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

Seventy-Ninth Session May 17, 2017

The Committee on Health and Human Services was called to order by Chairman Michael C. Sprinkle at 1:42 p.m. on Wednesday, May 17, 2017, 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/79th2017.

COMMITTEE MEMBERS PRESENT:

Assemblyman Michael C. Sprinkle, Chairman
Assemblywoman Amber Joiner, Vice Chair
Assemblywoman Teresa Benitez-Thompson
Assemblyman Richard Carrillo
Assemblyman Chris Edwards
Assemblyman John Hambrick
Assemblyman William McCurdy II
Assemblywoman Brittney Miller
Assemblyman James Oscarson
Assemblyman Tyrone Thompson
Assemblywoman Robin L. Titus
Assemblyman Steve Yeager

COMMITTEE MEMBERS ABSENT:

None

GUEST LEGISLATORS PRESENT:

Senator Heidi S. Gansert, Senate District No. 15 Senator David R. Parks, Senate District No. 7 Senator Joseph (Joe) P. Hardy, Senate District No. 12



STAFF MEMBERS PRESENT:

Marsheilah Lyons, Committee Policy Analyst Mike Morton, Committee Counsel Terry Horgan, Committee Secretary Trinity Thom, Committee Assistant

OTHERS PRESENT:

Brian McAnallen, Government Affairs Manager, Office of Administrative Services, City of Las Vegas

Connie McMullen, representing Personal Care Association of Nevada

Helen Foley, representing Nevada Assisted Living Association

Tiger Devore, Private Citizen, Las Vegas, Nevada

Jane Heenan, Director, Gender Justice Nevada, Las Vegas, Nevada

Arlene B. Baratz, Private Citizen, Pittsburgh, Pennsylvania

Georgiann Davis, Assistant Professor, Department of Sociology, University of Nevada, Las Vegas

Catherine O'Mara, Executive Director, Nevada State Medical Association

Mendy Elliot, representing Nevada Osteopathic Medical Association

Veronica Sutherland, Immediate Past President, Nevada Osteopathic Medical Association

Kathleen Conaboy, representing Nevada Orthopaedic Society; and Ambulatory Surgery Center Association

Susan L. Fisher, representing Nevada State Board of Osteopathic Medicine

Dane Hardy, Private Citizen, Las Vegas, Nevada

Clare E. Close, representing Society for Pediatric Urology

Delyse Hardy, Private Citizen, Las Vegas, Nevada

Tony Alexander, Private Citizen, Las Vegas, Nevada

Debra Sisco, Chief, Supplemental Reimbursement, Reimbursement, Analysis and Payment Unit, Division of Health Care Financing and Policy, Department of Health and Human Services

Marta Jensen, Acting Administrator, Division of Health Care Financing and Policy, Department of Health and Human Services

Joan Hall, President, Nevada Rural Hospital Partners

George Ross, representing Sunrise Hospital and Medical Center

Chairman Sprinkle:

[Roll was taken. Committee rules and protocol were stated.] We are going to start with a work session today.

Marsheilah Lyons, Committee Policy Analyst:

We will begin with Senate Bill 60 (1st Reprint).

Senate Bill 60 (1st Reprint): Revises provisions governing Medicaid payments for ground emergency medical transportation services. (BDR 38-411)

<u>Senate Bill 60 (1st Reprint)</u> authorizes the director of the Department of Health and Human Services (DHHS) to include in the State Plan for Medicaid a voluntary program in which certain qualified local governmental entities and Indian tribes may receive supplemental reimbursements for ground emergency medical transportation services provided to Medicaid recipients, in addition to the payments they would otherwise receive. The bill also requires the director of DHHS to include in the State Plan for Medicaid a voluntary program to provide increased per patient payments to a governmental entity or Indian tribe that provides ground emergency medical transportation services under a contract with a Medicaid managed care plan.

Brian McAnallen, on behalf of the City of Las Vegas, presented an amendment in a hearing and made a few changes in response to some of the concerns of Committee members. That amendment is included in the work session document (Exhibit C) for your review.

Chairman Sprinkle:

Committee, are there any questions or comments on Senate Bill 60 (R1) as amended?

Assemblyman Hambrick:

If it is appropriate, I would like to recommend a motion of amend and do pass.

Chairman Sprinkle:

I am waiting to see if there are further comments.

Assemblyman Oscarson:

I understand Mr. McAnallen may have another comment he wants to make about this, as there may be something additional that needs to be done.

Brian McAnallen, Government Affairs Manager, Office of Administrative Services, City of Las Vegas:

In drafting the amendment, there are three words that I did not strike out. I am asking to strike the words "through certified public" in the new section 10, subsection 4, at line 41 on page 4 of the amendment. That was a drafting error on my part.

Chairman Sprinkle:

Committee, does everyone understand what is being requested here with the amendment? It appears to be appropriate per our legal counsel. Are there any questions or comments from the Committee?

Assemblywoman Titus:

I have had some concerns over the legality from a federal standpoint on <u>S.B. 60 (R1)</u> and concerns about regulations on billing. I will vote yes to get it out of Committee, but I still have some concerns and may change my vote on the floor.

Chairman Sprinkle:

Are there any other comments or questions?

Assemblyman Oscarson:

I had significant meetings with the City of Las Vegas and with the Department of Health and Human Services. They have assured me that, at this point in time, the conflicts do not exist. I hope my colleague can be involved in that discussion as well after we take this vote.

Chairman Sprinkle:

I will take a motion for amend and do pass.

ASSEMBLYMAN OSCARSON MOVED TO AMEND AND DO PASS SENATE BILL 60 (1ST REPRINT).

ASSEMBLYMAN EDWARDS SECONDED THE MOTION.

Is there any discussion on the motion? [There was none.]

THE MOTION PASSED UNANIMOUSLY.

Assemblyman Oscarson can have the floor statement.

Marsheilah Lyons, Committee Policy Analyst:

Next in our work session is Senate Bill 253 (1st Reprint).

Senate Bill 253 (1st Reprint): Establishes the Nevada Pregnant Workers' Fairness Act to provide protections to female employees and applicants for employment who are affected by a condition of the employee or applicant relating to pregnancy, childbirth or a related medical condition. (BDR 53-773)

<u>Senate Bill 253 (1st Reprint)</u> establishes the Nevada Pregnant Workers' Fairness Act which provides protections to female employees similar to the protections of the federal Pregnancy Discrimination Act. The Act makes it an unlawful employment practice, with certain exceptions, for an employer to refuse to provide reasonable accommodations, upon request, to female employees and applicants for employment for a condition relating to pregnancy, childbirth, or a related medical condition, unless the accommodation would impose an undue hardship on the business of the employer. The measure applies to employers with 15 or more employees and also applies to state and local governments.

Senator Cannizzaro proposed the following conceptual amendment, which can be found in the work session document (<u>Exhibit D</u>). First, it would amend section 6, subsection 3, paragraph (d), to add clarification that assistance with manual labor is for manual labor that is incidental to the primary job duties of the employee. Second, it would add Senator Joe Hardy as a cosponsor for the bill.

Chairman Sprinkle:

Thank you for that overview. Are there any questions or comments on the bill?

Assemblywoman Titus:

Unfortunately, I am going to have to be a no on this bill. I am concerned that it involves employee applicants. For a company to have to make accommodations for someone applying for employment as opposed to an employee is a bit onerous on businesses, and I will have to be a no.

Assemblywoman Benitez-Thompson:

In regard to my colleague's comments, that seems to be more of an interpretation, or is there a specific section that can be cited, so we could get clarity from our legal counsel?

Assemblywoman Titus:

In section 5, subsection 1, paragraph (a) on line 20 of the actual bill talks about ". . . refuse to provide a reasonable accommodation to a female employee or applicant for employment."

Assemblywoman Benitez-Thompson:

So, during the application process, providing a chair or other reasonable accommodation?

Assemblywoman Titus:

I have no problems with personal courtesy to anyone—providing a chair—but there is nothing in the bill that specifies something like that. It is just open. I am concerned about putting that kind of mandate on a business. It is just not reasonable.

Assemblywoman Joiner:

Along those lines, in section 5 it does say, "... unless the accommodation would impose an undue hardship on the business ..." so I think there is an exemption there. Am I reading that correctly? So they would not have to do it if it were an undue hardship, right? I would be concerned about that, too, except that there seems to be an out if it is really an undue hardship.

Chairman Sprinkle:

Mr. Morton, did you want to weigh in?

Mike Morton, Committee Counsel:

Assemblywoman Joiner's reading of the bill is correct. It provides the exception that, for either an employee or an applicant for employment, if the accommodation will present an undue hardship to the employer or the potential employer, it would not be required.

Assemblyman Edwards:

I think some of the wording in the bill is a little bit loose or could be open to a lot of interpretation. I know it is not the intention to do that, but I am afraid that it could be interpreted multiple ways. I think that could lead to the unintended consequence of hurting a lot of small businesses. Out of concern for that, I am going to have to be a no on this bill.

Chairman Sprinkle:

Are there any other comments or questions? [There were none.] Not seeing any, I will take a motion for amend and do pass.

ASSEMBLYWOMAN BENITEZ-THOMPSON MOVED TO AMEND AND DO PASS <u>SENATE BILL 253 (1ST REPRINT)</u>.

ASSEMBLYMAN CARRILLO SECONDED THE MOTION.

Is there any discussion on the motion? [There was none.]

THE MOTION PASSED. (ASSEMBLYMEN EDWARDS, HAMBRICK, OSCARSON, AND TITUS VOTED NO.)

Assemblyman Carrillo, would you take that floor statement, please?

Marsheilah Lyons, Committee Policy Analyst:

Moving on, we have Senate Bill 274 (1st Reprint).

Senate Bill 274 (1st Reprint): Revises provisions relating to sibling visitation in child welfare cases. (BDR 38-925)

<u>Senate Bill 274 (1st Reprint)</u> revises provisions relating to sibling visitation in child welfare cases involving certain children who are placed with someone other than a parent and separate from their siblings. Specifically, the bill:

- Requires a child welfare agency to update a child's sibling visitation plan to reflect any change in the placement of the child or his or her siblings;
- Requires the court to provide any sibling granted a right to visitation with notice of a hearing to review the placement of the child and the case number of relevant proceedings and allow the sibling to inspect records to petition the court for visitation or enforce an order for visitation;
- Revises various provisions concerning agreements for postadoptive contact between a natural parent and a child or the adoptive parents of the child; and
- Requires the court to incorporate a sibling visitation order in the decree of adoption, unless a petition to exclude or amend the order or visitation is filed.

Senator Farley presented an amendment at the hearing for this measure, which is included in the work session document (<u>Exhibit E</u>).

Chairman Sprinkle:

Are there any questions or comments on <u>S.B. 274 (R1)</u>? [There were none.] Not seeing any, I will take a motion for amend and do pass.

ASSEMBLYMAN THOMPSON MOVED TO AMEND AND DO PASS SENATE BILL 274 (1ST REPRINT).

ASSEMBLYWOMAN TITUS SECONDED THE MOTION.

Is there any discussion on the motion? [There was none.]

THE MOTION PASSED UNANIMOUSLY.

Assemblyman Thompson, will you please take that floor statement?

Marsheilah Lyons, Committee Policy Analyst:

The final measure is Senate Bill 480 (1st Reprint).

Senate Bill 480 (1st Reprint): Revises provisions relating to the protection of children. (BDR 38-1089)

<u>Senate Bill 480 (1st Reprint)</u> requires certain health care providers to notify a child welfare agency if the provider knows or has reasonable cause to believe that an infant is affected by a fetal alcohol spectrum disorder or prenatal substance abuse—regardless of whether the substance use was legal or illegal. The bill amends existing state law to align it with certain requirements of the federal Child Abuse Prevention and Treatment Act. There are no amendments in the work session document for this measure (Exhibit F).

Chairman Sprinkle:

Are there any questions or comments on <u>S.B. 480 (R1)</u>? [There were none.] Not seeing any, I will take a motion for do pass.

ASSEMBLYWOMAN JOINER MADE A MOTION TO DO PASS SENATE BILL 480 (1ST REPRINT).

ASSEMBLYMAN YEAGER SECONDED THE MOTION.

Is there any discussion on the motion? [There was none.]

THE MOTION PASSED UNANIMOUSLY.

Assemblywoman Joiner will take that floor statement.

That does it for the work session. Now, we will open up the hearing on Senate Bill 388.

Senate Bill 388: Revises provisions relating to persons who provide personal care in the home. (BDR 40-613)

Senator Heidi S. Gansert, Senate District No. 15:

I am here to present <u>Senate Bill 388</u>. With me I have Connie McMullen, who works in senior care services.

Several years ago when I was in the Assembly, I sponsored legislation to make sure that folks who have businesses that provide nonmedical services to individuals in homes, mostly seniors, had background checks. In my mind, this bill is a follow-up to that.

Nonmedical services are things such as dressing and undressing, bathing, grooming, preparation and eating of meals, et cetera. What has evolved over time is that employment agencies have gone into this business. Essentially, you could call a 1-800 number to have someone go to your parent's or grandparent's home or to the home of someone with disabilities. Those agencies do not fall under the same requirements under the State Board of Health that brick-and-mortar companies do in Nevada. This bill places those employment agencies under the State Board of Health and requires the same of them as far as getting background checks, et cetera. It is a pretty simple bill, but I think it is very important to make sure someone who goes into a senior's home or into the home of someone with disabilities to provide those services has had a background check.

Connie McMullen, representing Personal Care Association of Nevada:

We support <u>S.B. 388</u> and, as a matter of fact, we brought it. A situation such as using Craigslist was unforeseeable a few years back. <u>Senate Bill 388</u> was proposed to protect people from harmful practices, some of which are being conducted on the Internet and oftentimes by businesses based in other states. These registries or employment agencies such as Care.com, or Hallmark Homecare, Inc., currently based now in Las Vegas, place people in the home, oftentimes without background checks or follow-up oversight of previous work history.

<u>Senate Bill 388</u> will protect consumers who, for a fee, hire personal caregivers, home health attendants, nursing staff, or anyone in the home health care industry but do not go through the process that is spelled out already in Nevada regulation.

Last session, Governor Sandoval signed into law a bill that included fines and penalties for facilities for the dependent that provided services but did not obtain a license in the state. The Bureau of Health Care Quality and Compliance in the Division of Public and Behavioral Health, Department of Health and Human Services, investigates these businesses operating without licenses. However, they cannot act on existing law unless the industry is included in *Nevada Revised Statutes* (NRS) Chapter 449. Senate Bill 388 seeks to correct this by including employment agencies in the provisions of NRS Chapter 449 that requires all businesses listed as facilities for the dependent be licensed without exception.

We think this is really a good safety bill for the consumer. When someone goes into the home, we oftentimes do not know what happens behind closed doors. It discourages abuse, neglect, and exploitation of people of all ages, even children. We appreciate our sponsor, and thank you for allowing us to present this bill.

Chairman Sprinkle:

All right, thank you. Are there any questions?

Assemblyman Thompson:

I understand the purpose of a background check, but I think the bill needs to tell us a little bit more. Instead of just having a background check for the sake of just having a background check, what are the areas that would exclude a person?

Connie McMullen:

In the NRS, personal care agencies are required to have the background check, tuberculosis testing, fingerprinting, and previous work history. They are also required to do training. They have extensive training in elder abuse and eight hours of training in other things such as activities of daily living. This would also require that the Internet company has to be licensed. When a personal care agency is licensed, generally the fee is \$1,400. They send out the caregiver to a home. They do not have care on the premises. They do not do beds or anything that a health facility would provide, but they do pay an initial fee; then there is a renewal fee, which is generally half of the original fee. They do this every year. They also are required to have a surety bond and other liability coverage in case someone gets hurt. They are not in the business for that. The Bureau of Health Care Quality and Compliance surveys if there is a complaint, as they do with all health care facilities, and they do follow up. If they do not come into compliance, they are fined heavily. I think it is \$10,000 for the first violation.

Assemblyman Thompson:

But the question is, what disqualifies the person who is an applicant who wants to render this service? What are the disqualifiers on a background check? What are the things you are looking for in a background check that would disqualify that person from working in this area?

Connie McMullen:

I am not sure, but I do know if you have committed a crime, that is one thing that would disqualify you from going into this business—if you have harmed somebody.

Chairman Sprinkle:

Mr. Morton?

Mike Morton, Committee Counsel:

In response to Assemblyman Thompson's questions, if you look at section 5, subsection 3, it states that the employment agency must be in compliance with the requirements set forth in

NRS 449.119 to NRS 449.125. *Nevada Revised Statutes* 449.125 requires termination of an employee or denial of that person going into the home if they have been convicted of certain crimes, or have substantiated complaints of abuse and neglect. Those crimes are listed in existing law and include murder, voluntary manslaughter, assault and battery, sexual assault, and domestic violence crimes. Those are all listed in existing law, and the bill references that.

Chairman Sprinkle:

Are there other questions from the Committee? [There were none.] Does anyone wish to come forward in support of <u>S.B. 388</u>?

Helen Foley, representing Nevada Assisted Living Association:

We appreciate Senator Gansert, as well as Ms. McMullen, bringing forward this legislation. This is one of our vulnerable populations—our seniors—and we do believe that background checks should take place. I think they intended to include everyone when the legislation was originally sponsored, but now, with the Internet, there are new opportunities and ways to identify people who come into homes. We strongly support this bill and ask you to, please, give it your careful consideration.

Chairman Sprinkle:

Is there anyone else here in support of <u>S.B. 388</u>? [There was no one.] How about in opposition to <u>S.B. 388</u>? [There was no one.] Is there anyone here neutral to <u>S.B. 388</u>? [There was no one.] Senator, did you want to come up for any closing comments?

Senator Gansert:

I appreciate your and the Committee's hearing this bill today. I think it is important legislation to help protect our seniors and those with disabilities. I would appreciate your support.

Chairman Sprinkle:

Thank you for being here and presenting the bill. I will go ahead and close the hearing on <u>S.B. 388</u> and open up the hearing on <u>Senate Bill 408</u>.

Senate Bill 408: Establishes conditions for the performance of certain surgical procedures. (BDR 54-615)

Senator David R. Parks, Senate District No. 7:

I am here to present <u>Senate Bill 408</u> for your consideration. This measure improves the communication of health care professionals with affected children who have disorders of sexual development (DSD) by establishing conditions for the performance of any surgical procedure to assign anatomical sex on a child. In the past, the potentially stigmatizing effects of DSD led to the assumption that physicians should withhold potentially threatening information from the patient. However, the physician-patient relationship has developed over time, so now there are increased patient participation and concepts of shared decision making, including the view of health care as different options and choices for patients.

Today, there is a general agreement that children should be informed about these health issues—be they acute or chronic.

As background, DSD refers to congenital conditions in which development of chromosomal, gonadal, or anatomic sex is atypical. This is a condition someone is born with, not who he or she is as a person. Disorders of sexual development is a blanket term that simply indicates a variation from the statistical norm where sex development is concerned. In DSD, the condition may be present at birth or very early as well as being detected in later childhood or during adolescence.

In some cases, a person with DSD may have sex chromosomes different from the male typical XY chromosomes or the female typical XX chromosomes. In other cases, the person may have typical male or female sex chromosomes but have a relatively unusual mix of male-typical and female-typical anatomical traits. In still other cases, a small number of sex organs are atypically developed and essentially missing.

In the late 1960s, early corrective surgery was thought to help affected children as well as their parents to facilitate stable gender identity and appropriate gender-role behavior. Those against early surgery argued the complexity of gender identity is not considered adequately and the mutilating and traumatizing effects of treatment are not sufficiently taken into account. Other than in the case of medical emergencies, many people now advocate a moratorium on any feminizing or masculinizing operations before full consent may be obtained from the child.

In summary, <u>S.B. 408</u> does the following:

- Generally prohibits a health care provider from performing or assisting in the performance of any surgical procedures to assign the sex of a child unless the provider or another qualified professional has first assessed the child to ensure that he or she understands the nature and risks of the procedure and assents to the procedure.
- An assent of a child is not required if the health care provider determines delaying the procedure is likely to endanger the life of a child.
- If the child has not been emancipated, the health care provider must obtain the consent of the parents or guardians of that child.
- The measure allows an occupational licensing board to also pursue disciplinary action.

I urge you to support <u>S.B. 408</u>, and I am available to answer any questions you may have. I would like to indicate that you have been provided with a copy of a proposed amendment to the bill and it should also be posted on the Nevada Electronic Legislative Information System (NELIS) (<u>Exhibit G</u>).

Chairman Sprinkle:

Is there anyone else you want to bring forward for your presentation?

Senator Parks:

I believe we have a number of individuals in Las Vegas who are a part of the presentation.

Tiger Devore, Private Citizen, Las Vegas, Nevada:

I am a psychologist with special expertise in the natural variation of normal genitalia. I am here in support of <u>S.B. 408</u>. My family has lived in Nevada for 27 years, and we all believe in making time to volunteer for public service. I serve on the board of the Nevada Psychological Association as well as on the board of Gender Justice Nevada.

I come before this body to ask you to take a first step in correcting a 60-year-long mistake. Every day, infants suffer non-medically necessary, cosmetic procedures on their perfectly healthy newborn genitalia because of the fears their parents have regarding a perceived imperfection in their child.

Since the early 1950s physicians and surgeons have experimented with reshaping genital tissue to make it look more male or more female, telling parents the natural variation in their infant's appearance needs to be corrected quickly and early for the good of the child. The promise is that the child will require only one or two surgeries before the age of one year, and that they will never remember the event and be fine for the rest of their lives. Far too often, the surgeries fail and require repair after repair with each successive surgery causing more scarring, more loss of sensitive tissue, and never achieving the more functional or more pleasing appearance the parents were promised.

I support a parent's responsibility to care for the concerns of their child's health; however, just as I cannot support a parent's wish to change the facial appearance of their child—for instance westernizing Asian-looking eye folds—I believe that the child or young adult should be the one to decide if and when they want surgery to change a part of their body that was perfectly healthy and, once changed surgically, can never be reversed from the effects of that surgery.

The bill before the Committee will ensure that any person considering this kind of genital surgery will be shown to be able to understand the risks and benefits of these surgeries as well as the outcome of having no surgery at all, when considered against the concerns that are attendant to any surgery. I am happy that the Committee will hear testimony from others supporting this bill, so that they will be well convinced as to the needless suffering that the current practices have allowed for.

Although in my case I could speak for many hours regarding the suffering I experienced, I will try to synopsize in this testimony the points of greatest concern for the Committee's consideration. I was born with a urethral opening at the base instead of at the tip of the penis. My parents were assured of the ease and simplicity of the repair that the surgeons would do. I had my first surgery at age three months. It failed—meaning the tissue did not heal as the surgeons wanted it to. I was scarred from the base of the penis to the tip of the penis. The penis was now flayed open with scarring on both sides of the incision that did not heal. An extensive surgery would be required to repair the damage done by this first failed surgery.

I had at least 12 repairs before age 12; most of which failed in a similar way. As I was opened up in the way that I was, I have been plagued all my life with infections that my natural body would never have had to suffer, but those tissues that protect all people with natural-born genitals from infection were destroyed by the surgeons who performed the experimental and failed surgeries. I had skin harvested by graft from various places around my body to try to cover the now-open aspects of my genitals that had not been open at birth, including the use of most of my testicular tissue for graft causing me to have hair growth in many places that did not make sense for human genitals and still does not to this day.

In total, at age 58, I have had at least 27 surgeries—all the result of the first, failed, medically unnecessary surgery at age 3 months. When I say surgery, I mean I was cut into with a scalpel and scarred. Some surgeons will try to minimize claims like mine by claiming that we are counting times when we were anesthetized for examination without cutting. That is not the case in my count, and there are many, many others who share my surgical and medical history. I could provide many details here, but I am hopeful that the outrageousness of the well-intentioned surgeons to make more normal my already-normal genitals can only be viewed as arrogance, given the lifelong damage and suffering I and so many like me have needlessly undergone.

Now, consider if the doctors who were present at my birth decided that I might live better, meaning be more functionally capable, as an infertile female. The nightmare of having been assigned female and having most of my genital tissue rearranged to look like female genitals only to arrive at the age of individual awareness—between 3 and 6 years of age—for me to say, "But I think I am a boy," and to have had all my boy tissues already removed by a well-meaning surgeon who just got it wrong. This tragedy happens far too often—mistaken sex assignment at birth—and commonly results in suicide for what I think are obvious reasons. This is not a decision for a surgeon and, I would argue, not even for a parent to make. This choice must be reserved for the individual themselves to make once they are of an age to do so.

I am more than happy to make myself available for questioning at another time to any member of the state Legislature who wishes to understand more from me. I can think of no more important contribution I can make than ending the needless suffering of future generations of infants than to stop these failed experimental surgeries on infants who may, in fact, not want these surgeries at all.

Jane Heenan, Director, Gender Justice Nevada, Las Vegas, Nevada:

I share this testimony in support of <u>S.B. 408</u>. I have been a licensed marriage and family therapist in Nevada since 2002 and the founder and director of Gender Justice Nevada (GJNV). Gender Justice Nevada is a nonprofit agency offering advocacy and direct services to sex gender-diverse persons in communities since 2011. Among the persons we are privileged to serve are intersex persons who are most directly affected by this legislation. Intersex persons are broadly represented in our organization, regularly receiving services while also serving as board members, volunteer staff, and as advisors to our activities. Indeed, intersex communities are integral to our queer communities and are akin to

transgender communities in particular even though more mainstream understandings and language live in inclusion to lesbian, gay, bisexual, and transgender communities, or so called LGBT communities.

Senate Bill 408, in our opinion, is essential because surgical interventions on infants and children before they are able to give their assent harm these people and their families throughout their lives, as Tiger said. These harms include incorrect assignment as boy or girl, doubts about their sexual orientation, and difficulties with sexual function. They commonly struggle with shame, betrayal, and being devalued as not good enough when they were born. These experiences cause psychological harm, often expressed as symptoms of post-traumatic stress disorder such as depression, anxiety, isolation, suicidality and self-mutilation, flashbacks, substance abuse, and work or school difficulties.

Further, because of family silence surrounding intersex births—indeed, it is not uncommon for medical professionals to counsel parents to remain silent—healthy family dynamics typically are disrupted. As a result, young persons who are intersex often lack accurate information about their bodies, medical histories, and the reasons surgical choices were made. These children are often angry and confused about why parents withheld information, and parents commonly experience guilt for harming their child or feel angry at the intersex child for "causing" such troubles.

Parents, meanwhile, have extremely limited opportunities for support because common systems of support such as family, worship communities, or counseling are ill equipped to discuss such things. Common outcomes of early surgeries for intersex persons and their families are not healthy in our direct experience at GJNV. Senate Bill 408 is clear and balanced and places power in the hands of families. It changes nothing when doctors are making the determination that procedures are medically necessary. It simply imposes a delay in the decision about surgeries until the young person can understand the consequences, risks, benefits, and alternatives, and only if both the child and the parents agree to a procedure. Decisions this personal, this profound, and this permanent should not be taken lightly; and, unless unavoidable, should not be taken without the full understanding and consent of the persons themselves. We in Nevada believe in empowering families. We in Nevada believe in personal choice and freedom. These are foundational Nevada values. These are the values, which S.B. 408 respects. Please vote "aye" on S.B. 408.

Chairman Sprinkle:

Committee, are there questions about <u>S.B. 408</u>? [There were none.] Is there anyone here in support of S.B. 408 who wishes to come forward?

Arlene B. Baratz, Private Citizen, Pittsburgh, Pennsylvania:

[Arlene Baratz spoke from prepared text (Exhibit H).] I am a physician specializing in breast radiology since 1990. I am also the mother of three adults—an older daughter and younger twins, a son and a daughter. Just as I finished my medical training in 1990, my 4- and 6-year-old daughters were found to have XY chromosomes and internal testes—a rare, intersex condition called complete androgen insensitivity, or AIS. Androgen insensitivity is

one of the conditions known medically as differences or disorders of sex development or DSD. Some girls are born this way because their bodies are immune to male hormones or androgens. Isolation and secrecy made me experience my daughters' condition as a tragedy, but I tried to be the best mother I could on my own. Ten years later, in 2000, I finally found a group of intersex people who helped me parent two happy and healthy daughters through adolescence. One is now a successful musician and the other is a psychiatrist, mother, and advocate herself.

In the support group, I also unexpectedly met people whose bodies and souls were badly damaged by unwanted genital surgery, and families distraught by having agreed to procedures that were not fully explained to them at the time. As a physician, I felt obligated to help, so I read everything and spoke to everyone I could. What I discovered shocked me. There was no real scientific basis for these operations. They were simply cosmetic and performed to allay parents' anxieties over having a child with unusual-looking genitalia. It was assumed that without surgery, families could not bond with their children.

Doctors who endorsed surgery did not follow their patients into adulthood, so they had no idea how these procedures turned out. The few patients who did speak up were dismissed as a disgruntled minority, and it was assumed that there was a vast, silent majority of patients who were perfectly satisfied. Doctors reasoned that if past surgery had caused damage that was because surgical techniques were always improving.

So, I became an advocate for intersex children. I served seven years on the board of the AIS-DSD Support Group, and I am currently its coordinator of medical and research affairs. I am a ten-year member of the board of InterACT advocates for intersex youth, and chair of its medical and research policy committee. To challenge the prevailing wisdom, I began writing and speaking on the experiences of families like mine. I have published numerous peer-reviewed articles and book chapters and contributed as an expert to a global update on care last year.

Although some aspects of our children's care has improved, cosmetic genital surgery has not. Rates of surgery have not changed for the most common condition, XX congenital adrenal hyperplasia where children with XX chromosomes are exposed to high levels of androgens. Some of these children are born with a fully-formed penis, and it is still advocated to parents that their children undergo surgery because it will make them into normal girls. But when you surgically remove a penis from a child who identifies as a boy, it is really a catastrophe.

We know that there is a real lack of education and support for these families, and research tells us that half of them do not receive adequate support, and half of them hardly even understand their child's diagnosis. They are seldom directed to receive support from families who are parenting happy and healthy intersex children. These operations are often performed on children before they are old enough to talk. The FDA recently issued its strongest possible warning for anesthesia on children. This surgery should be available to children

who are old enough to decide for themselves, and I would ask anyone who advocates these procedures how many they have performed, how many adults they have followed up on, and whether anyone has thanked them for performing it.

Georgiann Davis, Assistant Professor, Department of Sociology, University of Nevada, Las Vegas:

For more than ten years, I have studied the ways in which intersex is experienced and contested in contemporary U.S. society. I have published numerous peer-reviewed articles on the topic of intersex in a variety of scholarly journals. I am also the author of the award-winning book, *Contesting Intersex: the Dubious Diagnosis*, an empirical analysis of intersex in contemporary U.S. society. It was published by New York University Press in 2015. Generally speaking, it has been positively reviewed in 11 scholarly outlets including the *American Journal of Sociology* and the *Sociology of Health and Illness*—top journals in the sociology field.

Since the fall of 2014, I have been a sociology faculty member at the University of Nevada, Las Vegas, where I have flourished as an academic and as a Nevadan. I am a board president of InterACT advocates for intersex youth, and the past president of AIS-DSD Support Group—the largest intersex support group in the world for intersex people and their families.

Through my professional research and my personal involvement in intersex advocacy, I have met thousands of intersex people and their families from all around the world. I have interacted with nearly every medical expert who treats intersex people in the United States. In addition to being a proud Nevada transplant, I am also intersex myself. Intersex people are born with sex characteristics that are not typically male or female. While I do have a vagina, I was born with internal and undescended testes and XY chromosomes rather than ovaries, a uterus, fallopian tubes, and XX chromosomes. My intersex trait was not discovered until I was a teenager in the early 1990s—not that long ago.

Concerning to me are the irreversible interventions that doctors routinely perform on intersex bodies in order to squeeze them into a sex box. For example, when I was a teenager, doctors removed my healthy internal testes, solely because they thought I would not need them as a girl, despite the fact that I lived with them for 16 years of my life. The subsequent surgery left me sterilized. Despite all sorts of advancements in medical techniques such as in vitro surrogacy, I will never be able to have biological children. Aside from now being infertile, I also have other physical ailments as a result of the operation. Because doctors surgically removed my testes, the primary producer of sex hormones in my body and an important component of my bone health, I was left with brittle bones. I was eventually diagnosed with osteopenia. I additionally have extremely low sex hormone levels, which means I will be dependent upon external and artificial sex hormones for the rest of my life.

Some studies suggest that the number of intersex people ranges from 1-in-150 to 1-in-2000 live births, but this is just an educated guess. We do not have a reliable estimate of intersex in the population, but what I know is that this phenomenon is common enough

that I am confident that every single person on this Committee has met at least one intersex person—and that would be me—and then Tiger Devore, so that would be two.

Now that I have testified in favor of <u>S.B. 408</u>, I can be certain that you have met intersex people. I need your support of <u>S.B. 408</u> as do countless other Nevadans—both the living and those not yet born. <u>Senate Bill 408</u> will put an end to the injustices that intersex people like me have historically been forced to endure—medically unnecessarily and irreversible surgeries performed without consent. The testimony I am offering here is grounded in my empirical research and in my personal experience, but it is also congruent with statements from the United Nations and other governing bodies. They have determined that these surgeries are akin to mutilation. I plead with you to join me, to join the other countless scholars of intersex, intersex activists, and the United Nations and stand in support of intersex people and their families. Please vote yes on <u>S.B. 408</u>.

I just want to say that, when you hear from folks who are against <u>S.B. 408</u>, which I am sure you will, I would like you to consider if you are hearing from anyone who is intersex and what their thoughts are.

Chairman Sprinkle:

Is there anyone else in support of $\underline{S.B.408}$? [There was no one.] We will move on to opposition to $\underline{S.B.408}$.

Senator Joseph (Joe) P. Hardy, Senate District No. 12:

I am the grandfather of children who were born with what we used to call ambiguous genitalia. From the standpoint of science, this is still a work in progress—where we are at and what we do with or for these children. That being said, I would put your hats on as parents and recognize that a child is going to be growing up and the parents are going to have to figure out how to help that child. I know that there are imperfect parents, but the parents have the well-being of their children at heart. When I look at the mandate that something cannot be done, I worry that this takes precedent away from the family. There are lots of scientific opinions involved, but I will quote from an April 2017 article:

Long-term outcome data are now available to help predict gender identity for many infants with DSDs and provide insight into appropriate early management decisions. Nonetheless, there is an ongoing controversy about some aspects of management, especially with certain types of DSDs for which gender identity remain unpredictable. Thus, uncertainties about adult outcome, gender rearing and timing of surgery should contribute to discussions and informed decision making by the parents. Each child and family have unique characteristics, so that all decisions should be made on a case-by-case basis.

Catherine O'Mara, Executive Director, Nevada State Medical Association:

We are here in opposition to <u>S.B. 408</u>. <u>Senate Bill 408</u> is strongly opposed by every major organization representing physicians who have the most information on patients born with

a variety of medical diagnoses who have been termed intersex or having disorders of sex development differentiation. There are a number of letters submitted on NELIS [(Exhibit I), (Exhibit J), (Exhibit K), (Exhibit L), (Exhibit M), (Exhibit N), (Exhibit O), and (Exhibit P)]. The American Association of Clinical Urologists, the American Association of Pediatric Urologists, the American Urological Association Society for Pediatric Urology, and the Society for Fetal Urology are among some of the physician groups that are adamantly opposed to this legislation.

It is important to understand that when a child presents with DSD, which is not necessarily an intersex condition, the objective is not to immediately jump to surgery. We have so many more tools and resources available today than we did in the 1960s, and even since the early 2000s, that help inform a multidisciplinary team that can help advise the parents about what is best for that child.

We are very concerned that <u>S.B. 408</u> goes beyond the intended goal of some of the proponents who would like to see there be some delay in some of those procedures—sweeping in a lot of patients who are not really even intersex—even when their gender identity is not in question.

I want to point out, and I know there is a pending amendment, but the original bill talks about anatomical sex assignment. Experts in the field who are dealing with this tell me that there is no such thing as anatomical sex assignment. "We have come to understand that physical anatomy has very little to do with one's gender identity. Caring for these patients involves a multidisciplinary team, the operations in question restore normal function to existing anatomy."

From the most current research, 1-in-1000 to 1-in-4500 live births, not including hypospadias, are DSD births. It is an evolving specialty that is caring for these children. In 2008, pediatric urology became a subspecialty certification, so it is a very new developing practice within a new developing standard of care. Starting in 2006, there were consensus conferences on management of DSD, which included not only the United States but international entities who got together to study this, look at the research, and evaluate the outcomes. The Society of Pediatric Urology Intersex Taskforce, which was instrumental in putting together some of our comments and is against this bill, was founded in 2000.

Since then, there has been an explosion in studies. The experts are looking at the long-term outcomes for these individuals. One of the studies comes from Riley Hospital for Children at Indiana University. In the study, the experts looked at children who have congenital adrenal hyperplasia, one of the most common DSDs. They decided to look at decisional regret (Exhibit Q). What was the decisional regret of those patients who were treated for this condition when they were young compared with decisional regret for all types of surgeries that were done on children. They found that decisional regret was lower than the average both in the women and in their parents for having had the procedure done. In the cases

where decisional regret was present, it was mild to moderate, neither the women nor their parents would have preferred delayed intervention, and some would have preferred earlier intervention.

The point here is not that the physician community wants to be able to do surgeries on newly-born infants. The point is that these cases need to be done on a case-by-case basis using the best knowledge and research we have available with tools such as mandatory screening at birth—which was not present in the 1960s or even until 2000—but is present now. We have the ability to do an ultrasound to test the gonadal makeup of the child, and there is chromosomal testing to determine whether they are XY or XX. The point is really to do what is best for the child and to maximize that child's function, both in terms of physical function and in terms of later sexual function. Both are very important.

In the original bill, there was a section that said anything to relocate the urethral meatus. If that provision is in the bill, it will prevent hypospadias repair, which is one of the most common birth defects among young boys. It happens in 1-in-100 to 1-in-250 boys born in the United States, so many Nevadans are born with hypospadias where the urethra does not form at the tip of the penis. It is indicated that be treated within the first six months of life.

Chairman Sprinkle:

That has been amended out of the bill.

Catherine O'Mara:

There is an amendment pending on NELIS (Exhibit G). I appreciate your efforts, Mr. Chairman, in trying to improve this bill. I know you have worked very hard on this during the last week. We are opposed to the amendment as well as to the underlying bill. There is a section in the amendment where there is a piece of verbiage missing. I wanted to put that on the record, and I did discuss it with Committee Counsel before this hearing. The missing provision is that provision to assign anatomical sex.

Chairman Sprinkle:

I have spoken with Committee Counsel about that. That was a mistake—a typo. It is supposed to be removed from the bill as well.

Catherine O'Mara:

As I understand how the bill reads now with this amendment, there should be no medical intervention or surgical procedure when the intent is to correct an appearance of atypical or ambiguous genitalia for a cosmetic purpose. That is just simply not the standard of care. Function is always maximized over cosmetic. To have the Legislature try to put into statute a standard of care—we really encourage you not to do that. Let us leave the standard of care up to the experts—the people who are practicing in the field—obviously with input from the affected parties.

We welcome the input from Gender Justice Nevada and InterACT. We know that the national urological groups are in conversation with them. You heard some of them say that

they have met a lot of these practitioners. That communication should and will continue, but the Legislature should not put into statute a standard of care that actually ties the hands of Nevada families and prevents them from making decisions in early years that should be done to protect their children. To protect against potential cancer later on in life, to maximize their functional growth, and to ensure that the child has the healthiest outcome possible, we strongly oppose this bill.

Mendy Elliot, representing Nevada Osteopathic Medical Association:

With me today is Veronica Sutherland, a doctor of osteopathy, board-certified family medicine physician, and immediate past president of the Nevada Osteopathic Medical Association. I will turn my time over to Dr. Sutherland.

Veronica Sutherland, Immediate Past President, Nevada Osteopathic Medical Association:

Thank you for allowing me to speak on behalf of the Nevada Osteopathic Medical Association. I am a primary care physician. I take care of children; I take care of adults. I am also an active member of our LGBT community. I understand why we want to prevent what people would interpret as undesirable or haphazard reassignment of gender by sexual gender reassignment surgery, and I believe that is the intent of this bill—to not allow that to happen before a child and its family have grown, developed, and matured and determined truly what gender that child identifies with.

Unfortunately, when we look at this bill as physicians, we see this as a slippery slope. We see this as someone in the legislative process potentially creating a disciplinary action toward our medical community because another individual determines that we have assisted a family, a patient, in medically growing, medically correcting a deformity. I am not referring to intersex as a deformity, but there are other things that might fall under this in what is a very gray zone.

We do not want to be in the position of having someone else tell us that we are going to lose our licenses because we performed a surgery on a child. We do want the children to be able to grow. We want them to develop; we want to be able to help them identify who they are, but tying our hands and preventing the medical community and the parents from actually making an educated decision is not going to further the cause of intersex individuals or anyone in the LGBT community. It is actually going to create a roadblock. It is going to create more complications. People who truly need a surgery are not going to get that surgery. It is not beneficial.

I appreciate the efforts to amend the bill. My first very strong response to the bill had to do with the hypospadias. I do have patients with that, and I recently had a young child who, with very informed parental consent, went through a surgical procedure—so that was a big issue. I am glad that has come out of the bill, but the wording "cosmetic" et cetera, I believe there are medical reasons. There are congenital defects that are not necessarily intersex, and people are going to fall under this gray zone, this umbrella. Our medical community already

has enough legislative control over how we practice medicine. I mean no disrespect, but I do not practice law or legalities, so I think it is probably best that most of our lawmakers do not practice medicine.

Kathleen Conaboy, representing Nevada Orthopaedic Society; and Ambulatory Surgery Center Association:

You might wonder why an orthopedic representative is here at the table when we are talking about gender issues. This is certainly not a surgery that our physicians engage in; however, we have had two themes in our testimony in front of you this session. The first is the exercise of clinical judgment and the concept of shared decision making in making medical decisions—both between the families and the physician. We believe, as you have heard from others, that this bill limits, in fact negates, the concept of clinical judgment in saying that a physician shall not perform or assist in certain procedures. The standard of care is gray at best, and the physicians would stand to possibly lose their licenses. As you will see in the bill in section 2, line 30, they could lose their license if they violate a standard of practice. As you have heard from other people, the standard of practice in this situation is really not well defined. This is an emerging specialty.

I am also here on behalf the Ambulatory Surgery Center Association. While it is not absolutely clear in the bill, the Legislative Counsel's Digest references the fact that a medical facility could have its license to operate suspended or revoked for allowing such surgeries to take place. Again, because of the ambiguity and grayness of the standard of care in this situation, we would object to the bill on those grounds.

Susan L. Fisher, representing Nevada State Board of Osteopathic Medicine:

We, too, are opposed to the bill. We appreciate the effort to amend the bill to try to address some of the concerns that have been expressed, but the intervention with the standard of care is something that is of grave concern to our board. On that basis, we do oppose the bill.

Dane Hardy, Private Citizen, Las Vegas, Nevada:

I submitted my statement (Exhibit R). I prepared it before the amendment, so most of it is no longer applicable, but I just want to get on the record to say that I still think this amendment is painted with too broad a brush. As others have said, there is still a lot of ambiguity in what is presented in the bill. There are plenty of issues where infants and children are born with defects or things that have nothing to do with intersex or assigning gender or sex that will still be subject to punishing the doctors who perform them. I strongly suggest you either continue to amend this bill until it does what it is supposed to do without disqualifying others, or table it until a further solution appears.

Clare E. Close, representing Society of Pediatric Urology:

I am a pediatric urologist here in Las Vegas. I came to Las Vegas in 1997 after completing a pediatric fellowship at the University of Washington. I have been in Las Vegas for 20 years, so I have had a chance to follow my hypospadias patients from infancy up to their late teenage years. I also spent four years as chief of pediatric urology at the University of Chicago and was a member of the DSD board there, which included pediatric urology,

endocrinology, genetics, and ethics. I have served on an ethics board in which we made decisions not to do anything to children who had very ambiguous genitalia, as well as ambiguous genitalia with gonads that were ambiguous and chromosomes that were ambiguous.

I am very opposed to this bill because I think it does not really take into account the fact that 1-in-150 boys is born with a form of hypospadias, which can be corrected and can be corrected well. Just as we have made improvements in all sorts of surgeries in the last 50 years, we have made amazing advances in what we can do with microsurgery for the urethra. I deal with the urinary tract from the kidneys to the tip of the penis. Anything that happens in development that does not happen correctly has to be fixed in a very particular way, and we have the ability to do that in babies at a time during which the tissues are still developing, and therefore, they heal with very little scarring. I always say my practice is very happy because the babies get fixed, and I kiss them goodbye. In general, that is true. I would say that 95 percent of hypospadias that I see is of the mild form, which means, if this is the penis and this is the scrotum, the urethra just failed to fold together and roll into a tube the entire way up to the tip of the penis.

My job as a urologist for children and babies is to restore normal function. That means to allow them to have an erection that does not hurt because it is not bound down, to be able to stand up and pee and not dribble urine down their leg or spray, and to ejaculate in a normal way. That makes them fertile. I say that we are able to do this the vast majority of the time quite easily, and we use tissue that is only on the penis.

We do not practice those surgical repairs that were done 50 years ago where they were using all kinds of skin. In fact, when we have adults who come to us who have not had hypospadias repair done and want it done, our studies show that they are the ones who have a high complication rate. That complication rate can be up to 40 percent because the normal still-developing tissues present on the penis of a baby are no longer appropriate for turning into the urethra of an adult. So we end up having to go inside the mouth to harvest the inside lining of the cheek. We lay that in as a graft, and this is a very stressful thing for adults to go through. I have seen it done many times in patients who have not had the repairs done and then decide they want it done.

It is really important for everyone to understand that hypospadias is a very common malformation of the urinary tract, and it is easily fixed. You can look up anywhere what the complication rates are for that repair—they are very, very low. So if I have a baby boy sent to me who is 46 XY, two normal testicles in the scrotum, and a penis that is not formed completely normally, I can go forward now and recreate the urethra, so that he will void normally, have normal erections, normal ejaculations, and 95 percent of the time will not ever need another surgery. That should not be taken away.

Delyse Hardy, Private Citizen, Las Vegas, Nevada:

[Delyse Hardy spoke from prepared text (<u>Exhibit S</u>).] I am a registered nurse in a local neonatal intensive care unit, and the concerned mother of two sons born with atypical

ambiguous genitalia. I have been following <u>S.B. 408</u> closely and was able to view the amendment last night. I appreciate some of the changes made, but this bill would still prevent some of the care my sons and other children have received and will possibly need in the future. Accordingly, I oppose <u>S.B. 408</u>.

Many physical symptoms seen in patients can be of various etiologies. For example, a missing limb can be caused by genetic factors, uterine bands, maternal exposures to harmful chemicals, et cetera. Likewise, a person with a virus who needs symptomatic relief while his or her body fights the infection does not receive the same care and treatment as someone with throat cancer, even though they both have a sore throat.

Following this pattern, all children and adults born with atypical or ambiguous genitalia should not receive the same treatment. This condition can result from various causes and has a large range of accompanying factors. Yes, informed consent is important and should always be given; and, yes, there are times when care should be suspended until appropriate. But there are also times when, through tests and studies, underlying etiology is determinable. In these cases, gonadal and genetic sex are firmly established. In these instances when treatment—surgical, medical, and/or otherwise is available that can improve the outcome for an affected person, the opportunity to do so should not be legally denied.

My sons are two of these children. Senate Bill 408 would prohibit us from receiving medical care. My heart goes out to those who struggle with the things that were done to them and to their bodies by physicians and others without full consent of them and their parents. I observe that caregivers simply do their best with existing medical knowledge, but I do not assume this observation does much to relieve any of the unimaginable physical and emotional trauma individuals experienced. This is a delicate issue full of tender feelings for all and so many varying factors. It is true that children should be protected; people should be protected, but I also know that stopping treatment for all persons with atypical or ambiguous genitalia is not the best path. While S.B. 408 may potentially protect some from trauma caused by medical and surgical interventions, it would also certainly cause unnecessary emotional, physical, mental, and social struggles for other individuals.

A law that protects some to the detriment of others is not a good law, no matter how many people are affected. It is not right or ethical. A bill that affects your constituents in this manner should not be voted for or passed along party lines. It is not a partisan issue. You are all in office because you were voted in and trusted to do what is best for all persons in your districts. I ask you to vote with integrity. I ask you not to pass <u>S.B. 408</u>. Thank you for your time and for the service you give to us as Nevadans.

Chairman Sprinkle:

Is there anyone else in opposition to $\underline{S.B.408}$? [There was no one.] Does anyone neutral to $\underline{S.B.408}$ wish to come forward?

Tony Alexander, Private Citizen, Las Vegas, Nevada:

Thank you for this opportunity. I am a private citizen and not associated with any organization. I have been following this bill out of interest. There is one point I would like to make that I do not feel anyone in opposition or in support of this bill has made.

It was my understanding that this bill is not intended to limit the practice of medical professionals. It is, instead, intended to empower individuals to make choices about their own bodies.

Chairman Sprinkle:

Is there anyone else neutral to <u>S.B. 408</u>? [There was no one.] Senator Parks, would you like to come up for any closing comments?

Senator Parks:

Thank you. I appreciate your taking the time to hear <u>S.B. 408</u>. I would like to ask you to review testimony that was provided in the Senate. It is up on NELIS. There were a number of people who could not be here today to present their testimony. That testimony includes one of your former colleagues, Dr. Andy Eisen, who made some compelling arguments when this bill was heard in the Senate.

Chairman Sprinkle:

Thank you for being here today. With that, I will close the hearing on S.B. 408.

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

We will now open the hearing on Senate Bill 509 (2nd Reprint).

Senate Bill 509 (2nd Reprint): Authorizes the imposition of an assessment on the operators of certain agencies and facilities. (BDR 38-980)

Debra Sisco, Chief, Supplemental Reimbursement, Reimbursement, Analysis and Payment Unit, Division of Health Care Financing and Policy, Department of Health and Human Services:

The provider fees bill presented is a valuable way to leverage federal funds to increase reimbursement to providers. By doing so, it preserves and increases access to necessary medical services for Nevadans. There is a gap in coverage between what Medicare pays and what Medicaid pays. Supplemental payments can fill that gap. Provider fees are a way to fill that gap. Provider fees must be broad-based and uniformly based. As you know, in the two amendments we have had already, our bill includes permissive language allowing a provider fee program to be developed in collaboration with a majority of providers in a provider group.

The first reprint amended this bill to move from a majority to a super majority—or 67 percent of providers in a provider group. The second amendment was to limit the participants to only medical facilities and an operator of an agency to provide personal care

assistant services. If we were looking at some of the medical facilities that would be eligible for provider fee programs, we could design a provider fee program for as broad a base as all hospitals in Nevada, or it could be just for a certain group such as critical access hospitals or acute hospitals. There are ways available through the federal language to do limitations in some of these provider fee groups. If we do some limiting, it may require us to obtain waivers from the Centers for Medicare and Medicaid Services (CMS), but it is still possible. What we are trying to create is additional reimbursement for those valued Nevada Medicaid providers.

We currently have one provider fee program here in Nevada. It is for the nursing facilities. In 2016, we received \$31 million in provider fees paid to us. Using the federal Medicaid match funds, we paid out \$87 million. We find that was a significant help to those valued providers.

Our next steps in the permissive language in <u>S.B. 509 (R2)</u> would allow the Division of Health Care Financing and Policy (DHCFP) of the Department of Health and Human Services (DHHS) to develop the provider fee programs with only individual provider groups that have been identified by the amendments. The programs would be developed in close collaboration with providers and only proceed if we received an approval of 67 percent of the providers in the group. Provider fee programs would be operationalized in the *Nevada Administrative Code* (NAC) or Medicaid operations manual, both of which require public hearings, public workshops, and working in close collaboration with the provider fee groups. The DHCFP would develop a payment distribution model in partnership with each of the provider groups. Payment distribution models would be individualized to maximize every member in the provider group's ability to fill the upper payment limit (UPL) gap. This could be done in both the fee-for-service and managed care environments. All provider fee programs must be developed according to the State Plan for Medicaid and approved by CMS.

Chairman Sprinkle:

Are there questions from Committee members?

Assemblyman Edwards:

Will the money collected by these fees be put into a lockbox, so it actually gets to the providers we are trying to help? How do we make sure that the money goes where we are intending it to go?

Debra Sisco:

In the language of the bill, we have made sure that the fees will stay within a specified account. For instance with our nursing facilities, we bring the fees into an account designated for the nursing facilities. There is an administrative fee that is pulled out, and then it is redistributed back to the providers once we obtain the federal match.

Chairman Sprinkle:

That is part of the concern—to make certain that the money actually goes back to the providers and does not get skimmed off by administrative fees or handling fees or other fees. How do we prevent that from happening, so we actually achieve the goal of this program?

Debra Sisco:

Once we begin development and discussions with the program, we will discuss the administrative fee—that language and that amount will be included in the NAC or in the memorandum of understanding (MOU). That is a set percentage and it will move forward as that. There is not a way for those fees to be redirected once they are included in the NAC or the MOU. We make sure we are always compliant with the NAC and the MOU.

Assemblyman Edwards:

Was there any reason not to include a sunset in case this does not work out?

Debra Sisco:

We have been operating the nursing facility program since 2003. We have found that program continues to operate, and it is the desire to continue to operate. We do have the ability to revisit any provider fee program developed should federal regulations change, and some of that language is included in the bill.

Marta Jensen, Acting Administrator, Division of Health Care Financing and Policy, Department of Health and Human Services:

The bill itself is the more global opportunity to have conversations with individual provider groups that wish to participate in this program. Once we meet with the groups and come up with the methodology, at that point, we would put it into the NAC. The sunset could be put into the regulation level but not in the bill. We want to make sure our opportunities to continue having these conversations, for instance, if it is a benefit to that provider type or group, can still continue. When we start talking to the individual groups that will all go into regulations. At that point, if a sunset is desired, we would look at it at that level.

Assemblywoman Titus:

It seems to me that we are creating more hoops providers have to jump through to get reimbursed. Why do you not just pay the providers an adequate reimbursement and not try to do these games that try to get someone else to pay. Now, we have to pay to get paid. I know there is going to be some support for this because we might get more money. I just do not believe this makes it easier to practice, better for patients, and at the end of the day, everyone stays afloat. I am just not seeing that pathway. Is this a tried-and-true program that truly does benefit providers?

Marta Jensen:

To be quite honest, we do not have enough General Fund revenue to do our rate increases to the market level. The funding just is not available. This was an opportunity for us to receive enhanced federal funding with a smaller version—obviously \$31 million is not small, but when you get \$87 million back from the federal government that you can put back into the

marketplace, it is a way to supplement the state reimbursement, as we have hit our maximum in some cases. It was a way to enhance our federal participation and get money back into our communities for those recipients.

Assemblywoman Titus:

What is the delay in time? The provider pays; you submit it, and then what is the turnaround time for the provider to actually see the money coming back?

Debra Sisco:

We can design these programs. The soonest we can create a turnaround period is two weeks from the due date of receiving the intergovernmental transfer (IGT). Once all IGTs are in, within two weeks, we can obtain a federal match, and the funds can be paid back out.

Marta Jensen:

When you ask whether it is a proven program, we have looked at other states. Other states do it in a variety of markets. They can do it in personal care; they do it in different provider groups. In some cases it is very successful. It all depends on the methodology. We are not coming to the table with a pre-established methodology. We are coming to the table in collaboration with those provider groups because they may know of something that we do not. That is where that conversation starts because we want to make sure that it is beneficial. Otherwise, why do it?

Chairman Sprinkle:

Are there other questions from the Committee? [There were none.] You may have said this once already, but in reference to the operators being polled to get to the 67 percent, when does that happen and how often?

Debra Sisco:

The way the bill has been amended, it is limited to facilities and personal care agency groups. As far as the facilities go, all those facilities have to be licensed by Health Care Quality and Compliance, which is a Division of DHHS. That will be our 100 percent, and we will communicate with all of them. Please be aware that, as we begin the workshops and conversations, once we obtain that 100 percent list, we will continue to monitor and make sure all are notified as we proceed through the development of these programs.

Chairman Sprinkle:

So it is just at the start? I am having a hard time conceptualizing this. It is just at the start when you are trying to implement the program—that is when you are going to do this polling to see if you meet that 67 percent?

Marta Jensen:

You have to have the interested parties come forward. Once you come up with a methodology and the plan of what you are looking for, that is the time you present it to the provider base in its entirety. At that point, you would have to see who was for it, and who was against it. If you do it too soon in the process, you do not have anything to show them as

an example, so I do not think it is fair to do it too soon. Once we develop the process, then take it out so we can fully explain it, then they can vote however they choose for their individual practice.

Chairman Sprinkle:

Just stating the obvious, the 33 percent that chooses not to, as long as you hit that 67 percent, those 33 percent have to participate?

Marta Jensen:

That is correct if we still feel it is in the best interest. We have to take into consideration the population that will be affected, because remember, the money would come in from the entire provider base, but then it would be distributed up to the Medicaid providers because it is federal funding regarding the Medicaid program. We would have to take all of that into consideration. We certainly do not want to make our providers unhappy; we are trying to enhance the funding they receive from Medicaid, and I would like them to continue to do business with us.

Debra Sisco:

We have been working and brainstorming ideas. We realize that there will be winners and losers, and unfortunately, that is not the kindest way to put it, but that is what will happen. There are ways to help minimize those that may lose. It is a very creative program, and a process that we will be looking at and using, because we are looking to benefit and create more interest and develop more Medicaid providers.

Marta Jensen:

We are looking at some of the other states. There are 49 states that have at least one of these provider fee programs, so there is a lot of experience out there across the nation. They put together grant programs. As Ms. Sisco mentioned, some individual providers may not benefit if they are not a Medicaid provider but are still putting in the fee, but there are other programs that can be accessed through their association or through other means to make sure there is no harm done. We have looked very seriously at those other states to see if we can get some of those ideas.

Chairman Sprinkle:

Under section 6, it says, ". . . an assessment in an amount equal to a percentage of the net revenue" What is "a percentage"?

Debra Sisco:

According to the federal regulations, the maximum percentage that can be in a program is 6 percent of the net revenue, so we know that is our maximum. It is not going to be calculated 6 percent of net revenue. We can calculate that potentially based upon visits if we were looking at an outpatient facility; it could be inpatient stays, it could be net revenue, it could be any number of things. To meet the federal criteria, once we determine how that is calculated or what we want to base it on, then we will have to do the equivalent to meet that federal test.

Chairman Sprinkle:

And that cap is at 6 percent.

Debra Sisco:

That is correct.

Chairman Sprinkle:

Committee, are there any other questions?

Assemblyman Edwards:

You caught my ears when you said we would have \$31 million and get \$87 million back. That is fantastic, and I would ask why are we not doing \$310 million and getting a whole lot more than that back? But I want to make sure we will guarantee that this money actually goes to the providers and that the 6 percent cap is a cap and not a requirement, so that the fee could actually be 1 or 2 percent.

Debra Sisco:

When we began the nursing facility provider tax program in 2003, it started at a much lower percentage. It started at around 2 or 3 percent. It was eventually moved up to the maximum of 6 percent. There are other requirements if you move it to a maximum of 6 percent. Any programs that we would typically develop now would probably be around 5.5 percent because CMS is comfortable not requiring a quarterly waiver if you are down at 5.5 percent. If you do choose the 6 percent, each quarter we ask for a waiver, and CMS has the opportunity to look at it. They will say yes or no to the program. The numbers we gave you before, \$31 million and \$87 million, are the 2016 data from the nursing facility hospitals. It also is dependent on the creativity of the team and the willingness. If you have your 67 percent participation that wants to move forward, we will create as much money as we can. Keep in mind that, for some facilities, even though there may be large ones and small ones, we have to make sure everybody can participate in the program. We have to be mindful of that in developing the programs.

Marta Jensen:

You are correct. We will work out that percentage with that provider group once it is identified. If they would like to go lower, we can certainly look at it, and then increase over time if they so desire. The money itself, because you have matched the money and brought it in, has to go to the providers. We do take an administrative cost off the top because there is work that has to be done by the state to make this program work. But the percentages are relatively low for the administrative fee; however, I do not have the numbers right off the top of my head.

Assemblyman Edwards:

I might want to talk with you afterwards.

Marta Jensen:

Absolutely.

Chairman Sprinkle:

Committee, are there any other questions? [There were none.] Is there anyone here in support of <u>S.B. 509 (R2)</u> wishing to come forward?

Joan Hall, President, Nevada Rural Hospital Partners:

We include all 13 of Nevada's critical access hospitals in our consortium. We believe that this bill offers perhaps the only opportunity for enhanced Medicaid reimbursement for our facilities. Many of our facilities, our critical access hospitals, are financially fragile. With the uncertainty at the federal level about Medicaid funding; the potential changes to the Disproportionate Share and UPL programs; the possibility of Nevada Medicaid moving from fee for service in rural areas to managed care; the fact that Nevada critical access hospitals are currently not getting cost-based reimbursement for outpatient services as is allowed by CMS; and the fact that it has been stated that the state Budget has not been able to increase Medicaid rates, our members see this bill as perhaps the only opportunity to have a discussion with Medicaid on increasing reimbursement to our critical access hospitals.

We understand it is complex, we understand that there are many other provider groups that are not in favor, but we think that without this bill's passage, we do not have the opportunity to even uncover what could happen, so we urge your support.

Connie McMullen, representing Personal Care Association of Nevada:

Our members voted and considered this issue, and we attended a workshop hearing on it. As the previous speaker said, we too, believe this is our one opportunity. Personally, I would like to go on the record to say we support Assemblywoman Titus' bill, <u>Senate Bill 95</u>, but this is an opportunity for us to participate. I do not know if we will be able to with CMS, but we would at least throw our hat in.

Chairman Sprinkle:

Is there anyone else here in support of <u>S.B. 509 (R2)</u>? [There was no one.] Is there anyone in opposition to <u>S.B. 509 (R2)</u>? [There was no one.] Is there anyone neutral to <u>S.B. 509 (R2)</u>?

George Ross, representing Sunrise Hospital and Medical Center:

You have heard me testify a number of times in the past about Sunrise's status as the largest Medicaid provider in the state. When I come up here not in fulsome support, you may be wondering why we are looking a gift horse in the mouth. Sunrise Hospital is part of Hospital Corporation of America (HCA), a company that operates in 20 states. They have experience with this in nearly every one of those states, and it is the experience with these programs that got them very concerned.

We are happy that this bill represents a recognition that the whole Medicaid program in the state of Nevada is woefully underfunded. It has a tremendous impact on every health care provider in the state's ability to operate and make operating decisions. This proposal on its face looks like a great thing, but when you get into the details, there are problems. It is what has happened to these programs over time in other states that makes Sunrise very concerned.

Chairman Sprinkle:

Mr. Ross, I just want to confirm. Are you here in neutral?

George Ross:

If we have such a program, there are some things that should be taken into account—based upon HCA's experience in those other states—to make it a better and more workable program. First, every state has a sunset provision, which gives the ability to stop, take into account those things that are working well, those developments that have caused problems, and start over and recalibrate as necessary. We feel that is an absolutely essential feature.

Second, we are very concerned that the money would in reality come down to the intended recipients—in particular, the managed care organizations have a tendency to charge fees, have a tendency to deny claims, and have a tendency to downgrade claims. There must be a way to make sure that the hospitals can tell if they are getting the money that is intended to come to them.

This bill has provisions that say the money is segregated into that account. What we know from other states is, the current legislature cannot bind the next legislature. That changes. There are states where the provider fee has become in reality a great source of money for their general funds. We have actually had to pass initiatives to keep that from happening. Similarly, the revenue take from the hospitals, one way or another, seems to get larger and larger. Since Sunrise is the largest hospital in the state, we are concerned about how that revenue is going to be calculated—it seems to go up and up.

We are concerned about how the vote will take place. I know it is a two-thirds vote, and we are very happy to see that get amended in, but is it two-thirds of the hospitals? Is it going to be weighted, so that a hospital with hundreds and hundreds of beds, and who therefore would be supplying more of the revenue, will have a bigger voice in that vote than would a hospital of 100 beds, or are they all equal? That makes a difference.

The bill does have protections against changes in federal law, but we are all exposed to all the uncertainties about what is going on in Washington, D.C., and that can have a major impact on all of this. If we are going to go forward with this, we think it is imperative and very important that we take into account some of the lessons we have learned in other states.

Chairman Sprinkle:

Is there anyone else here in neutral for <u>S.B. 509 (R2)</u>? [There was no one.] Would you like to come up for any closing comments?

Marta Jensen:

Remember, this is just the framework to allow the conversations to happen with those individual providers, whether it is the hospitals or the personal care facilities. This allows the opportunity to have a conversation at any point. We are not waiting every two years. That is why we did not do this similar to the nursing facility fee and put it in statute. All the things Mr. Ross indicated would be things we would talk about with those individual provider

groups. When we put it into regulation that is the most appropriate place to put the sunset date. You are putting a sunset on that methodology, that agreement. At this level, to put a sunset on the opportunity to have the conversation limits the opportunity for discussion concerning possible federal funding that we have not even thought about just yet. Thank you for the opportunity to present this before the Committee.

Chairman Sprinkle:

Thank you for presenting this bill. We will close the hearing on <u>S.B. 509 (R2)</u> and open up for any public comment. Does anyone wish to come forward under public comment? [There was no one.] We will close public comment. With that, we are adjourned [at 3:29 p.m.].

	RESPECTFULLY SUBMITTED:
	Terry Horgan Committee Secretary
APPROVED BY:	Committee Secretary
M: 1 10 0 : 11 01 :	
Assemblyman Michael C. Sprinkle, Chairman DATE:	

EXHIBITS

Exhibit A is the Agenda.

Exhibit B is the Attendance Roster.

Exhibit C is the Work Session Document for Senate Bill 60 (1st Reprint) presented by Marsheilah Lyons, Committee Policy Analyst, Research Division, Legislative Counsel Bureau.

Exhibit D is the Work Session Document for Senate Bill 253 (1st Reprint) presented by Marsheilah Lyons, Committee Policy Analyst, Research Division, Legislative Counsel Bureau.

Exhibit E is the Work Session Document for Senate Bill 274 (1st Reprint) presented by Marsheilah Lyons, Committee Policy Analyst, Research Division, Legislative Counsel Bureau.

Exhibit F is the Work Session Document Senate Bill 480 (1st Reprint) presented by Marsheilah Lyons, Committee Policy Analyst, Research Division, Legislative Counsel Bureau.

Exhibit G is a proposed amendment to Senate Bill 408 presented by Senator David R. Parks, Senate District No. 7.

Exhibit H is written testimony dated May 17, 2017, presented by Arlene B. Baratz, Private Citizen, Pittsburgh, Pennsylvania, in support of Senate Bill 408.

<u>Exhibit I</u> is written testimony dated May 13, 2017, addressed to Chairman Mike Sprinkle and the Assembly Committee on Health and Human Services, submitted by Kathryn Eckert, M.D., Associate Professor of Pediatrics, University of Nevada School of Medicine, Reno, in opposition to <u>Senate Bill 408.</u>

Exhibit J is written testimony dated May 15, 2017, addressed to Chairman Mike Sprinkle and the Assembly Committee on Health and Human Services, submitted by Frieda Hulka, M.D., in opposition to Senate Bill 408.

Exhibit K is written testimony dated May 15, 2017, addressed to Michael Sprinkle, Chair, Health and Human Services Committee, submitted by Charles A. McWilliams, M.D., President, American Association of Clinical Urologists; Gregory E. Dean, M.D., President, American Association of Pediatric Urologists; Christopher Gonzalez, M.D., Chair, AUA Public Policy Council, American Urological Association; Hillary L. Copp, M.D., Secretary/Treasurer, Society of Fetal Urology; and Douglas A. Canning, M.D., President, Society of Pediatric Urology, in opposition to Senate Bill 408.

Exhibit L is written testimony dated May 16, 2017, addressed to Chairman Mike Sprinkle and the Assembly Committee on Health and Human Services, submitted by Jessica T. Casey, M.S., M.D., Children's Urology Associates, Las Vegas, Nevada, in opposition to Senate Bill 408.

Exhibit M is written testimony dated May 15, 2017, addressed to Michael Sprinkle, Chair, Health and Human Services Committee, submitted by Betsy Huang, M.D., F.A.A.P., President, Nevada Chapter, American Academy of Pediatrics, in opposition to Senate Bill 408.

<u>Exhibit N</u> is written testimony dated May 15, 2017, addressed to Mike Sprinkle and the Assembly Committee on Health and Human Services, submitted by Andrew H. Hwang, M.D., F.A.C.S., in opposition to <u>Senate Bill 408</u>.

<u>Exhibit O</u> is a written statement titled "Nevada Senate Bill 408 Establishes conditions for the performance on a child of any surgical procedure to assign anatomical sex," submitted by the American Association of Clinical Urologists, State Society Network, in opposition to <u>Senate Bill 408</u>.

Exhibit P is a letter dated May 15, 2017, addressed to Chairman Sprinkle, submitted by James C. Plaire, M.D., in opposition to Senate Bill 408.

Exhibit Q is a document titled, "Decisional regret and views about optimal timing of female genital restoration surgery in CAH: patient and parental perspectives," with a forward dated May 16, 2017, submitted by Catherine O'Mara, Executive Director, Nevada State Medical Association, in opposition to Senate Bill 408.

Exhibit R is written testimony dated May 17, 2017, addressed to the Assembly Committee on Health and Human Services, submitted and presented by Dane Hardy, Private Citizen, Las Vegas, Nevada, in opposition to Senate Bill 408.

<u>Exhibit S</u> is written testimony dated May 17, 2017, addressed to Members of the Nevada Assembly Health and Human Services Committee, submitted and presented by Delyse Hardy, Private Citizen, Las Vegas, Nevada, in opposition to <u>Assembly Bill 408</u>.

<u>Exhibit T</u> is written testimony dated May 17, 2017, titled "Hearing on SB408: Establishes conditions for the performance of certain surgical procedures," submitted by Edward S. Devore, Private Citizen, Las Vegas, Nevada, in support of <u>Senate Bill 408</u>.