the knowledge to provide quality nutrition support care to patients. Unfortunately, despite my advanced education credentials, I am unable to practice to the full extent of my competency in the hospital setting due to the inability to independently order patients' diets. Having to call or track down a physician to obtain an order is time-consuming and demanding on both myself as a dietitian and the physicians.

The amendment to <u>S.B. 95 (R1)</u> addresses this need for hospitals to grant clinical privileges to dietitians, a move I believe will greatly expedite and improve patient care. Again, based on calculations presented by CMS in their final rule published in 2014, Nevada hospitals, on average, could save about \$3.2 million per year if registered dietitians had the ability to implement orders without physician consent. Up to 60 percent of patients are malnourished upon hospital admission. If registered dietitians are given hospital privileges to independently order supplements, diets, and nutrition support, these patients' nutritional needs can be fully addressed within the first 48 hours of their stays, which I believe can make a huge difference in their length of stay, cost of health care, and most importantly, patient outcomes.

Tyre L. Gray, representing Nevada Hospital Association:

As has already been detailed, this is a bill we support. Dietitians have an advanced education and they are able to practice at a higher scope. Because this law is now in conformity with the 2014 CMS regulations, we are here to support this bill.

Stephen Lencioni, representing Nevada State Medical Association:

I am a premedical student at the University of Nevada, Reno, and am interning with the Nevada State Medical Association. To keep our comments brief, we would like to point to our comments recorded in the Senate [February 20, 2019, meeting of the Senate Committee on Health and Human Services]. We would just like the Committee to know that Nevada physicians appreciate our cooperation with certified registered dietitians and support this bill.

Dillon Martin, Private Citizen, Las Vegas, Nevada:

[Dillon Martin spoke from prepared text (Exhibit N).] I am a registered dietitian in Nevada and work at the University Medical Center of Southern Nevada. I am here today to voice my support for S.B. 95 (R1). Dietitians are competently trained to independently order an appropriate nutrition intervention and monitor the effectiveness of nutrition treatments in the clinical setting. As it stands, the current Nevada law does not allow me to deliver optimal nutrition care to clinical patients as efficiently and directly as this proposed law would allow me to do.

When patients get appropriate nutrition in a timely manner, it contributes to decreases in lengths of hospital stays, reduced health care costs, and improved patient outcomes. I hope this Committee agrees and will support <u>S.B. 95 (R1)</u>.

Chairwoman Cohen:

Anyone else in support, please come forward. [There was no response.] Seeing no one, we will move to opposition. Anyone in opposition, please come forward. [There was no response.] Seeing no one, anyone in neutral, please come forward. [There was no response.] Would you like to make closing remarks, Mr. Hackett?

Michael Hackett:

We want to thank you, Madam Chair and the Committee, for your consideration of this bill and we urge your support.

[(Exhibit O) and (Exhibit P) were submitted but not discussed and are included as exhibits for this meeting.]

Chairwoman Cohen:

With that, I will close the hearing on <u>S.B. 95 (R1)</u>. I will now open the hearing on <u>Senate Bill 390 (1st Reprint)</u>.

Senate Bill 390 (1st Reprint): Revises provisions governing the slaughtering of livestock. (BDR 51-258)

Senator Ira Hansen, Senate District No. 14:

I represent a district that encompasses 38,000 square miles of Nevada and contains a lot of farms. There are individuals who like to process animals on farms, and current law requires anything like that to be done in an established facility. Some people wanted to get mobile facilities and went to the Nevada State Department of Agriculture (NDA). The State

Department of Agriculture contacted the Legislative Counsel Bureau (LCB), which stated that NDA did not have the current statutory authority to do that. This bill will authorize the State Quarantine Officer, who is actually the Director of the State Department of Agriculture, Jennifer Ott, to follow some minimal requirements that would allow people to process animals as part of the homegrown Farm to Fork organic food movement. This bill allows NDA to now have the authority to set up this program. It does not get into the minutia of the program, it does not deal with the specifics of the program; it will simply allow NDA to do something LCB felt they did not have the statutory authority to do.

There is nothing in this bill that is controversial. There were some people in opposition; however, that gets into the weeds that will be dealt with by NDA if they want to go forward with this regulation. The purpose of <u>S.B. 390 (R1)</u> is to allow the State Quarantine Officer, that is the Director of the State Department of Agriculture, the authority to set up this type of system.

Randy Robison and Pawl Hollis are with me today; they are friends with Senator Ratti. Senator Ratti had used up all her bill draft requests and asked me if I would sponsor this bill. They talked to me about this bill. Is there something you think we need to get on the record, Randy? [In the interest of time, (Exhibit Q) was submitted but not discussed, and will become part of the record.]

Randy Robison, Owner, Plan B Ranch, Reno, Nevada:

No. We can make this very easy. All they have to do is follow the policy set up by NDA. As far as going through the minutia, it will be quick and easy as long as this bill gives them the ability to set policies and procedures in place after the bill is passed.

Chairwoman Cohen:

I have a question about the State Department of Agriculture. I see the word "may" throughout the bill: in section 2, subsection 1, "The State Quarantine Office may adopt regulations." Is this "may" adopt regulations so this can go forward, or will it go forward and the State Quarantine Officer may or may not adopt regulations, and then we will have these mobile units out there with no regulations?

Senator Hansen:

I have no problem switching the language from "may" to "shall." We actually wanted to leave it up to NDA and give them as much flexibility as possible. These people would not be authorized to do anything without permission from NDA. If we shift the language to "shall" it will require NDA to set these up rather than allowing their board to determine whether or not they want to. I am in favor of "shall"; we just left the language as LCB recommended.

Karly O'Krent, Committee Counsel:

As the bill is currently drafted, the language is permissive, so if you want to require them to adopt the regulations, you would need to change it.

Chairwoman Cohen:

Permissive, so if they do not adopt the regulations, the processors cannot do the mobile processing?

Karly O'Krent:

Right.

Chairwoman Cohen:

So we will not end up with a situation where we have the mobile processors and the quarantine officer has not done the regulations? That is what I am getting at.

Karly O'Krent:

That is correct.

Chairwoman Cohen:

I just want to make sure that if we have the processors out there, we are going to have the regulations.

Assemblywoman Titus:

Is there anything currently prohibiting mobile processing? Folks have come to my house to take care of some steers I raised, so where in statute are they prohibited from doing that?

Senator Hansen:

Actually, representatives from the State Department of Agriculture are here. They were going to testify in neutral, and they are probably better at answering that than I am. When I read the bill, I did not see any problem either, but LCB did, and that is why this bill came into existence.

Assemblywoman Titus:

As our Chairwoman pointed out, this is enabling language—they "may" adopt it—so what are they doing in the meantime? I know there are already folks out there doing this, so I am curious about what we have been doing?

Randy Robison:

Poultry is different from beef or swine. What we are looking at specifically here is poultry processing. When you have a mobile processor, they are doing a kill and slaughter at your ranch and taking it back to a U. S. Department of Agriculture (USDA) inspection facility. All of those are currently recognized and regulated by NDA, and those are inspected regularly. What we are looking at specifically here are poultry regulations, and it is defined as a mobile poultry processing unit, which is completely different than what you are currently looking at. So, to answer your question, they are completely different units and this poultry processing unit will need to be inspected just as those are.

Assemblywoman Titus:

That was what I was trying to clarify, because they already exist.

Randy Robison:

Yes, correct.

Assemblywoman Titus:

So, just walking around with a hatchet finding chickens is not mobile enough for you?

Randy Robison:

What we are trying to do is get away from that. We are trying to make sure these facilities are inspected and meet the minimum standards set up by the USDA and that they have the facilities to be able to check that out—the same as a regular butcher shop or any place else. They go through the same inspection process.

Assemblywoman Titus:

Thanks for that clarification.

Chairwoman Cohen:

Just to be clear, this does not affect anyone on their own farm doing their own thing with their own chickens and livestock.

Randy Robison:

Currently in the state of Nevada, if you are processing chickens for yourself, there are no implications. If they process a thousand birds or less, and they meet the qualifications and they apply for the permits, they will be able to sell their birds.

Chairwoman Cohen:

That was my point—for home use there is no issue.

Randy Robison:

Correct

Chairwoman Cohen:

Are there other questions?

Assemblyman Carrillo:

In east Las Vegas there are places that will process a chicken for you. I am not sure if they currently do it, but will places like that be affected? Obviously, it is a facility; they bring chickens in and you pick which one you want for dinner. Is that a good example of a facility for the purpose of slaughtering chickens?

Randy Robison:

The answer is yes, it will affect them. They are one of the processing plants in the state of Nevada. Kennedy Ranch out of Elko [Lamoille], Nevada, is another. They are a processing facility that is currently inspected by the state. They are not, however, a mobile processor. You bring your birds to their facility. What we are trying to do with this legislation is make it available for people in northern Nevada. We have nothing in the northern Nevada area for

people to be able to process chickens at this point in time like you have in the Las Vegas area. What we are trying to do with this legislation is change that.

Senator Hansen:

This legislation will not have an effect on the processor in Las Vegas as far as putting them out of business or having them go through some new regulatory process. They are already set up to do that. Mobile facilities are primarily what we are aiming at.

Chairwoman Cohen:

Thank you for respecting our time crunch today and not showing your presentation; however, I would like to remind the Committee that we do have it on the Nevada Electronic Legislative Information System, and there are pictures of the mobile units (Exhibit Q).

Assemblywoman Krasner:

Currently, if people want their animals to be slaughtered, they would bring them to a slaughtering facility—an establishment that is approved by the State Department of Agriculture. I am guessing there are regulations and that it is inspected to make sure there are no germs or diseases when they are slaughtering animals. If this is just a mobile unit that rolls itself from house to house, who is inspecting it to make sure there is no disease from the animals being slaughtered? Would they then go to the next person's house where the filthy, bloody blades full of disease might then infect the next person's meat that the family is going to eat? I am just wondering.

Randy Robison:

That is a great question and it is why we are asking for the NDA to be involved in this. They are currently the people responsible for all of the slaughterhouses. They currently administer all those places where, as you said, they bring in the dead animals and clean them up. Part of that process is that every night they have to go through and clean those facilities. The mobile processors would be responsible for the same type of cleanliness based on the USDA and NDA's standards. They actually have a list of standards which is included in the slide presentation (Exhibit Q). They have policies and procedures which are cleaning standards. Everything is exactly the same in these mobile processing units as it is in a standard slaughterhouse facility. These would be exactly the same standards that are set up for any butcher house/slaughterhouse based on the standards set up by the Food Safety Modernization Act—basically a governmental agency within the federal Food and Drug Administration. They have to be set up through that, and the inspection process is what we are trying to get through here today.

Senator Hansen:

We use the term "processing" now, not "slaughtering," because there is a less-than-desirable side to food consumption. For the record, 9 billion chickens are processed every year—or 18 billion wings, for you pizza and wings fans.

Chairwoman Cohen:

Seeing no other questions, we will call up anyone in support in Las Vegas or Carson City.

Nancy Ogan, Owner, Ogan Family Farm, Gardnerville, Nevada:

I have Ogan Family Farm. We have a producer's certificate for honey, eggs, produce, and cut flowers through the State Department of Agriculture, so they are already coming out and inspecting us. We harvest chickens for ourselves and right now we have dozens of customers who would like to buy poultry from us also. Right now, the only way to do that is for them to come out to our house and learn the process—be truly a part of it—and harvest their own poultry. However, some customers just do not want to go through that. We still want to have access to local and humanely raised and safely harvested chicken. I believe our NDA will be a perfect Department to put these regulatory procedures in place and safely harvest poultry.

Both the NDA and the Department of Health and Human Services work together to put in proper handling procedures for eggs and produce, so they already are working together. We are lacking the bridge between the producer and the consumer, and approval of this bill would allow NDA to build a bridge.

Kelli Kelly, Private Citizen, Fallon, Nevada:

I volunteer as the Executive Director of the Fallon Food Hub. I also serve on the Boards of Directors for Nevada Grown, the Western Nevada College Specialty Crop Institute, and the Nevada Farms Conference. I have a unique opportunity in that I interact with consumers of local produce and local products as well as working with farmers who are the producers. Currently, there is a large market that is not even beginning to be tapped into for local poultry. We have the producers who are raising chickens who would like to be able to sell those to the customers. Senate Bill 390 (1st Reprint) removes the first obstacle toward bridging that gap and enables NDA to start taking these steps so the supply that exists within the state can begin to meet the demand that exists within the state.

Chairwoman Cohen:

Seeing no one else in support, we will move to opposition. Anyone in opposition in Carson City or Las Vegas, please come forward.

Paul E. Quade, representing Kennedy Ranch; and The Farmer's Table at Girlfarm:

[Paul Quade spoke from prepared text (Exhibit R).] We are in opposition to S.B. 390 (R1). We wish this bill provided the protections that already exist under NRS Chapter 583, but it does not. This is an end-around those regulations. With me is Sue Kennedy of Kennedy Ranch who did go through the process, was certified by the State Department of Agriculture, and is the largest producer of chickens in the state of Nevada. There are provisions for small producers to sell to the consumer. The problem with this bill is that section 2, which allows on-farm processing, essentially exempts from the other requirements under Chapter 583 for USDA approval. It is not true that the bill as written would have the USDA requirements Mr. Robison spoke about. That is one of the main problems. It would not have the restriction of the thousand birds that the USDA and other states implement, and we would support the bill if it did. We would support the bill if those provisions for USDA supervision, regulations, and inspections were in place.

With respect to section 4, and please distinguish between these two—there is on-farm processing and then there is section 4 that addresses mobile processing units or custom processing units. Again, those units could not only be processing chickens or poultry, but also other livestock such as beef, and there are no restrictions in section 4 related to just poultry. Understand that the bill as written does not provide for compliance with USDA regulations. There is a specific exception under NRS 583.455. The bill states that these other establishments, the mobile establishments, would be deemed to be official establishments but would not be required to meet the compliance with NRS Chapter 583 restrictions. As written, we oppose the bill but we would be happy to work with the bill's sponsor, Senator Hansen, as well as with the proponents, and try to get a bill that would protect the public health.

Sue Kennedy, Owner, Kennedy Ranch, Lamoille, Nevada:

I own Kennedy Ranch as previously mentioned by Paul Quade. I am here today because I do not want the Legislature to make a mistake. In my experience, passing this bill as amended would be a mistake that would jeopardize not only the public health, but also the industry in which I have invested significant time and money. Earlier, it was asked how poultry gets processed right now in the state. As it is right now, if you want to process poultry legally in the state of Nevada, you are required to meet the facility standards required in *Nevada Administrative Code* (NAC) Chapter 446, which basically means you have to build a commercial kitchen. I have met those standards and it is both onerous and expensive, and it is unrealistic to ask that of someone like Nancy Ogan, who wants to process a few hundred birds to sell to her neighbors. Producers all over the state—in Ely, in Elko, and people who work for me—may process birds illegally "under the table." If they sell them, they are processing them illegally.

There needs to be a way for people who want to sell a few hundred birds to their neighbors to do so without going to the expense that I did, but you cannot throw the baby out with the bathwater. There still needs to be facility standards, sanitation standards, temperature control and labeling standards, and there needs to be limits on where birds processed under that exemption can be sold. As it is written, this bill creates an end-run around the requirements of NAC Chapter 446, and for everyone other than farmers operating under the thousand-bird limits who sell directly to consumers either on-farm or at a farmer's market; that is not right. These are real businesses accepting money from consumers with the expectation that they are providing a product that meets sanitation standards consistent with what people expect from their local grocer.

I live my professional life under these rules: an HACCP [hazard analysis critical control point] plan, standard operating procedures, an employee health plan, packaging requirements, and recordkeeping. None of it is onerous, and all of it should be required—even of thousand-bird operators. An annual inspection is critical both for operator education and for keeping us all honest. I welcome my inspector, and anybody who does not should not be in the business of processing food for human consumption. My concern with how this bill is written is that none of these requirements are written into the bill. Some of that is addressed in section 4, but none of it shows up in section 2, and if the Legislature's intent is to make

sure those things get written into the regulations, it needs to be part of the legislation as well to make sure they are required.

I am a member of the American Pastured Poultry Producers Association, have had the privilege of meeting with small farm poultry processors from around the country, and I have toured many of their facilities. Some of them are very small USDA plants, some are statelicensed. I have also toured a facility run by a farmer who was not subject to state inspection, who did not have an HACCP plan or have to meet any of the state requirements such as I am suggesting we ensure in this legislation. After touring his facility, I would never eat one of his birds. The shortcuts he was taking were appalling and dangerous, and I do not want to play Russian roulette with my dinner. I do not think anyone else does either.

Chairwoman Cohen:

Seeing no questions and no one else in opposition, I will invite anyone up who is neutral on the bill.

Douglas Farris, Administrator, Animal Industry, State Department of Agriculture: I am here on behalf of the Department to testify neutral on this bill.

Wendy Baroli, Owner, The Farmer's Table at Girlfarm, Reno, Nevada:

I am the owner of The Farmer's Table at Girlfarm, a former employee of the USDA, and a local small farm and food advocate. I am speaking in support of responsible legislation, which may not be this particular bill, but I am also not opposed. I think it is very important that we not overly regulate the nascent small farm community into rules and regulations they cannot handle, much like Nancy Ogan's farm or some of the other small ones. But what I do understand is that the legislation has language that could easily be amended and satisfy the need for public safety. I put forward these particular amendments:

- For small farm poultry and cavy harvest, set on-farm harvest limits of 1,000 to 1,500 birds.
- Strike any reference to mobile processing in this bill, and leave it to NDA to develop the standards and regulations governing mobile processing.
- Require all on-farm processors of poultry and rabbits to complete an online food-safety handling course. That course already exists within the health department, so there is no fiscal impact and the fees would be paid by the producers to get the certificate.
- Require all on-farm processors of poultry and cavies to register with their local Farm Service Agency; that way we have true labels affixed to these animals that we can then trace to that farm. When you register with the Farm Service Agency, your individual farm is globally positioned and has a number, so it is super easy and super safe to handle food safety concerns.
- To address any fiscal impacts, I suggest that we establish an inspector fee on a sliding scale which can be done either in this piece of legislation or handed down to NDA to do, so that each producer is inspected once a year for safety and following hazardous materials and other food-handling issues.

I do think there is a need for establishing some clear rules; however, I do believe those that place the details should be at NDA. I suggest the guidance we have through CDFA [California Department of Food and Agriculture], which is what I work under—an already very, very successful small poultry program—we could adopt those regulations at NDA.

Chairwoman Cohen:

I do not think we have your proposed amendments. Have you submitted them?

Wendy Baroli:

No, but I can.

Chairwoman Cohen:

Please submit them, and also please speak with the sponsor about them.

Wendy Baroli:

Absolutely.

Chairwoman Cohen:

Mr. Farris, I think we have some questions for you, but we are going to ask them offline. Between you and Jennifer Ott, we will be in contact. Seeing no one else in neutral, I will invite the sponsor back up for any closing remarks.

Senator Hansen:

All the concerns mentioned will be addressed through regulations by the State Department of Agriculture. It will all comply fully with USDA requirements as well as those of the State Department of Agriculture. There have been amendments suggested, but we would rather leave that up to the regulatory boards. They are much more experienced in these matters than we are to determine what those regulations should be, rather than us trying to force it. The framework LCB recommended and the rest of the processes and the regulations will be done by the State Department of Agriculture through their own board.

Chairwoman Cohen:

I assume any regulations the State Department of Agriculture would promulgate would have to comply with USDA regulations.

Douglas Farris:

That is correct. It would be through the USDA.

Chairwoman Cohen:

With that, I will close the hearing on <u>S.B. 390 (R1)</u> and open the hearing on <u>Senate Bill 315 (1st Reprint)</u>.

Senate Bill 315 (1st Reprint): Revises provisions relating to public health. (BDR 40-581)

Senator Joyce Woodhouse, Senate District No. 5:

Pediatric cancer, by definition, is a rare disease accounting for less than 1 percent of cancer diagnoses each year. While rare, more than 15,000 cases of pediatric cancer are annually diagnosed in the United States. This means that 1 in 408 children will be diagnosed with cancer before they are 15 years of age and 1 in 285 children will be diagnosed before they turn 20 [American Childhood Cancer Organization, Cancer Facts & Figures, 2014, Special Section: Cancer in Children and Adolescents]. These children and their families have faced some of the worst news imaginable—often without warning. I am here today presenting Senate Bill 315 (1st Reprint) because I had the opportunity to get to know one family that received such news. They fought; but they lost their young son to cancer. The bill before you today is their effort to raise awareness about childhood cancer, to study and identify strategies to prevent such rare diseases, and to encourage health care providers to receive continuing education in the diagnosis of these diseases. I am honored to be able to assist them in this effort to commemorate their son and grandson, Carson, and I will let them tell you their story in just a moment.

Going through the bill, sections 2 and 3 create the Rare Disease Advisory Council within the Department of Health and Human Services (DHHS). The Council is composed of health care professionals, individuals and their families, and organizations that have experience with or knowledge of rare diseases. At least seven other states have established such councils, and many more have considered similar legislation. In Nevada, our Council would: examine the incidence, causes, and economic burden of rare diseases in our state; increase awareness among the general public and health care providers; identify strategies to prevent and control rare disease; study the effects of early treatment as well as delayed or inappropriate treatment; establish a comprehensive plan for rare disease management; and develop a registry of rare diseases diagnosed in our state.

Sections 4 through 6 increase public education about the importance of annual physical examinations for children. What we know about childhood cancer is that early diagnosis is difficult in part because this is a rare condition and in part because the symptoms are similar to other common childhood diseases. No widely recommended screening tool exists to identify the wide variety of childhood cancers; however, experts agree that routine childhood physicals provide an extremely important opportunity for parents to discuss a child's growth and development with trained health professionals. If necessary, the physician can refer a child to additional testing based on the child's symptoms and history; however, many parents only seek medical care when their children are sick. The goal of these portions of the bill is to emphasize the importance of annual physicals for children. This is achieved by requiring DHHS to include such information in appropriate public health programs and activities by requiring school districts and charter schools to include such information in written communications with parents regarding the health of pupils and requiring health and physical education courses to include instruction on the topic.

The third piece of the bill requires the Department of Motor Vehicles (DMV) to design, prepare, and issue special license plates to increase awareness of childhood cancer. The license plates would include the phrase "Cure Childhood Cancer." These and related changes are provided for in sections 7 through 16.

Finally, sections 17 through 22 aim to help health care providers better diagnose childhood cancer by requiring appropriate licensing boards to annually disseminate information concerning the signs of pediatric cancer and by encouraging their licensees to receive training and education in the diagnosis of rare diseases as part of their required continuing medical education.

Now, if it is all right, we could go to southern Nevada to hear from Carson's father, grandmother, and family friend who would like to share their stories.

Chairwoman Cohen:

Thank you, Senator, and please go ahead in Las Vegas.

Marc Arreola, Private Citizen, Las Vegas, Nevada:

I am here today to support Senator Woodhouse's bill, <u>S.B. 315 (R1)</u>. This bill will create the Rare Disease Advisory Council that will provide a central hub for knowledge to ensure pediatricians and medical professionals across the state can receive time-sensitive information, training, education, and support in families' greatest times of need. Today, I come here as a Nevadan and a devastated father who lost a child to a senseless disease that could have been caught sooner with adequate training and a central system of knowledge around childhood rare disease and cancers.

Carson Gage Arreola was born on October 29, 2009. He was our first child and the light of our lives. As he grew older, his personality grew larger than he was. As Carson grew, he earned the nickname "Hurricane Carson; Category 5" and he was every bit of that nickname. He was a force to be reckoned with. We took Carson to his pediatrician on May 4, 2016, for what we thought was strep throat. After a week on antibiotics and still running a fever, we took him back to the pediatrician and received another type of antibiotic. Carson still was not feeling well, so on May 15, 2016, we took him to urgent care to see why, after two rounds of antibiotics, his strep throat would not go away. After two blood draws at an urgent care facility, we were sent to St. Rose Dominican Hospital's emergency room (ER) for three more blood draws. It was there that we received the devastating news that Carson most likely had a rare and aggressive childhood leukemia. Our family was shocked that our highly trained, capable, and trusted pediatrician was not able to identify and diagnose any symptoms of this childhood disease. We were even more shocked to discover that our pediatrician was himself a childhood leukemia survivor. When we arrived at the St. Rose ER, Carson's white blood cell count was 400,000. A normal white blood cell count in a healthy child is 4,500 to 11,000. Due to his dangerously high potassium levels, he was rushed to Sunrise Children's Hospital where he would have a port placed and begin dialysis immediately.

As you can imagine, the impact this had on our family was devastating. Just 24 hours earlier, we thought our son had a nasty case of strep throat and now we stood helplessly as he was placed under anesthesia and had a port placed in his chest. On May 16, Carson was diagnosed with T-cell acute lymphoblastic leukemia. We spent the next three days watching our six-year-old boy's body slowly shut down. He experienced breathing troubles, kidney problems, and heart arrhythmia. At 3:30 a.m., Wednesday, May 18, his heart stopped twice. The doctors were able to revive him at 3:58 a.m. After doctors tried everything humanly possible to save him, we held our little boy as he quietly went to Heaven. Little did we know that when we were sent to Sunrise Hospital and were reassuring our son that everything would be okay and that we loved him, that those would be the last words we ever spoke to him.

Carson was a shining light with a heart of gold. He was outgoing, funny, smart, kind, artistic, fearless, and happy. He was obsessed with dinosaurs, and knew the name of every one by the time he was three years old. He loved his stuffed Tiggers, dancing, drawing, baseball, motorcycles, and monster trucks. He loved and thought the world of his little brother and his little sister. He had a zest for life that was contagious and refreshing. It was impossible to be in a bad mood around him.

Joseph P. Kennedy, Sr. said, "When the young bury the old, time heals pain and sorrows; but when the process is reversed, the sorrows remain forever." Because of this, we have a drive, passion, and commitment to share our story. I am here today to stand with Senator Woodhouse to support this legislation and help raise awareness for early childhood cancer detection and do what we can to make sure that no other family has to endure the earth-shattering devastation we had to experience. We will talk about the tragic day and we will talk about losing Carson, but Carson is not lost. We know exactly where he is. He finished the work he was sent here to do, and he was called home. He will continue to influence us for good as we try to become better because of him.

I would like to thank Senator Woodhouse; Julie Pazina; my mother-in-law, Pat Gerber; my father-in-law, Jerry Gerber; and my wife, Aubrey Arreola for being advocates for this bill.

Chairwoman Cohen:

Thank you, Mr. Arreola, for sharing Carson with us.

Pat Gerber, Private Citizen, Las Vegas, Nevada:

I am grateful for the opportunity to speak today in support of <u>S.B. 315 (R1)</u>, brought before you by Senator Joyce Woodhouse. I would like to thank her and her committee for their hard work in spearheading this bill and for their concern for the children in the state of Nevada. I am Carson's grandmother and I stand today with my son-in-law, Marc Arreola, as we represent our family and share Carson's story.

When Carson was born, our lives were changed forever. Marc and Aubrey became Mom and Dad, and we became grandparents and felt the love only grandchildren can bring into your lives. Carson lived a life of fun and adventure surrounded by love. He loved going to the

"Dad Store"—Home Depot—with his dad and to the "Mom Store"—Target—with his mom. He also loved playing with his little brother Mason and his little sister Kinsey. During the day, he lived in a world filled with dinosaurs, and at night, he fell asleep with his Tiggers.

On this very day three years ago, May 15, 2016, Carson would again change our lives forever. That was the day he was hospitalized and we found that Carson had acute lymphoblastic leukemia. Just three days later on May 18, Carson lost a battle he did not even get to fight. To say we were shocked, stunned, and devastated would be an understatement. Leukemia was not a word we were very familiar with. I knew the cure rates were very high—close to 90 percent. Unfortunately, Carson was not in that percentile. His cancer was very aggressive and totally caught us off guard. May 15 is also Marc and Aubrey's anniversary—a bittersweet day for the rest of their lives. It was the last day they spoke to Carson, but now they speak for Carson. I am proud of them for choosing to take this tragedy to make a difference in the lives of others.

Our family joins them in hopes of sparing other families from the experience we have had. By bringing awareness of childhood cancer and other rare diseases that affect children in our state, we will improve their lives, the treatments they receive, and ultimately, the outcome they have. I would like to share a quote by the late Hubert H. Humphrey that summarizes my belief in government: "It was once said that the moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; and those who are in the shadow of life, the sick, the needy, and the handicapped." I hope that with your support of this bill, it can be proven once again that government can truly be a protector and guardian of its citizens and even more so of its greatest and most precious resource—its children. Thank you for the work you do and for listening to us today.

Chairwoman Cohen:

Thank you, ma'am, and thank you for sharing Carson as well.

Julie Pazina, Private Citizen, Las Vegas, Nevada:

Thank you to Committee Chairwoman Lesley Cohen, Senator Joyce Woodhouse, and the Assembly Health and Human Services Committee for the opportunity to speak before you today on <u>S.B. 315 (R1)</u>. This legislation is very important to me as a result of my friendship with Aubrey Arreola and her family.

It feels like yesterday that she shared with me that she was pregnant with her second child and how incredibly excited Carson was to be a big brother. Senate Bill 315 (1st Reprint) has the ability to educate parents and children about the importance of annual physical examinations and provide continuing education to Nevada's medical professionals about the diagnosis of rare diseases. Further, it would create a Rare Disease Advisory Council to study and treat rare diseases and make recommendations based on their studies for future legislation.

Education and communication are critically important in preventing more families from suffering the tragedy of a child's passing. These are commonsense steps that can save lives. As Nevadans, we can come together and take steps to prevent these tragedies by passing S.B. 315 (R1). Thank you again so much for the opportunity to speak with you today.

Chairwoman Cohen:

Are there any questions?

Assemblywoman Gorelow:

Thank you so much for sharing this story with all of us. I have a question about the license plate. Specialty license plates usually have a minimum of 1,000. Does this also pertain to meeting that minimum?

Senator Woodhouse:

I do not know, but someone from the DMV is here and I will let him answer that question.

Sean P. McDonald, Administrator, Central Services and Records Division, Department of Motor Vehicles:

No, this would be outside the constructs of the Commission on Special License Plates, so it would not be subject to the 1,000- or 3,000-plate thresholds.

Chairwoman Cohen:

For the record, Mr. McDonald, should we have you down as neutral?

Sean McDonald:

Yes, please.

Assemblyman Carrillo:

My question relates to the annual checkups. Obviously, there are certain things that should be checked, but would that include bloodwork? What would be the effect of annual checkups? Parents will take their children on a regular basis, but a lot of times their growth is checked and their weight, et cetera—real preliminary things. I do not think they ever really go as deeply as bloodwork or anything like that. Can you talk about that?

Senator Woodhouse:

I am not a medical health care provider, but this is what I know from my experience as an elementary school teacher. One of the things we addressed in the bill is that this whole process would never have helped Carson. His family did everything they should do for their children. What we are trying to address is the fact that when babies are born, before they leave the hospital, the parents are present and take care of the things they need to in order to leave the hospital. One of the things we find is that a lot of the care that most people have for their children drops off until it is time to give the immunizations that need to be given for students, young children, to start either pre-K or kindergarten. Parents get those immunizations done, and they usually have an examination when they go in to see the family doctor. Then it drops off again until the HPV [human papillomavirus] vaccines are given.

As a result, we are trying to raise awareness in our parents and caregivers across the state of Nevada that we need to be so much more cognizant of how important an annual exam is for children. Children do need to see their pediatricians or family doctors annually and not just when the child is sick, which can lead to a rush to urgent care or to the ER.

The best way to put it is that this would be an awareness campaign for parents and caregivers, and also to medical personnel who are seeing these children. They should look at what the children's medical records are as well as the history of the family. All those things come together in trying to make sure that our children are healthy as they grow up and that we catch these tragic diseases as early as we can so that when these symptoms arise the pediatricians or family physicians can address those problems with the families.

Assemblyman Carrillo:

I am a parent and also a grandparent. When you are a grandparent, you are probably more of a stickler about the kids even though they only come to visit and then you can send them away. I want to make sure this is going to be something that is really going to be effective. You are talking about a public campaign, and I do not want it to fall short of that. Still, it is up to the parent to decide if a child is not at his or her best. Then, do they run to the hospital to see what is going on? It could just be him or her having a bad day. Are we reaching far enough?

Senator Woodhouse:

I believe it will. I believe the Rare Disease Advisory Council we are establishing in this measure will do good work. To me, it is similar to the one we passed in the 2015 Session relating to palliative care [Senate Bill 265 of the 78th Session]. The work they are doing on that side of the issue has brought all kinds of rewards for both patients and their families. I will keep my eye on them to make sure they have what they need in order to pursue this and make sure that our children are healthy.

Assemblywoman Titus:

Thank you, Senator. To the family in Las Vegas, it is difficult to experience and difficult to live with, and it is even more difficult sometimes to share that experience. I definitely appreciate your passion and desire to do something, and I do understand that.

I have some specific questions about the bill, however. I wish this bill would have helped Carson, but this bill, as you have stated, would not have saved Carson. When I teach residents and students, I train them that if something does not make sense and is out of the ordinary—that routine strep throat, that fever just does not make sense—you must look for other things, you must be willing to think outside the box. I would hope that our training already does that, but we still do not catch everything, and, unfortunately, horrible things can happen to wonderful people. That is in Someone's hands who is greater than we are.

Specifically to the bill, in section 17 you refer to *Nevada Revised Statutes* (NRS) Chapter 630. I know that is the physicians' practice and the language reads that "The Board shall develop and disseminate annually to each licensed physician . . . who cares for children

information concerning the signs and symptoms of pediatric cancer." I certainly think that is an easy lift. That chapter covers the Board of Medical Examiners, which is whom I assume you are referring to in that section. That is an easy lift, as I said. Those are available; the National Institutes of Health have them as does the National Cancer Institute. I think that would be an easy thing to do, but then in section 18, subsection 6, the language reads, "The Board shall encourage each holder of a license to practice medicine or as a physician assistant to receive, as a portion of his or her continuing education, training and education..." to recognize the signs of pediatric cancer. You are not mandating it there, but are you encouraging all physicians or are you going to look at those who only see children? At least you did not mandate that for each of us—including those who never see a pediatric patient. Could you clarify that you are looking at encouraging folks who may encounter pediatrics to make sure they have that education? The Board supervises all physicians across all specialties, so I have a concern there.

Then, in section 19, and I am pleased to see that you included the physician assistants—but when the "Board" is mentioned in that one, I do not see a clarification. Would that be the Board of Nursing? Is that just presumed? Did you mention their NRS chapter? Will it cover NRS 632.120? I just want to clarify which board we are discussing. If you refer to the chapter, then that automatically refers to the Board of Nursing, because they are the ones who supervise the nurse practitioners.

Karly O'Krent, Committee Counsel:

If you will give me one moment, I will look up the definitions in NRS Chapter 632.

Assemblywoman Titus:

I hope that chapter is what covers the Board of Nursing.

Senator Woodhouse:

That was my understanding.

Karly O'Krent:

Nevada Revised Statutes 632.013 defines Board for the purposes of this provision to mean the State Board of Nursing.

Assemblywoman Titus:

Perfect; so that answers that question. Going to section 22, subsection 6, the language states that "The Board shall encourage each holder of a license to practice osteopathic medicine or as a physician assistant" You have repeated that because that is a different licensing board, and I appreciate it, but again, you left it that it would "encourage each holder of a license," but I do not know that each holder needs to do that. Is it those who would come in contact with pediatrics, if that is the goal of this, as opposed to all providers? That is just an observation

Chairwoman Cohen:

Are there any other questions? [There was no reply.] Seeing no further questions, we will start with testimony in support in Carson City or in Las Vegas.

Cari Herington, Executive Director, Nevada Cancer Coalition:

[Cari Herington spoke from prepared text (Exhibit S).] I am the Executive Director of the Nevada Cancer Coalition. I am also the mother of twins, so this legislation is near and dear to my heart. It is estimated by the National Institutes of Health that 50 percent of people affected by a rare disease are children. Thirty percent of children with a rare disease will not live past the age of five; as such, early diagnosis and treatment of these diseases is critical, as is increased research into these diseases. Cancer remains the number one cause of death by disease in children across all ages, ethnic groups, and socioeconomic status.

As Senator Woodhouse mentioned, 15,000 children will be diagnosed with some form of cancer this year alone. The Rare Disease Advisory Council will take the lead on both raising awareness of these diseases and establishing and implementing a plan to address them—including childhood cancer. The bill also calls for promoting the importance of an annual physical exam to assist in the early detection of childhood diseases, including hearing and visual impairments we heard about in <u>Senate Bill 203 (1st Reprint)</u>. It also encourages the continuing education for our health care providers and diagnosis of these rare diseases. Again, thank you to Senator Woodhouse and the cosponsors of <u>S.B. 315 (R1)</u> for addressing rare childhood diseases in Nevada and raising awareness of childhood cancer. The Nevada Cancer Coalition and our membership support this bill.

Alexis Motarex, Private Citizen, Reno, Nevada:

Most days I am here representing the Nevada Chapter, Associated General Contractors of America, but today I am here as a mom of a cancer survivor. On February 20, 2012, my four-year-old son was diagnosed with acute lymphoblastic leukemia (ALL)—the most curable type. Hours after receiving the news, we were flown by air ambulance to [UCSF Benioff] Oakland Children's Hospital because there was no pediatric oncologist in Reno. Cooper began treatment on February 22. It was the first of 1,129 days of chemo—3 years, 2 months, and 4 days. We spent the first three weeks in the hospital where Cooper was given high doses of chemo and steroids to induce remission. He got violently ill from the chemo, and the steroids made him irritable and caused him to gain a third of his body weight in just two weeks. His beautiful hair began to fall out and his face became so bloated he was unrecognizable.

Acute lymphoblastic leukemia is the most curable form of leukemia, but it is not easy. Cooper had to have at least one form of chemo every night. He had to take steroids every month. He had 35 or 40 spinal taps—so many that I lost count—and every month he had chemo through the port surgically implanted above his heart. He missed most of kindergarten and a good part of first and second grades. He could not spend time with friends and had to stop playing sports. He woke up with chemo hangovers, lost all his hair, gained weight, lost weight, and gained it again. He broke out in rashes; got sores in his

mouth. The skin on his hands, neck, and face became so inflamed and chapped it looked like it would split open.

About a year into treatment, he got really sick and it got really bad, really fast, as it can in immunocompromised patients. He had pneumonia, but the standard treatment was not working. We were watching him die. He knew it too. At one point he looked at me with his big brown eyes, and said, "Mom, I'm scared." The doctors here did not have the training or experience to know how to manage the care of a child with cancer. After several days in the hospital without improving, his oncologist recommended he be transported to Oakland so she could oversee his treatment. He was Care-Flighted for the second time to be under the care of some of the best pediatric specialists in the world, and they saved his life. It was determined that the pneumonia was caused by the rhinovirus—the virus that causes the common cold. Because of what the current treatment for leukemia does to the body, he almost died from the common cold.

He took his final chemo on April 26, 2015, and he is healthy and strong. Despite everything Cooper had to suffer through for over three years, we consider ourselves lucky. No family should have to suffer at the hands of pediatric cancer, and no parents should have to bury their child because we cannot find a cure. We need more awareness about pediatric cancer. Awareness will save lives by parents and doctors being able to recognize symptoms, understand complications, and note the treatment options. But it could also lead to a cure. Awareness leads to funding, funding means research, and research means better treatment options and maybe someday a cure.

Chairwoman Cohen:

Thank you very much for sharing about Cooper's bravery, and we are very glad to hear that he is doing well.

Shirley Folkins-Roberts, Executive Director, Northern Nevada Children's Cancer Foundation:

[Shirley Folkins-Roberts spoke from prepared text (Exhibit T).] I am a 15-year advocate for children and brave families like the Arreolas, Cooper, and Alexis who have battled this horrific disease. This disease takes these beautiful families out of what is normal and devastates their lives. Our organization provides financial and emotional support to try to ease the burden of childhood cancer. Another big part of our mission is awareness and advocacy. For 15 years, I have been advocating nationally and in the state for new and improved research and treatment. I can tell you that awareness is a big key to improving the treatment and experience of these children.

In our office, we have a tradition. When a child survives cancer, we have what is called a "no more chemo" or "no more radiation" bell ringing. We have one going on right now as we are speaking. I hope that more awareness and better detection through this wonderful council—the Rare Disease Advisory Council—could help us have more bell ringings and fewer sad stories. I am absolutely certain that awareness and advocacy and things like the license plate and early detection are very, very important to the survival of these children.

Thank you so much and thank you to the Arreola family for sharing their brave story and making such an amazing effort in the face of tragedy.

Katie Roe Ryan, Director, Public Policy, Dignity Health-St. Rose Dominican Neighborhood Hospitals:

I am here on behalf of my employer to thank the bill's sponsor for this fantastic bill, and also for appointing our own Veneta Lepera, Director of Palliative Care for our hospitals, and Chair of the [Division of Public and Behavioral Health, DHHS] Advisory Council on Palliative Care and Quality of Life. I know she is very excited to be on this Council once this bill has passed.

I am also here as someone who lost their only sibling to childhood leukemia. It will be 20 years ago in October. He died on his sixteenth birthday. He was not at my graduations from high school or college; was not at my wedding; and was not there when my son was born. Twenty years later, it is very difficult to talk about it because these stories bring so many memories back. Just know that passing the bill is really going to do something to help families and these kids.

Chairwoman Cohen:

Is there anyone else in support? [There was no response.] Is there anyone in opposition in Las Vegas or Carson City? [There was no response.] If there is anyone neutral in Las Vegas or Carson City, please come forward.

Tom McCoy, Nevada Government Relations Director, Cancer Action Network, American Cancer Society:

[Tom McCoy spoke from prepared text (Exhibit V).] The American Cancer Society Cancer Action Network (ACSCAN) is the advocacy arm of the American Cancer Society. I had a couple of thoughts to share. In the time I will be speaking, somewhere in the world a child will be diagnosed with cancer. It happens every two minutes, every hour, every day. In the United States, 1 in 5 of those children who are diagnosed will not survive. Unfortunately, there are childhood cancers with no known cure. As an organization, we were instrumental in helping to pass the most comprehensive childhood cancer legislation ever approved by It is called the [Childhood Cancer] Survivorship, Treatment, Access, and Research (STAR) Act [of 2017]. Among several key provisions, as the name implies, the STAR Act calls for grants to state cancer registries like ours here in Nevada. The purpose would be to track childhood cancers. Presently, our cancer registry does not do that. The federal budget has to spend some money to make that happen. Also, to advance the quality of care for childhood cancer patients and their families, we have been urging passage at the federal level of PCHETA—the Palliative Care and Hospice Education and Training Act. We heard that the bill you are considering, S.B. 315 (R1), has been amended to include the Chair of the State of Nevada Advisory Council on Palliative Care and Quality of Life as part of the Council, and we certainly see that as a strong addition to the bill.

The childhood cancer survivor often has to deal with issues as an adult that we may not know about. Mariah, one of our ACSCAN volunteers, was diagnosed with neuroblastoma—the most common cancer in infants. She had 18 rounds of radiation and several surgeries at the age of one year. Survival was questionable, she was given experimental chemotherapy, and it saved her life.

Chairwoman Cohen:

Sir, we have to vacate this room in about four minutes.

Tom McCoy:

I will wrap this up. We commend Senator Woodhouse and the cosponsors of <u>S.B. 315 (R1)</u> for responding to the challenging issues that accompany childhood cancer. Our neutral position results from certain aspects of the bill dealing with such things as license plates. There are so many hundreds of cancers, and we do not support all the license plates that would be generated by that. That is the reason we are in a neutral position.

Chairwoman Cohen:

Seeing no one else in neutral, Senator, do you have any closing remarks?

Senator Woodhouse:

Please note that I am wearing a dinosaur on my lapel this afternoon in remembrance of Carson because, as you heard from his dad, he loved everything dinosaur. We do these kinds of things, and this is one of the reasons we brought this bill forward. Unfortunately, the Arreola family and Cooper's family had these experiences, but we do not want there to be other families who have to experience this. If <u>S.B. 315 (R1)</u> helps one family—but we know it will help more—it will put us all in a much better place. This bill will enhance awareness and education among children, families, health care providers, and our general communities to give children the best chance possible for an early diagnosis. We thank you so much for your rapt attention this afternoon as you heard this bill. It is hard to hear these stories, but as elected officials we hear these stories so we can put a face to the work we are doing.

[(Exhibit U) was submitted but not discussed and is included as an exhibit for this meeting.]

Chairwoman Cohen:

I will close the hearing on <u>S.B. 315 (R1)</u>. We will now open for public comment in either Carson City or Las Vegas. [There was no response.] Seeing no one for public comment, our next hearing is scheduled this coming Friday. I would like to thank Assemblywoman Titus and Assemblyman Assefa. They came to this meeting directly from the floor meeting and will now be going right into another committee meeting, so I really appreciate your hard work. I know this is not the only day you have had to do that. Thank you, and this meeting is adjourned [at 3:47 p.m.].

	RESPECTFULLY SUBMITTED:
	Terry Horgan
	Committee Secretary
APPROVED BY:	
Assemblywoman Lesley E. Cohen, Chairwoman	
DATE	

EXHIBITS

Exhibit A is the Agenda.

Exhibit B is the Attendance Roster.

<u>Exhibit C</u> is the Work Session Document, dated May 15, 2019, for <u>Senate Bill 364</u>, presented by Marsheilah Lyons, Committee Policy Analyst, Research Division, Legislative Counsel Bureau.

Exhibit D is the Work Session Document, dated May 15, 2019, for Senate Bill 33 (1st Reprint), presented by Marsheilah Lyons, Committee Policy Analyst, Research Division, Legislative Counsel Bureau.

<u>Exhibit E</u> is the Work Session Document, dated May 15, 2019, for <u>Senate Bill 258</u> (<u>1st Reprint</u>), presented by Marsheilah Lyons, Committee Policy Analyst, Research Division, Legislative Counsel Bureau.

Exhibit F is the Work Session Document, dated May 15, 2019, for Senate Bill 262, presented by Marsheilah Lyons, Committee Policy Analyst, Research Division, Legislative Counsel Bureau.

Exhibit G is the Work Session Document, dated May 15, 2019, for Senate Bill 270 (1st Reprint), presented by Marsheilah Lyons, Committee Policy Analyst, Research Division, Legislative Counsel Bureau.

Exhibit H is the Work Session Document, dated May 15, 2019, for Senate Bill 362 (1st Reprint), presented by Marsheilah Lyons, Committee Policy Analyst, Research Division, Legislative Counsel Bureau.

Exhibit I is the Work Session Document, dated May 15, 2019, for Senate Bill 470 (1st Reprint), presented by Marsheilah Lyons, Committee Policy Analyst, Research Division, Legislative Counsel Bureau.

Exhibit J is a letter dated May 15, 2019, addressed to the Assembly Committee on Health and Human Services, presented by Penni Echols, Private Citizen, Las Vegas, Nevada, in support of Senate Bill 203 (1st Reprint).

<u>Exhibit K</u> is written testimony, submitted by Candace Emerson, Private Citizen, Las Vegas, Nevada, in support of <u>Senate Bill 203 (1st Reprint)</u>.

Exhibit L is a letter dated May 13, 2019, addressed to Chairwoman Cohen and members of the Assembly Health and Human Services Committee, presented by Allison Schnitzer, State Policy Representative, Nevada Academy of Nutrition and Dietetics, in support of Senate Bill 95 (1st Reprint).

<u>Exhibit M</u> is a letter dated May 13, 2019, addressed to Chairwoman Cohen and members of the Assembly Health and Human Services Committee, presented by Kristina LaBouff, Board Secretary, Academy of Nutrition and Dietetics, in support of <u>Senate Bill 95 (1st Reprint)</u>.

<u>Exhibit N</u> is a letter dated May 15, 2019, addressed to Chairwoman Cohen and members of the Assembly Health and Human Services Committee, presented by Dillon Martin, Private Citizen, Las Vegas, Nevada, in support of Senate Bill 95 (1st Reprint).

<u>Exhibit O</u> is a letter dated May 13, 2019, addressed to Chairwoman Cohen and members of the Assembly Health and Human Services Committee, submitted by Aurora Buffington, Convener, Southern Nevada Food Council, in support of <u>Senate Bill 95 (1st Reprint)</u>.

<u>Exhibit P</u> is a letter dated May 13, 2019, addressed to Chairwoman Cohen and members of the Assembly Health and Human Services Committee, submitted by Madeline Belaustegui, Private Citizen, Las Vegas, Nevada, in support of <u>Senate Bill 95 (1st Reprint)</u>.

<u>Exhibit Q</u> is a copy of a PowerPoint presentation titled "Senate Bill No. 390 NDA Inspection of Mobile Chicken Processing," submitted by Senator Ira Hansen, Senate District No. 14, in support of <u>Senate Bill 390 (1st Reprint)</u>.

Exhibit R is a letter, dated May 9, 2019, addressed to Chairwoman Lesley E. Cohen, Assembly Health and Human Services Committee, and Senator Ira Hansen, Sponsor, presented by Paul E. Quade, representing Kennedy Ranch; and The Farmer's Table at Girlfarm, in opposition to Senate Bill 390 (1st Reprint).

<u>Exhibit S</u> is a letter dated May 10, 2019, addressed to Chairwoman Cohen and members of the Assembly Committee on Health and Human Services, presented by Cari Herington, Executive Director, Nevada Cancer Coalition, in support of Senate Bill 315 (1st Reprint).

Exhibit T is a letter dated May 13, 2019, addressed to Chairwoman Cohen and members of the Assembly Committee on Health and Human Services, presented by Shirley Folkins-Roberts, Executive Director, Northern Nevada Children's Cancer Foundation, in support of Senate Bill 315 (1st Reprint).

Exhibit U is a statement dated May 13, 2019, submitted by the Pharmaceutical Research and Manufacturers of America, in support of Senate Bill 315 (1st Reprint).

<u>Exhibit V</u> is a letter dated May 15, 2019, addressed to Chairwoman Cohen and members of the Assembly Committee on Health and Human Services, presented by Tom McCoy, Nevada Government Relations Director, Cancer Action Network, American Cancer Society, in a neutral position to <u>Senate Bill 315 (1st Reprint)</u>.