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

Eightieth Session
April 24, 2019

The Committee on Health and Human Services was called to order by Chairwoman Lesley E. Cohen at 1:05 p.m. on Wednesday, April 24, 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
Assemblyman Tyrone Thompson
Assemblywoman Robin L. Titus

COMMITTEE MEMBERS ABSENT:

Assemblyman John Hambrick (excused)

GUEST LEGISLATORS PRESENT:

Senator Julia Ratti, Senate District No. 13
Senator David R. Parks, Senate District No. 7

STAFF MEMBERS PRESENT:

Marsheilah Lyons, Committee Policy Analyst
Karly O'Krent, Committee Counsel
Christian Thauer, Committee Manager and Secretary

OTHERS PRESENT:

Katie Anderson, Private Citizen, Reno, Nevada
Trudy A. Larson, M.D., Dean, School of Community Health Sciences, University of Nevada, Reno
Tom Clark, representing Nevada Association of Health Plans
Catherine M. O'Mara, Executive Director, Nevada State Medical Association
André C. Wade, State Director, Silver State Equality
Briana Escamilla, Nevada State Director, Human Rights Campaign
Sherrie Scaffidi, Director and Advocate, Transgender Allies Group, Reno, Nevada
Joelle Gutman, Government Affairs Liaison, Washoe County Health District
John J. Piro, Deputy Public Defender, Legislative Liaison, Office of the Public Defender, Clark County
Antioco Carrillo, Executive Director, Aid for AIDS of Nevada
Kendra G. Bertschy, Deputy Public Defender, Washoe County Public Defender's Office
Michael Hackett, representing Nevada Public Health Association
Margot Chappel, Deputy Administrator, Regulatory and Planning Services, Division of Public and Behavioral Health, Department of Health and Human Services
Brooke Maylath, President and Advocate, Transgender Allies Group, Reno, Nevada
Zachary Kenney-Sontiwun, Legislative Intern, Human Rights Campaign
Vivian Leal, Team Leader, Indivisible Northern Nevada
James L. Wadhams, representing Nevada Hospital Association

Chairwoman Cohen:
[Roll was called. Committee rules and protocol were explained.] For anyone who is not aware, today is Denim Day. Denim Day began after the Italian Supreme Court overturned a rape conviction on the premise that since the victim was wearing tight jeans, she must have helped the perpetrator remove her jeans and, therefore, consented to the act. The following day, women in the Italian Parliament came to work wearing their jeans to protest the ruling. Today, we continue that tradition by wearing denim to stand in solidarity with survivors of sexual assault and to protest against destructive attitudes around sexual assault that still exist today. If you are not a regular at the Legislature and are wondering why we are so casual today, that is why.

I will open the hearing on Senate Bill 291.

Senate Bill 291: Revises provisions governing the testing of infants for preventable or inheritable disorders. (BDR 40-111)

Senator Julia Ratti, Senate District No. 13
I am here to talk to you about newborn screening. I would like to introduce Katie Anderson, who is a friend of the person who brought this issue to my attention. I would also like to introduce Dr. Trudy Larson, who is, in addition to many other hats she wears, the director of the Nevada State Public Health Laboratory.

With respect to newborn screenings, Ms. Anderson and I are among the same circle of friends. Unfortunately, her family received some life-changing and devastating news when their child was diagnosed with a rare genetic disorder. As time went by and as they were coping with that diagnosis, a question came up as to why this disorder was not on the newborn screening panel that happens for every child born in Nevada. I agreed to look into that issue to see why that was and what was happening. I learned a whole bunch about the process of newborn screening in Nevada and, frankly, nationally.

Nationally, there is a group that is housed under the U.S. Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Resources. They have a process to review what disorders should be included for screening on what they call the Recommended Uniform Screening Panel (RUSP) (Exhibit C), which you will hear referred to multiple times during today's testimony.

The RUSP is put together by a body of professionals who review all disorders and determine what would be in the best interest of the entire country. The reason it is called "Uniform" is they are really advocating for having newborns be tested for similar disorders across the country based on an identified set of standards, which I am going to let Dr. Larson talk to you about a little more.

When I learned about the RUSP, I discovered the X-linked adrenoleukodystrophy (X-LAD), which is the disorder Ben Anderson was diagnosed with, was on the RUSP and yet the state of Nevada was not testing for it. I did not understand why this was a recommended best practice, yet we were not testing for it in Nevada.

I reached out to Dr. Larson and received an education on how we do it in Nevada, and I decided to bring this bill forward. I could have done this a couple of different ways. I could have just said we need to screen for X-LAD, which is the specific condition for the family whom I know and care about. That probably would have been the easier path. That would also be somewhat on trend with what is happening across the nation where individual families will have contact with an individual legislator who will come to the legislative body and indicate a certain disorder needs to be on the screening panel. However, by doing it that way, we have 63 legislators making decisions on winners and losers based on whether they happen to know a Senator or happen to know how to navigate the process rather than using an independent body to do a meaningful evaluation.

It was not too long after I learned about this that I was approached by another constituent who was advocating for another disorder, Krabbe disease [globoid cell leukodystrophy], to be added to our screening panel. Krabbe disease was not on the RUSP. It puts us in a position of whether we want a wonderful body of elected officials who are intelligent, capable people but may not necessarily be the best people to be making these choices about which disorders are in and which disorders are out for screening, or do we want to follow a standardized process that has good criteria and strong evaluation systems in place to get the disorders onto the RUSP that should be there. So I decided to bring this bill forward.

This bill seeks to make it the law in Nevada that we will keep up with the best practice that come from HRSA on the RUSP. This will put a box around what we would be doing in Nevada in terms of not adding any disorders outside of the RUSP, but we are going to keep up with the best practice. Understanding there are reasons why we may not always be able to do it immediately, it gives a four-year window of time for us to catch up. If a disorder is added to RUSP, the state of Nevada has four years to add that disorder to our panel as well. That allows two legislative sessions and two budgeting cycles, which should be all the time needed to do two things. One is to figure out how to pay for it because 55 percent of births in Nevada are covered by Medicaid, so it does have some financial impact if we need to raise fees to add a disorder. Secondly, it is important that the health care community in Nevada has the time to develop the resources necessary to support those families. What we do not want to have is a position where someone is getting a diagnosis but there is no place for the laboratory to refer them for further counseling and further support. That four-year window gives us time to make sure everything is in place.

The bill also sets up a little bit of an out, if you will. If, for some reason, the national level recommended a screening that was just exorbitantly expensive, it allows for a couple of individuals to go to the State Board of Health of the Division of Public and Behavioral Health, Department of Health and Human Services to ask for an exemption for that particular disorder. Should there be a reason Nevada could not get there within that four-year time frame, it allows for a public process for us to opt out. That is based on either not having the resources available or not having the provider community ready to cope with that diagnosis.

In a nutshell, that is what this bill does. When we were going through the process of drafting this bill, we learned there are some things that are currently practiced that did not necessarily line up perfectly with *Nevada Revised Statutes*, so there is also some clean up in this bill to take out some processes that are no longer the case in Nevada and line it up with what is actually happening in the real world today as well as where we would like to be moving forward.

I would like to introduce Katie Anderson, who is going to tell you a little bit more about her personal story.

Katie Anderson, Private Citizen, Reno, Nevada:
My husband, Matt, wanted to here today, but it is impossible for us to coordinate opportunities like this based on the demands of our new schedule—balancing work and not working; caring for Ben and our older son Luke; and maintaining, as best we can, the health and well-being of our family.

After over a year of perplexing behaviors at home, at school, and in athletics, our eight-year-old, Ben, was diagnosed with X-LAD on March 9, 2018. Up until that point, Ben was meeting all of his developmental benchmarks and was excelling at school and in all of his athletic pursuits. He is a bright, tenacious, clever, curious, and athletic boy.

Beginning in the fall of 2017, we found ourselves in the offices of a psychologist, a pediatric neuropsychologist, optometrists—the most immediate and profound loss was Ben's vision—and in the office of his head of school after shockingly low results from an early literacy screening.

Because this disease is incredibly rare and masked in similar behaviors that manifest in boys Ben's age around the same time—attention-deficit/hyperactivity disorder, attention deficit disorder, and oppositional defiant disorder—experts around us were dumbfounded and clueless about what was going on with Ben. Believing the issues were vision-related, a neurosurgeon friend scheduled a magnetic resonance imaging (MRI) at the University of California, Davis. The diagnosis was instant because the demyelination in Ben's brain was already past the point of all medical treatments. We learned that Ben would die within the next several years and that his death would be a slow, agonizing process, eventually destroying his entire nervous system. He would die in a vegetative state. A clock that we did not know existed was ticking and time ran out. This all could have been avoided with a simple test.

Following Ben's diagnosis, our older son, Luke, was tested. We learned he also has the X-LAD, but not the cerebral form. Like Ben, Luke is adrenal-insufficient and will need to take hydrocortisone for the rest of his life. We have made radical changes to his diet, his supplement regime, and he is under the care of a doctor at Stanford University Medical Center, which means MRIs twice a year. If anything changes in Luke's body, we will be aware of it and able to make decisions that will save his life. Because of Ben, Luke's life can be saved.

Had there been a newborn screening for X-LAD, we would have known about Luke immediately and been able to pursue the best preventative medical care for him. We would have also been able to make an informed decision about having a second child. While we could never imagine our lives without our dear, dear Ben, other options such as adoption or specialized in vitro fertilization would have been available and could have prevented not only our own suffering, but the extreme suffering of our beautiful boy.

While the screening requires a nominal investment by our state, that investment will end up saving boys and their families from the excruciating reality we are living out and also end up saving money, as the cost of walking through this disease is substantial. Additionally, if baby girls are born with the mutated X gene, the screening would identify that also. It would give these girls, of which I was one, the opportunity to make educated decisions about family planning and their futures.

This screening will not change anything for our family or for Ben. The thought of being here doing this a year ago was unfathomable. However, after a year of processing and adjusting to the new trajectory of our life, Matt, Luke, and I, with the deep love and support of our community—which not every family has access to—have garnered enough strength and conviction to share with you from our personal experience why this newborn screening is important.

We have connected with counselors, doctors, and families across the nation who have been instrumental in the implementation of the newborn screening in Washington and California. I love my state. I am a fifth-generation Nevadan. My boys are sixth-generation Nevadans. My hope and prayer is that you will make the right decision and move forward with this bill, thereby saving the boys and their families, and protecting babies from all the genetic disorders able to be tested and treated from birth.

Chairwoman Cohen:
Thank you for sharing your family's story with us. Senator Ratti, would you like Dr. Larson to speak or would you like to answer questions now?

Senator Ratti:
With your permission, Chairwoman Cohen, I would love to have Dr. Larson provide just a little bit more information about newborn screening just in case that answers some of your questions. The three of us will then stand for any questions.

Trudy A. Larson, M.D., Dean, School of Community Health Sciences, University of Nevada, Reno:
I am here today to provide more information about Senate Bill 291, a bill related to newborn screening. I currently serve as the Dean of the School of Community Health Sciences at the University of Nevada, Reno, and I oversee the newborn screening program.

The newborn screening program in Nevada was originally started in the 1990s, primarily as a result of identification of PKU [phenylketonuria] and recognition that early identification coupled with a special diet would offer a normal life to children who had this genetic condition. The screening was originally done by Oregon State Public Health Laboratory until 2014, when the program moved to the Nevada State Public Health Laboratory.

Currently, the Nevada program screens for 57 conditions, and we recently added severe combined immunodeficiency (SCID), which is a fatal disease early in infancy that can be cured with a bone marrow transplant. The availability of treatment is just one measure that is used to recommend these conditions for screening.

In your packet, there is a briefing paper on how the U.S. Department of Health and Human Services uses an advisory committee to recommend these screening tests (Exhibit D). The list the committee produces is known as the RUSP. Each genetic condition that is brought forward for inclusion is thoroughly investigated with four overarching considerations. To be included as a primary target, a condition should meet the following minimum criteria:

1. It can be identified at a period of time—24 to 48 hours after birth—at which it would not ordinarily be clinically detected. In other words, there are no symptoms early on.

2. A test with appropriate sensitivity and specificity is available, also one that is easy to scale up and do many samples.

3. There are demonstrated benefits of early detection, timely intervention, and effective treatment.

4. Public health departments are actually able to screen and provide this follow-up care to minimize the effect.

Each state is actually responsible for selecting its own screening list based on a number of factors. Currently, Nevada screens for all but three conditions. These three conditions are mucopolysaccharidosis, X-linked adrenoleukodystrophy, and spinal muscular atrophy. All of these are rare, genetic diseases.

The impetus for this bill, as well as most revisions around newborn screening, really are requests from families impacted by the genetic conditions that are not listed on the RUSP. For Nevada, this bill would add the three conditions to the newborn screening panel already approved by the federal advisory group.

Nevada does have an advisory committee for newborn screening. It is a community group composed of physicians who have specific expertise, nurses, program leads, hospitals, and support agencies. This group has already recommended inclusion of these three disorders. Inherent in this addition is that we identify adequate resources to support the diagnosis, treatment, and follow-up. We are actually very secure that we now have those resources and the specialties that are required in Nevada.

To support the newborn screening program in Nevada, fees are collected from birthing hospitals and sites that are mandated to obtain specimens from every newborn. The current fee covers two testing screens, one between 24-48 hours of birth, and the second two weeks later. There are some conditions that are actually more noticeable after a diet has been started, so that two-week screening really increases the sensitivity of these tests. In order to add the three tests that would bring Nevada to federal standards, we would need to increase fees.

Senate Bill 291 identifies a mechanism that will allow for transparency in the development of increased fees and puts in place a means to delay adding tests if the resources will not permit it. We believe it is important for the families of Nevada that we keep up with federally recommended screenings and put in place a mechanism that will help us do this.

In your packet is included the number of conditions found since the start of newborn screening in Nevada in 2014 (Exhibit E). From over 150,000 Nevada babies who have been screened, 235 critical conditions have been identified that have allowed families and children to benefit from early diagnosis and treatment. As a state growing in numbers and in resources, we need to extend these options for all families. I would be happy to answer any questions you may have. [Written testimony was also submitted (Exhibit F).]

Senator Ratti:
I have one last piece of history. We used to outsource this testing to Oregon. There were some significant efforts to bring it back to the state. We actually have another person here if you want some more of that history. We did a really good thing by bringing it home, but when we brought it home, we did not set up any framework or system for adding new conditions. The newborn screening process—this very important public health process—is frozen in time to where we were when we brought it back from Oregon. The laboratory did some yeoman's work to figure out how to add SCID without raising any fees. However, between normal inflationary costs of doing business and new screenings coming on, they are not in a position to act unless we create this process for them to be able to do a public hearing to examine what the increased fees would be and for Medicaid to be able to look at it and address it in the normal Medicaid rate setting process for the babies who are covered by Medicaid so there is an ongoing, regular, consistent process.

Again, I could have just brought a bill about the one disease, but we really need to fix the underlying system to make sure there is an ongoing mechanism so this important public health benefit is not frozen in time from when we brought it back from Oregon. That is what this bill seeks to do.

Chairwoman Cohen:
Are there any questions from the Committee?

Assemblywoman Gorelow:
I love this bill. Ms. Anderson, I want to express my sincere condolences to your family. How does this test impact babies who are born preterm?

Trudy Larson:
There is a provision in the way the tests are done that allows for early diagnosis, so the babies do get their screens early. We do add one more screen for preterm babies, but these are genetic tests and those genetics are already set, even in preterm infants. We do have to look at a third test because many of the preterm babies are on artificial nutrition. Those have to be weeded out by confirmatory tests to make sure they are accurate.

Assemblywoman Gorelow:
I also have a question regarding Medicaid covering the births. I believe it is $81 for the birth registry and that goes to pay for newborn screening. Does Medicaid cover that or are those families required to pay the $81?

Senator Ratti:
For patients who are covered by Medicaid, the fee is paid by Medicaid. The estimate to add all three conditions would be around $450,000. Again, because of how we chose to bring this bill forward, you do not see the fiscal note or the appropriation in this bill because it

would go through the normal Medicaid plan process in the interim rather than it always needing to be a legislative process to add new conditions so we know the dollar amount to get caught up and to add these three conditions. As new conditions come on, it would be the normal Medicaid plan process to address them.

Starting in the fall, we did have stakeholder working groups—working with the Medicaid team, representatives of hospitals, and representatives of the other payers besides Medicaid. We were all in agreement that it was important for the laboratory to have a public hearing to justify any rate increase. They would have to show what the new conditions were and what new equipment or staff would be necessary to justify the fee setting, which would give the hospitals and the payers the opportunity to participate in that public hearing to have the accountability. That would be built into the Governor's *Executive Budget* as part of the overall Medicaid costs. That is the process it sets up. Fifty-five percent of births in Nevada are covered by Medicaid.

Assemblywoman Gorelow:
Could you clarify the process? I know most of the process is going to go off the RUSP on what has been recommended, but will there be a mechanism for this state to determine to go outside the list and pick up other diseases, such as Krabbe disease, as several other states have done?

Senator Ratti:
The Legislature clearly retains the authority. We cannot tie the hands of any future Legislatures. This bill would make it the policy for the laboratory to automatically work with the State Board of Health to do anything that is on the RUSP. Anything outside that would have to come back to the Legislature.

Assemblywoman Gorelow:
Would you please consider adding me as a sponsor?

Sentor Ratti:
Yes.

Assemblyman Carrillo:
My question pertains to the Medicaid recipients. How does it work when someone has private insurance? Would those individuals be subjected to these increased fees as well?

Senator Ratti:
The way it works today, there is a flat fee. It is—I do not want to say hidden because it is not the right word—buried as part of the daily rate for a birth. That is true in the Medicaid system, and it is also true to the vast majority of other payers. If I chose to have a baby, which is not going to happen, and I gave birth at the hospital, whatever my payer source is, that hospital charges that payer for a daily rate that has been negotiated between that provider and that payer. The newborn screening fee comes out of the first day. If the birth were to

take two days, then the daily rate would be paid twice. If the birth were to take three days, that daily rate gets paid three times. The newborn screening fee comes out of the first day of the daily rate for most payers.

That was a conversation we had as part of the working group, and I would anticipate that in the first public process where the rate increase is considered, there will be some conversation about pulling this fee out as a separate fee so it is not buried in the daily rate. That would be done through the regulatory process in the public hearing with the Medicaid folks, and then each payers' contract with each provider would be adjusted as they see fit. We are not inserting ourselves into the negotiations between payers and providers with this bill. Did that answer your question?

Assemblyman Carrillo:
Yes. What happens to blood spots?

Trudy Larson:
The blood spot is the testing material that is collected between 24 and 48 hours and also at two weeks. They use little cutouts for the specimens that go into this very sophisticated equipment that tells us the appropriate levels and looks at the genetics. Those blood spots are then stored just in case we need to go back and do a second test. Over time, those blood spots are then disposed of. There is a consent process for this, as you may know. There is not a mandate; individuals can opt out of this test.

Assemblyman Carrillo:
This is not something that we deal with on a daily basis. My other question is regarding the 57 conditions that are currently screened. Would this be adding three more conditions to be screened for in Nevada? I am about to become a grandfather in the next five to six months. Obviously, when we were growing up, we did not have genetic testing. We cannot predict the future, but will this leave it open so that when conditions come up, we can just add them or does it have to go through the Legislature? Is this going to continue to fall along those lines as things progress and technology becomes better? This is something I want to ensure does not have to come back to the Legislature for permission every time.

Senator Ratti:
You have hit the nail on the head. There was probably discretion for the state laboratory to add conditions if they wanted to add conditions. It was not allowed for or disallowed for in state law, but they did not have the resources to do it. For all intents and purposes, using SCID as an example, they went ahead and added SCID. They did not need legislative authority and it was on the RUSP at the national level, but they had to shoehorn it in with the resources they had available.

In the next round, when the RUSP was updated, three conditions were added. There is no way to get blood from a turnip in the laboratory's budget to add three more conditions without the Legislature figuring out how to unfreeze what we did when we brought it back from Oregon, when we set a rate but never set any process in motion for the laboratory to be able to raise its rates.

What this bill does is it adds to *Nevada Revised Statutes* that the state will, through the State Board of Health, follow the RUSP. If HRSA adds a condition to the RUSP, that trigger allows the state laboratory to hold a public hearing in collaboration with the Medicaid team to be able to raise the rate in order to add that condition. That then gets handled for 55 percent of the births through the normal Medicaid plan update process to absorb that extra cost. No additional permissions or steps from the Legislature are needed. If, as Assemblywoman Gorelow alluded to, this body feels they want to do something in addition to what is the best practice RUSP at the national level—since our state policy will now be that we are going to keep up with the RUSP—they would have to come back to the Legislature to add a condition outside the recommended list. That becomes a slippery slope. There are literally thousands of these conditions. We currently test for just under 60. There is balancing of critical public health needs where we really can make a difference for a family if we know. For some of the other conditions where the family has the benefit of knowing their child has that condition but there is no well vetted medical interventions that could actually make a difference, is that then the best use of our public health resources?

I would say the Legislature is going to want to be very thoughtful about doing anything outside the RUSP because we do not have the same level of infrastructure to do the scientific evaluations of all these very rare conditions and determine whether or not they merit being added to the panel. However, as the Legislature, we retain the ability to do so if we choose. To very pointedly answer your question, if we pass this bill, there would be no additional steps necessary if the condition is on the national RUSP.

Chairwoman Cohen:
Today happens to be the birthday of a young woman I know who was born via in vitro fertilization after her family went through having a child with Tay-Sachs disease. That makes me think about different genetic disorders based on ethnicity. Is the national panel looking at that? Certainly, there are neighborhoods and areas in states where Tay-Sachs would be much more prevalent than in Nevada.

Trudy Larson:
The states set the screening. If there is consideration of a particular genetic condition that might be more prevalent in their population, they can choose to add that. The overall national recommendation sort of homogenizes the population so they can look at large populations and identify if there are enough incidents of a particular disorder and if there are excellent screening tools and good resources to do something about it. Those are the easiest to put on the list. The disorders we are putting on the list now have probably been known as

orphan diseases in the past, but as we get better at screening and treatment, they will be added to the list nationally. In the past, we did not realize all the benefits bone marrow transplantation treatment would provide. However, the states always retain the right to add to the list. That goes back to being able to show there is an added need in a state.

Assemblyman Thompson:
To Ms. Anderson, I am going to call you Tough Mom. Thanks for being tough and being an advocate. That helps so many people. I do have some questions. Is this for all newborns or is it based on information that is gathered around a family's health history?

Senator Ratti:
It is for all newborns, with the exception that families can opt out. If they choose not to have the test, they do not have to have the test. It is a very low incidence of people who opt out.

Assemblyman Thompson:
What if something is determined in the infant? Should the bill state what happens after that? A good example is doing work in the community with diabetes screenings. If it is determined someone has diabetes, we cannot just leave them there. We have to have a plan for care. Is that in the bill?

Senator Ratti:
The care and services are not specifically in the bill, but Dr. Larson can talk to you about what does happen when the results come back positive.

Trudy Larson:
Part of our newborn screening program is not just the screening. The program also includes follow-up. Every abnormal test is followed up on immediately. We have a fax system in place that is pretty new. We finally got into the twenty-first century with our information technology. We can fax results now, phone calls are made, providers are notified, and parents are notified. Typically, we need a second specimen to be able to confirm that there is a condition. If there is a condition identified, we have specialists as part of our program whom we immediately connect to the primary care physician to make sure those babies who are identified get an immediate response.

Assemblyman Thompson:
How quick is the turnaround on the screening? The reason why I ask is because depending on the level of insurance, a woman who has delivered a baby can be out of the hospital in one to two days. If the test takes longer and the mother is already discharged, what are the efforts? You have to realize, not everyone has access. We have to find that mother and let her know. Sometimes a letter is not sufficient. It takes door knocking and so forth. At the end of the day, we want to have healthy babies; and for the babies who have an identified illness or disease, we want to be able to care for them.

Trudy Larson:
That is part of the follow-up that is difficult. We use provider's offices, public health nurses, last known numbers, and cell phones. It is a very intensive process. The tests take about 48 hours, so the mothers are discharged by the time the results come back. That is when our follow-up coordinators, who I have to tell you are some of the most dedicated people I have ever met, stay on it and make sure they find the parents and get them connected to care. You are exactly right. For some of these families, it gets very difficult to connect them with care. For some of them it is critical and the babies need treatment within the first week of life.

Assemblyman Titus:
I need to ask some specific questions about the bill itself. I am concerned it is not necessarily going to accomplish its intent. I have been on the finance committees at times in the past when we brought this screening back from Oregon. When we sent the screening to Oregon during the years I delivered babies, how often did the Oregon laboratory update what they were testing for?

Trudy Larson:
Oregon would update periodically, but their rates raised almost every year about $2 or $3. We had no control over that piece at all, but they did regularly raise their rates as they added new tests.

Assemblywoman Titus:
When we brought it back to Nevada, did we stick with what Oregon had been testing for in 2015? Other than the one test Nevada added, were there other tests added?

Trudy Larson:
When we brought it back, because it was a new program for us, we kept it exactly as it was in Oregon. It had already been updated periodically. We kept the tests and the rate the same so we could get experience. Since we have taken it over, the turnaround time is much faster than it used to be with Oregon. We are pretty happy about that. I think we are providing much better service. Our follow-up service starts much sooner, so we are happy about that as well. The only thing we have added was what was added to the RUSP, which was SCID. That was actually added because we received grant money.

Senator Ratti:
I do not want to leave you with the impression that the laboratory was not trying to be proactive and do something additional. When Ms. Anderson and I, and our circle of friends, were having the conversation about adding X-LAD, I approached the laboratory. The laboratory has an advisory committee that had already made the recommendation for adding the three conditions. They were doing what they needed to do to keep up with the new process, but they had no mechanism for raising the fees.

What is interesting is that the state laboratory is housed at the University of Nevada, Reno. Because it is housed at the university, the rate-setting increase process unilaterally lives in the hands of the president of the university where it would be treated like any other university fee increase. That put the president of the university in the position of having to be the arbiter of deciding if it was time to raise fees, and then the president would have to listen to the ensuing dialogue between hospitals and payers about who was actually going to absorb that cost. That turned out to be a real barrier and is where I got involved. We need to have a standard process for doing this.

Assemblywoman Titus:
Getting back to where I was going with my actual question, you already had a process with a review committee. How often did that process take place? You were meeting quarterly. Was that part of your plan? You already had a process where the review committee meets and reviews the testing that is done? Is that correct?

Trudy Larson:
Our community advisory board meets quarterly, and has since bringing the program back to Nevada. We have experts on the board who help us understand what resources we have and do not have in the state. We were very deliberate before we ever went looking at adding a new test. With SCID, it had become a test that was more easily put into the laboratory. Secondly, we had something we could treat with and we had immunologists and hematologists who could actually do that. We voted on SCID probably two years ago. We received a grant and were able to implement it. Last year we heard a very long, wonderful educational program on the three conditions we do not test for yet, identifying that it is time now because we have specialists. Our committee voted last year to do this.

I started looking at raising fees three years ago. What Senator Ratti has referred to is, it has been extremely difficult to identify a good process that involves all the stakeholders who need to be at the table.

Assemblywoman Titus:
On a quarterly basis you meet and on the agenda each time there are new genetic testings that need to be considered. Is that always on the agenda?

Trudy Larson:
Yes.

Assemblywoman Titus:
I want to help you here because I want to make sure this gets reviewed on a routine basis. It sounds like you are already doing that. However, this is going to put in statute that you follow this particular recommendation, but it does not say you have to keep following it. In section 1, subsection 2, it says the testing "must include tests and examinations for each disorder recommended to be screened by the Health Resources and Services Administration of the United States Department of Health and Human Services by not later than 4 years after the recommendation is published."

I do not see anywhere in this bill that it has to be reviewed and updated on an annual basis, nor does it identify how often that publication comes out. Are they published once a decade or every quarter? How often do they review themselves? What I am going at is perhaps you need an additional line that says publications will be updated on a quarterly basis, so it is an automatic update. The bill says you have four years to do it once it is published. Is it every time it is published? How often will this mandate that we update? Perhaps committee counsel could help with that question.

Karly O'Krent, Committee Counsel:
The bill just specifies as it is published.

Assemblywoman Titus:
It does not say "every time" it is published, or is that inferred?

Karly O'Krent:
I believe the implication is each time it is published.

Assemblywoman Titus:
I just want to make sure you are covered for that. How often is it published?

Senator Ratti:
I appreciate your sincere efforts to make sure this is the best bill it can be. Very specifically, this bill is a mandate and the "shall" language is a mandate. The tests "shall" be done and Nevada "shall" do what is on the RUSP. I can defer to Dr. Larson, but I would say, looking at the research I have done, it is updated when HRSA has conditions that have made it to the point that they are ripe for putting on the RUSP. It is not necessarily a regular schedule. They meet regularly, but they do not make that recommendation even at the national level until it is ripe for a recommendation. It would be the job of the Board of Health as well as the State Public Health Laboratory to continue to monitor the RUSP. The way I read the bill, when a new condition comes up, it starts the time clock ticking. There are four years from the time of the date stamp of the condition to be added to the RUSP. That would give the state four years to conform with the mandate.

Assemblywoman Titus:
So the current wording in this bill would cover that when a new recommendation is published, whenever that is, it would mandate that we have four years to figure out whether we are going to use it or not.

Karly O'Krent:
That is correct.

Senator Ratti:
I certainly do not want to argue with committee counsel, but I want to make sure. It is not whether or not we are going to follow the recommendation. The bill mandates that we do follow the recommendation. It gives two exemptions, but those exemptions require either the head of the State Public Health Laboratory or the chief medical officer for the Department of Health and Human Services to go to the Board of Health and, in a public forum, ask for an exemption. It is not an easy out. They have to justify to the Board of Health why they may not want to meet that four-year time frame.

Assemblywoman Duran:
This is a bill that is really needed. What about midwives and people who do not necessarily go to a hospital or facility? Is this going to be mandated for them also?

Senator Ratti:
Yes. All births, no matter where they take place, follow the mandate. We were specifically concerned with midwives and some of the other non-facility births because their fee comes out of their provider rate. Their billing happens in a very different way and it literally comes out of their direct payment as a provider, which, I think, is another reason when we get to the public hearing, you will see some advocacy for pulling this rate out as a stand-alone rate so it can be handled directly on its cost and not be buried in the daily rate for a facility or having to come off the top of a provider rate for a nurse, midwife, or other similar type of practitioner.

Assemblywoman Duran:
As you receive the standardized testing from HRSA and as they add new testing, do any of the other conditions fall off the list, or does the list continue to grow?

Trudy Larson:
The list continues to grow. The conditions were put on the list because of a lot of evidence. There is no reason we would ever take them off the list because they do exactly what they are supposed to do. This is just adding. There will be technological advances so we will have some changes in how we test for some of these things, but the conditions will never fall off the list.

Chairwoman Cohen:
Seeing no further questions from the Committee, I will open the hearing for those wanting to testify in support of S.B. 291 in Las Vegas or Carson City.

Tom Clark, representing Nevada Association of Health Plans:
Many of the questions that were brought forward by Assemblyman Carrillo and others are the reasons why we support this bill. The predictive piece of this in section 1 regarding the four years allows the insurance companies to know what is coming down the road. If it is on the RUSP, in four years it could land as a Band-Aid for the insurance company to pay for these particular tests. Again, there is the advisory board at the state level that may decide it will not be added. That predictive process makes it a much more manageable process from

the insurance carrier's perspective rather than if every two years a new mandate shows up with a new test. We will know exactly where it is going to sit. If something does come up that is not on the RUSP, of course we will be in that public process. Having this bill passed and the reason we support it is because of the RUSP and the process.

Catherine M. O'Mara, Executive Director, Nevada State Medical Association:
We also wholeheartedly support this legislation. I do not often get to agree with Mr. Clark, so it is a rare day for me. We also agree that the process is elegant and well thought out. We agree with the approach of looking to federal standards and ensuring that Nevadans are given at least the benefit of those federal guidelines. Really, this is about giving our Nevada families a chance. It is about giving them an opportunity to benefit from early detection and intervention. It allows them to make the best choices for their families. It allows them to maximize the efficacy of available treatment and to maximize the quality of life for their loved ones. We wholeheartedly support this bill and thank the sponsor and the presenters for being here.

Chairwoman Cohen:
Seeing no further testimony in support, is there anyone present who would like to testify in opposition to the bill? [There was no one.] Is there anyone present who would like to testify as neutral to the bill? [There was no one.] Are there any final remarks? [There were none.] I will close the hearing on Senate Bill 291. I will open the hearing for Senate Bill 284 (1st Reprint).

Senate Bill 284 (1st Reprint): Creates the Advisory Task Force on HIV Exposure Modernization. (BDR S-742)

Senator David R. Parks, Senate District No. 7:
Senate Bill 284 (1st Reprint) seeks to make recommendations for revisions to existing statutes and regulations through the creation of an Advisory Task Force on HIV Exposure Modernization. This advisory task force would be akin to the Statewide AIDS Advisory Task Force created by former Governor Richard Bryan some 30 years ago in 1986, which continued in existence until 2016.

During the early years of the HIV and AIDS epidemics, states, including Nevada, implemented HIV-specific criminal exposure laws. These laws imposed criminal penalties on people living with HIV who knew their HIV status and potentially exposed others to HIV.

In 1990, the Ryan White CARE [Comprehensive AIDS Resources Emergency] Act, which provides states with funding for HIV/AIDS treatment and care, required every state receiving federal funds to certify that its criminal laws were adequate to prosecute any HIV-infected individual who knowingly exposed another person to HIV.

In our legal system, criminalization of potential HIV exposure is largely a matter of state law and not federal legislation. An analysis by the Centers for Disease Control and Prevention (CDC) and the U.S. Department of Justice found that a total of 67 laws explicitly focused on persons living with HIV had been enacted in 33 states. The majority of these laws were passed before antiretroviral therapies were developed that reduce HIV transmission risk to zero. In case you are not aware, it is possible to be an HIV positive individual and have no detectable presence of the AIDS virus.

As a person who has helped develop Nevada's HIV/AIDS statutes and regulations in the late '80s and early '90s, this is an issue that I personally wrestled with for the last three legislative sessions, but unfortunately got nowhere. Today, an informal coalition of health care professionals across the state has been working to address this issue and develop recommendations for consideration by the Legislature. Senate Bill 284 (1st Reprint) will create a task force of concerned individuals appointed by the Governor to address both the criminalization and stigma surrounding HIV and AIDS.

Since Senate Bill 284 was introduced, an amendment [No. 162] to the bill has been drafted and it can be found on the Nevada Electronic Legislative Information System. Most importantly, the amendment seeks to revise the summary on the bill. We would like for it to reference "modernization" and not "criminalization" since our efforts are directed toward statutes and regulations to deal with the disease as it impacts society today and not nearly 40 years ago.

With regards to the changes in the bill, what we are seeking to do is study and research the implementation and impact of such statutes and regulations to identify disparities in arrests, prosecutions, or convictions under such statutes and regulations; to evaluate current research with respect to HIV implications by these statutes and regulations; and identify court decisions enforcing or challenging these statutes and regulations.

With that, I will conclude my presentation. I would happy to try to answer any questions the Committee may have.

Chairwoman Cohen:
Just to be clear, when you mentioned the amendment, we are actually working off the first reprint and there has not been an amendment since that point. Is that correct?

Senator Parks:
Yes, we are working from the first reprint.

Chairwoman Cohen:
Are there any questions from the Committee?

Assemblyman Carrillo:
This is definitely a good thing. My question is regarding the task force. Section 1, subsection 2, paragraph (b) limits the task force to 15 members. How was that determined? Obviously, you want to have an odd number, but are there concerns about meeting a quorum if that is necessary for the task force? Sometimes getting 15 people together could be difficult.

Senator Parks:
I wrestled with that question and the number of members. I know there is somewhere in the range of 20 individuals who have expressed interest in addressing these issues. I felt that while it is less of a committee and more of a task force to develop recommendations, 15 members seemed to be a middle number that we could seemingly easily live with. There are tight time constraints placed on the task force, so we would be working under those constraints. I think a 15-person membership is certainly something that is doable.

Assemblyman Carrillo:
If there is an opportunity to be considered as a cosponsor on your bill, I would be appreciative.

Senator Parks:
I invite any and all individuals wishing to cosponsor on this bill.

Assemblywoman Titus:
Thank you for bringing this bill forward and being persistent with it. You have worked hard for many sessions on this kind of information. It is nice to see some things come together.

Back to the bill itself, and I know we are looking at the bill that has been amended, we do not want to criminalize the disease. We want to understand the process, who is exposed, how to treat folks, and where we go from here. You do list the roles of the task force but you do not recommend how often they are going the meet. At least I cannot see that in the bill. I know you mentioned the first meeting, but at the end it is going to disband after it reports back to the Governor and the Legislature during the 81st Session. Is that the intent of this task force or is it going to be ongoing?

Senator Parks:
The intent is to have a one-time shot with the possibility that the Legislature might want to reestablish the previous Statewide AIDS Advisory Task Force that was established under executive order but was subsequently made a legislative interim committee. As I indicated, it had appointees after the 2015 Session, but no meetings were called. In 2017, it was abandoned by the Legislative Counsel Bureau. What I would like to see happen is to give this a good opportunity of working out and making recommendations. Upon receipt of the report next September, the report would be the method by which we can amend statute and use that to change some of the laws.

As for the continuation of the task force, I would certainly welcome that. The important thing here is to hopefully reduce the stigma and change some of the laws. I believe the testimony I gave in the Senate was that Nevada has some of the more stringent statutes on the books. Those were all developed between 1986 and 1989 when the Legislature enacted them. I believe the Legislature enacted a second set of laws in the 1993 Session.

Assemblywoman Titus:
I really would like to see this succeed and bring back good information. Looking at the bill itself, it is going to be staffed by the Department of Health and Human Services. They are all on board, can provide the staffing necessary, and have the program. We would then look for funding for them to have the staff. Has that been clarified?

Senator Parks:
In the past, not only has the Department of Health and Human Services been involved, but we have always had involvement of the two major health districts in the state. I would envision that, as powers of appointees to this committee, there would be at least one appointee from all three of those organizations.

Assemblywoman Titus:
I want to make sure it succeeds by making sure we have a direction. It is pretty open-ended as far as how many times the task force will meet, where it will meet, or how it will meet. I guess if you are looking at having representatives from the different health districts, they could certainly meet via teleconferencing. I really like what you are trying to do. In section 1, subsection 10, you have provided specific issues, paragraphs (a) through (f). You are really trying to give them some direction in solving a problem. I really like that you have put it out there and are telling them what you want them to do, which is really important. I just want to make sure they have the tools to do that. The direction is clear. We as a Legislature can then choose to run with that. We do not know what will happen with the findings. We may need further information, but we will find out.

Assemblywoman Nguyen:
I appreciate this bill. I think it is a long time coming to modernize our understanding. I am curious if it is also your intention as part of this task force to communicate and keep open lines with the sentencing commission regarding some of the criminal statutes that are currently in place that may be affected by some of the information that comes out of this task force.

Senator Parks:
I envision that we would be reaching out as a task force to all interested parties in trying to get a good handle on what the problems are and how we can best address them.

Chairwoman Cohen:
I am wondering about the composition of the task force. I do not see anyone who is specifically in the medical field. Is that the intent or did it just happen?

Senator Parks:
We are not trying to rule anyone out. We definitely want those individuals who have day-to-day interaction with individuals with HIV and AIDS. People in the medical field would definitely be a necessary group of individuals, including all areas of health care and mental health care as well.

Chairwoman Cohen:
I am thinking it might need to be specifically spelled out that there will be a designated seat for mental health and one for health care in general.

Senator Parks:
There have been some informal discussions. There is currently a coalition of individuals, both north and south, and they have been communicating with each other. They represent the health districts, community advocates, and organizations like Aid for AIDS of Nevada and the Gay and Lesbian Community Center of Southern Nevada. I could go on, but there are a number of other organizations, including Planned Parenthood and the Human Rights Campaign.

Chairwoman Cohen:
Is there anyone else who is part of your presentation, or would you like me to move to support?

Senator Parks:
If you could just open it up to support, I think you will find that both here and in Las Vegas there are a number of individuals who would like to speak. Before I yield the microphone, I would like to add that the CDC has put together a program. It is a guide that says "Let's Stop HIV Together." That is a major portion of what we are trying to do. We enacted statutes back in 1989 that really caused a larger degree of stigma. This addresses both the issues of stigma and discrimination.

Chairwoman Cohen:
It is certainly still a concern today. As we know, we have heard some national public figures make comments about whether certain events are punishment for people's orientation, and they still group HIV and AIDS in with that as well. I will open the hearing for those in support in Las Vegas and Carson City.

André C. Wade, State Director, Silver State Equality:
Silver State Equality is a Nevada-based, statewide LGBTQ [lesbian, gay, bisexual, transgender, queer] civil rights program affiliated with and supported and managed by Equality California and Equality California Institute. Silver State Equality brings the voices of LGBTQ people and allies to institutions of power in Nevada and across the United States striving to create a world that is healthy, just, and fully equal for LGBTQ people.

I am here today in support of S.B. 284 (R1) which has the goal of creating an advisory task force on HIV exposure and criminalization. HIV criminalization is a term used to describe statutes that either criminalize legal conduct or that increase penalties for illegal conduct based on a person's HIV-positive status. In Nevada, it is a category B felony punishable by 2 to 10 years in prison and a fine of up to $10,000 for a person living with HIV who knows their status to intentionally engage in conduct that is intended or likely to transmit the disease to another person. Neither the intent to expose and alert to HIV nor actual transmission is a required element of the crime. Accordingly, conduct likely to transmit HIV is not defined.

For too long, states have kept outdated and antiquated laws on the books that stigmatize those living with HIV. Much has changed in the area of research and medical advancements regarding HIV that need to be taken into consideration when modernizing laws around HIV.

There is no evidence that laws targeting people living with HIV for criminal penalties actually reduces the number of new cases of HIV or improves public health in any way. In fact, research suggests that such laws may be a disincentive to testing and disclosure of one's HIV status and a barrier to seeking care for people living with HIV. In addition, these laws may give HIV-negative people a false sense of security with respect to the health of their sexual partners, thereby encouraging riskier behaviors and more sexually transmitted infections.

Undoubtedly, these laws further isolate and increase stigma toward people living with HIV, which are known to be significant drivers of the HIV/AIDS epidemic by discouraging people from seeking care and treatment that could prevent transmission. By reducing HIV-related stigma and potential criminal consequences for knowing and sharing one's HIV-positive status, HIV law modernization encourages HIV testing, treatment, and disclosure to sexual partners.

To be effective, the task force should be composed of no more than 15 members to be manageable, while ensuring that most members are those living with HIV, people affected by HIV/AIDS, and/or people from occupations, organizations, or communities who are more broadly affected or at risk of being affected by current statutes and regulations. Additionally, the task force should solicit, in part, input from nongovernmental persons and agencies with expertise in matters relevant to the duties of the task force.

The responsibility of the advisory task force should not be to make recommendations but to focus on identifying and reviewing current statutes and impact disparities in arrests, prosecutions, or convictions. Also, the advisory task force would evaluate current medical and scientific research, identify court decisions, and assess developments in other states.

We support the use of the word "modernization" instead of "criminalization" to not further stigmatize those living with HIV.

Thank you for allowing me the opportunity to testify in support of this crucial legislation. Additionally, I would like to thank Assemblymen Thompson, Carlton, and Spiegel, and of course Senator Parks, for their leadership on this matter to destigmatize and modernize HIV laws.

Briana Escamilla, Nevada State Director, Human Rights Campaign:
We represent about 15,000 members and supporters across the state of Nevada. We support this bill.

Sherrie Scaffidi, Director and Advocate, Transgender Allies Group, Reno, Nevada:
Thank you for giving me the opportunity to testify today in favor of S.B. 284 (R1). As this bill points out, there is good empirical evidence that laws against HIV exposure do not reduce risk-taking sexual behavior, and so do not reduce the spread of HIV. They do deter people from getting tested, which makes the spread of the disease more likely. When people living with HIV are in care with HIV levels at an undetectable level due to adherence to HIV medication treatment and achieve undetectable viral levels for six months and ongoing, they will not transmit HIV sexually. Those individuals with other sexually transmitted diseases do not face the same stigma or criminalization as those with undetectable viral levels. These people should not be discriminated against simply because they have HIV.

Studies support the modernization of language to end the stigma. Stigma is the significant driver of the HIV epidemic. People living with HIV are reluctant to get tested and receive other critical sexual health services because of the stigma attached to those living with HIV. Modernization of laws related to HIV exposure and criminalization should significantly reduce this stigma. By doing so, people may be less reluctant to get tested and receive the medical help and care they need. I respectfully request that you pass S.B. 284 (R1). [Written testimony was also submitted (Exhibit G).]

Joelle Gutman, Government Affairs Liaison, Washoe County Health District:
We are here today to support S.B. 284 (R1). We want to thank the bill sponsor for bringing this forward. The Washoe County Health District has been involved in the coalition for many years. This task force provides an opportunity to engage with communities who experience discrimination, stigma, and barriers to health care while living with HIV. Please support this bill.

John J. Piro, Deputy Public Defender, Legislative Liaison, Office of the Public Defender, Clark County:
I would like to thank Senator Parks and the other sponsors for bringing this important piece of legislation forward. For those who do not often see us in the Assembly Committee on Judiciary, research and data are the things we harp on the most as public defenders. I think this bill will place research and data before this legislative body in the future to inform policy going forward. It is a good thing to go back and look at the stigmas and the mistakes we have made in the past and modernize our laws to conform to what is really going on in today's society. I urge your support of this legislation.

Antioco Carrillo, Executive Director, Aid for AIDS of Nevada:
Aid for AIDS of Nevada is the oldest and largest AIDS service organization in the state. We are here in support of the bill. Obviously, we have seen some of the struggles that our clients have experienced over the last several years. Since our focus is to ensure that our clients get medication, adhere to medication, and live happy and productive lives to the best of their ability, oftentimes we see it as a challenge for us to deal with the criminal justice system.

The current laws we have are not congruent with what we are trying to accomplish, which is eradicate HIV/AIDS. Everyone has talked about the fact that if people adhere to medication, they can reduce the risk of transmission to a minimum. Part of what needs to happen in order for us to implement additional prevention programs is to ensure that the laws that we have in the state are at a par with the research we have, specifically as it relates to HIV treatment and reduction of viral load and reduction of transmission.

We strongly support this bill. I am one of the people who have been working in the committee that Senator Parks mentioned during his presentation.

Kendra G. Bertschy, Deputy Public Defender, Washoe County Public Defender's Office:
I also want to thank Senator Parks for bringing this legislation forward. As Mr. Piro indicated, we have a lack of data on most of our laws in Nevada. We believe this would provide the additional information with Nevada-specific evidence and data that would allow us to make sure our laws are congruent with what they are supposed to do.

Michael Hackett, representing Nevada Public Health Association:
We want to be on record in support of this bill. We also appreciate the comments you made, Madam Chairwoman, regarding including health care providers as part of this task force.

Chairwoman Cohen:
Is there any further testimony in support? [There was none.] Is there anyone present who would like to testify in opposition to the bill, either in Las Vegas or Carson City? [There was no one.] Is there anyone present who would like to testify as neutral to the bill? [There was no one.]

Margot Chappel, Deputy Administrator, Regulatory and Planning Services, Division of Public and Behavioral Health, Department of Health and Human Services:
I just want to address Assemblywoman Titus' question. The Division of Public and Behavioral Health, Department of Health and Human Services is prepared to support the work of the task force.

Chairwoman Cohen:
Seeing no further testimony in neutral, are there any closing remarks?

Senator Parks:
I want to follow up on the fiscal notes on this bill. The Division of Public and Behavioral Health did submit a fiscal note indicating the cost would be zero. Thank you for hearing the bill. I envision that in bringing this forward, the people who would be making the recommendations and serving on the committee would be those people who everyday roll up their sleeves and try to address the issue of HIV and AIDS in the community and are part of the medical establishment. There is nothing saying that individuals cannot be active and involved in the process even though they are not appointed to the committee. My expectation is that while it will be up to 15 individuals appointed, there will be far more individuals who will want to participate and be instrumental in bringing forward some recommendations.

[Written testimony in support of Senate Bill 284 (1st Reprint) was also submitted but not discussed (Exhibit H).]

Chairwoman Cohen:
I will close the hearing on Senate Bill 284 (1st Reprint). I will open the hearing on Senate Bill 364.

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

Senator David R. Parks, Senate District No. 7:
Senate Bill 364 makes revisions to statutes prohibiting discrimination against and provides protections for persons who reside in or receive services from certain health care facilities. Senate Bill 364 relates to the protection of vulnerable persons. It prohibits a medical facility, facility for the dependent, and certain other facilities from engaging in certain discriminatory actions, requiring such facilities to take certain measures to protect the privacy of persons receiving care from the facility, and requiring administrators and employees of such facilities to receive certain training.

Joining me today at the table is Brooke Maylath, the president of Transgender Allies Group, and Sherrie Scaffidi is joining her. With your permission, I would like to pass the microphone to these ladies.

Brooke Maylath, President and Advocate, Transgender Allies Group, Reno, Nevada:
[Ms. Maylath speaks from (Exhibit I).] I would like to begin by sharing a bit of personal background. I served for several years as an emergency medical technician in the Midwest and several eastern cities. When a person was in need of emergency care, the thought of treating that patient with anything less than affirming compassion was simply unthinkable. I have seen things that no human being should ever have to see, and I have experienced things that are beyond your imagination, I guarantee.

More recently, I have been employed as a strategist and business development consultant for hospitals, both throughout Nevada and across the United States. That has provided much more insight as to our overall health care delivery system and the internal and external forces that can come to bear on an individual patient.

Under the [Patient Protection and] Affordable Care Act (ACA), section 1557, the nondiscrimination clause, explicitly called out civil rights protections for all persons, including LGBTQ+ people [lesbian, gay, bisexual, transgender, queer], for any facility that accepts federal funds such as Medicare and Medicaid. Unfortunately, the current administration has made the decision to deny hearings of any civil rights complaints for LGBTQ persons. Upholding the tenets of the ACA has been effectively left to the states.

For that reason, we propose to add specific nondiscrimination language to the licensing of health care facilities in Nevada. My examination of the existing licensing chapter revealed that comprehensive language already exists for the licensing of psychiatric hospitals. This legislation already has Nevada-specific precedent.

The mission of Transgender Allies Group (TAG) has been to educate and advocate for persons of diverse genders. We have been active for the past six years providing education at the University of Nevada, Reno School of Medicine and continuing education to providers in the community through the Sanford Center for Aging, Project Echo, Nevada Coalition to End Domestic and Sexual Violence, Immunize Nevada, Nevada Cancer Coalition, and our own annual open house and educational events. We have brought in local and national experts covering cultural awareness, endocrinology, behavioral health, suicide prevention, facial feminization surgery, genital surgery, and more. We are currently engaged with Renown Health developing a systemwide transgender inclusive policy that includes electronic health record updates, clinical education, and top to bottom cultural awareness education.

Essentially, TAG has worked diligently to bring awareness to the issues that this law addresses. However, for years, LGBTQ patients have been met with an aversion by many medical professionals.

I would like to refer you to the statistics provided in our supporting documents that I dropped off—and I am sure you have all had a chance to memorize them before today—that gives an example of generic model policies for all types of different facilities, as well as some of the anecdotes and issues that individuals have experienced. This type of discrimination also leads to an avoidance of accessing any health care services, leading to a diminished quality of life. I would like to turn the microphone over to Sherrie Scaffidi, who can illustrate some of the examples of what those numbers mean on an individual basis.

Sherrie Scaffidi, Director and Advocate, Transgender Allies Group, Reno, Nevada:
[Ms. Scaffidi speaks from (Exhibit I).] When Jakob Rumble presented at the emergency room of Fairview Southdale Hospital [June 2013, in Edina, Minnesota], he was in severe genital pain and running a fever. At check-in, Jakob explained he was a trans-man, though his driver's permit still identified him as female. The clerk eventually found his records on file and checked him as female. Jakob and his mother endured a wait of four and a half to five hours before a doctor arrived to examine him. The doctor began with aggressive questions, such as, "Who are you having sex with?" The examination included the doctor repeatedly jabbing Jakob's genitals with his fingers until Jakob was screaming in pain for him to stop. Jakob was admitted to the hospital for six days to fight a severe infection, while undergoing mistreatment at the hands of physicians and staff. To this day, Jakob is reluctant to see a doctor or to be in an examination room alone with a health care provider. You can read further details in the document *Rumble v. Fairview Health Services, et al* [No. 14-cv-2037 (SRN/FLN) (D. Minn. Mar. 16, 2015)] that has been submitted to the Committee. [Information referred to was not submitted as an exhibit.]

This next example is from Columbia, South Carolina, from the document *LGBT Older Adults in Long-Term Care Facilities* [Co-authored by National Senior Citizens Law Center; National Gay and Lesbian Task Force; Services and Advocacy for GLBT Elders; Lambda Legal; National Center for Lesbian Rights; and National Center for Transgender Equality] that has been submitted to the Committee. [Information referred to was not submitted as an exhibit.] A patient writes:

> I went for nine days without heart medicine during a rehabilitation stay in a nursing home. For 17 days, I received another inappropriate medication. Even though I had been out for many years, I was so dependent on the nurses that I became afraid. It took all the courage I could muster up to keep pushing the staff to solve the problem.

Previously in this Committee, we have referred to Cassie, a trans-woman who suffered a gunshot wound in a random hate attack. To refresh, when admitted to a rehabilitation facility in North Las Vegas, she was subjected to ridicule, misgendering, staff's refusal to use her preferred name, as well as the withholding of medications and prescribed treatments.

No person deserves to be mistreated by a health care adviser. Nevada must strive to do better than these examples. There are approximately 109,000 LGBTQ+ voters in this state who need to know they will be treated with dignity and respect when they are in need of health care services. [Written testimony was also submitted (Exhibit I).]

Brooke Maylath:
To elaborate just a little more on the story of Cassie, she was a victim of a hate crime. An individual who was walking past a club in Las Vegas unleashed several rounds of 9 millimeter ammunition striking her in the ankle. Her immediate wound was treated and she was transferred to the rehabilitation facility where they refused to treat her as she needed to be treated. By that, I mean avoiding simple human dignity like using her preferred name and preferred pronouns. In addition to withholding medications and other rehabilitation treatments, they refused to change the sheets on her bed, they refused to dress her wound, and they would throw the bandages at her so she could treat her own wounds because they did not want to touch a transgender woman. That is unacceptable.

We seek health care to be treated and to regain health, not to be tortured. This nondiscrimination clause is comprehensive for every marginalized community because no one, whether they are transgender, gay, black, Hindu, Muslim, needs to be punished when they are ill or injured. [Ms. Maylath continued speaking from (Exhibit I).]

Senate Bill 364 (1st Reprint) takes the nondiscrimination concepts that are within the ACA and clearly states that a licensed health care facility in this state must comply with inclusive policies, training, and treatment for any patient they encounter. This comprehensive nondiscrimination has been in place for psychiatric facilities for several years, and it has worked. It needs to be extended to all health care facilities.

I also wish to address what this bill does not do. It does not require any facility to perform a procedure they do not already perform. It does not hold any individual liable. It does not force a belief on anyone. The bill simply mandates that every person treated in a health care facility be treated with dignity and respect, in a manner that promotes healing and comfort.

We have included several model policies to this Committee that facilities can freely access so they can be compliant to this bill with minimal effort. We encourage their success. Education and training are already available from multiple sources with more currently in development. Most of those things can actually be accessed on our website, transgenderalliesgroup.org. The links can be found to other sources and other national organizations that provide this kind of cultural awareness.

We are currently in the twenty-first century. We need to treat all people with respect. Please pass this bill.

Chairwoman Cohen:
Are there any questions from the Committee?

Assemblyman Thompson:
It is really sad that it is 2019 and we have to have such a bill. Is this just a matter of posting statements in the workplace? I do not see any specified training in the bill.

Brooke Maylath:
There is an educational component in the bill. It does hold the employees accountable through the facility to be able to uphold that training and the cultural sensitivity under section 6, subsection 1, paragraph (e).

Assemblyman Thompson:
It prescribes required training by regulations, but does that actually add the action of implementing and facilitating the training?

Brooke Maylath:
With any of these organizations and any facilities, there is ongoing continuing education that is mandated by the medical providers. There is also training that is necessary within each facility. Those types of facility trainings that usually accompany new hires, but also include continuing education, is critical to any organization's success. Many of those trainings typically talk about what is done with policies for evacuation in case of emergency; what is the role in biohazards; what is the role in being able to follow Health Insurance Portability and Accountability Act regulations; who has the appropriate access to a patient and who does not. All of these different issues could include the cultural awareness training. As I said, this resource is available online for free. It is downloadable, is easy to access, and is another component that desperately needs to be added to the ongoing education. It does not really take up any more time than is already being used on how to deliver quality patient care.

Marsheilah Lyons, Committee Policy Analyst:
I am just following the questioning and looking at section 7 of the bill [lines 2-3], which states, "The Division may deny an application for a license or may suspend or revoke any license issued" if the requirements of the bill are not met. I believe that is addressing part of Assemblyman Thompson's question.

Assemblyman Thompson:
What I am trying to get at is we have had bills on suicide training and it has specified the hours of training required. I know it says "in regulation." Would you not want it to be in the law that a specified number of hours needs to occur so you can create some uniformity across the state? I have a feeling you are going to get people who go at the lowest level possible and then, at the end of the day, have you really accomplished what you are trying to accomplish? We do not want people to just check a box. We want people to understand that this is an additional tool on how they can better do their work and approach people.

Karly O'Krent, Committee Counsel:
In addition to what Ms. Lyons suggested regarding section 7 of S.B. 364, section 6, subsection 1, paragraph (e) of the bill requires the board to adopt regulations that prescribe the required training. These facilities would then be required to comply with the regulations that are adopted by the State Board of Health, Department of Health and Human Services (DHHS), pursuant to that provision.

Brooke Maylath:
As far as the length of time required for training, I have found from doing these trainings that the time can vary depending upon the familiarity of the audience. Frankly, when teaching, younger people are much easier to reach about the concepts of gender fluidity, same sex relationships, and where our society has grown. We do not necessarily need to go into some of the basics and we can get a good competent understanding of cultural awareness in 30 minutes or so.

With other people who tend to be older, more isolated, and have more of a fixed view on a gender binary and a heterosexual normativity, we see that it takes longer, maybe an hour or an hour and a half, to gain that thorough understanding. To be able to place an arbitrary time, it is definitely something for consideration. I do not want to rule it out, but I also want to be sensitive to where we need to get to and grow and where there is an understanding that people are people, and when they are a patient, they need healing. What does torture look like, and what does healing look like. Often, it just comes down to kindness, compassion, and dignity. Many of those things we can work into an educational awareness, especially within a facility where they can adopt, create, and embrace that weaves through their scope of training in ways that bring it to life and is not a separate component.

This is not just about cultural awareness for transgender people, gay people, or lesbian people. This is about a cultural awareness that promotes healing. I would hope that all of these facilities are going to be able to look at the larger view rather than have to go through a mandatory training about people they think they will never see or they do not have to worry about. The following week, they may just get a patient like that and they are going to be caught unaware. It is about the adaptivity. We can look at a specific time length, but I would want to look at that very carefully with a lot of input before we were to jump to that conclusion at this point.

Assemblyman Carrillo:
My question is regarding section 2, subsection 4, paragraph (a), which states, "Notice that a person who has experienced prohibited discrimination may file a complaint with the Office of the State Long-Term Care Ombudsman." I was looking at the statute under *Nevada Revised Statutes* (NRS) 427A.125. When individuals have complaints, is this the agency they go to? If I was mistreated in the hospital, would I be looking at the long-term care ombudsman to file a complaint? I am trying to see where this is going and if they would be

talking to the right person. After looking at the statute, the ombudsman even develops a course of training to be made available to officers, directors, and employees of the facility. Are we talking to the right people regarding this, and will it make things happen or fall on deaf ears? Because the Legislature only meets every two years, I think this is something we want to make sure does not fall on deaf ears.

Brooke Maylath:
This is the suggested methodology, expanding the role of the long-term care ombudsman. Several of the facilities that this bill covers are going to be long-term care facilities, skilled nursing facilities, rehabilitation facilities, et cetera, who are already covered within the long-term care ombudsman role. Expanding the statute for ambulatory surgical centers, hospitals, and the other places this bill would cover is expanding the role of the ombudsman, who is then linked in the reporting structure to be able to get that information through the chain of command at DHHS to the health care inspectors. If there is a complaint, the inspectors have the ability to investigate and confirm there really is an issue. We all know there are times when people raise a complaint that may or may not be completely founded. If there is a legitimate complaint where we want to apply the rule of law as stated in the bill, we want to make sure it is thoroughly investigated and that there are appropriate remediation attempts to correct whatever has not gone right. Only in the absolute drastic case of a refusal would there be any threat to a license. We want people to succeed.

In the case of Cassie, as an example, that case did not go through the long-term care ombudsman, it went directly to inspectors and others in the hierarchy of DHHS, which is a good thing because it circumvented a lot of time. I think it is very important to put this into a regular process that is posted for all people to access if they do not feel they are being treated appropriately in a licensed medical facility. We need to be able to uphold the requirements and standards as a state and as a licensing authority, for ourselves individually, and for other citizens.

Assemblyman Carrillo:
As I read further into NRS Chapter 449, I can see how that brings together what you just described. This is actually a question for Senator Parks. This is some great legislation, and I would be honored to be accepted and added as a cosponsor on this bill as well.

Senator Parks:
I would invite anyone and everyone who wishes to be included to add their name. The Legislative Counsel's Digest states:

> Existing law creates the Office of the State Long-Term Care Ombudsman within the Aging and Disability Services Division of the Department of Health and Human Services to advocate for the protection of residents of facilities for long-term care and authorizes the Ombudsman to investigate complaints concerning such facilities.

It also gives several NRS citations.

Chairwoman Cohen:
I am happy to hear that Cassie stood up for herself and sought what we hope to provide in the state to ensure no one else has to go through what she did.

Assemblywoman Krasner:
It sounds like this bill is definitely necessary. I have a question about section 6 and the regulations that prescribe required training for administrators and employees of the medical facilities. I know you talked a little bit about it. Are you thinking the training would occur upon hiring? Medical providers can take continuing education, but they can choose what training they want to take. Would this be one of the choices to fulfill the hours they need? I know other professions this session have indicated they are already receiving so much training and do not want us to give them more unless they are going to be paid for it. What are your thoughts on that?

Brooke Maylath:
As I indicated, we do have ongoing continuing education pieces for doctors and other providers that have traditionally been free of charge. However, we also make sure they are able to fulfill the component for medical ethics. Medical ethics is a required annual piece of continuing education for physicians. We are not adding anything new, but we are making sure that what we are doing in cultural awareness is an ethical approach to cultural awareness in providing for patients. We can hit two birds with one stone with what is already mandatory without requiring anything extra. That is one piece that I think is very important.

Traditionally, when a new hire comes on, they have to go through an orientation and training. At a hospital, it is usually at least one full day. That is the cost of doing business. With ongoing education, there can be other outreach within the facilities in team or shift meetings that are currently normal within the operating scope of a facility when new changes come about, whether it is in billing status, infectious control, or other medical changes in protocol that need to be rolled out. These are common occurrences within a medical facility, so incorporating this is within the culture of health care facilities already. It is not burdening them with anything additional.

If anything, what this kind of education would do is minimize risk for the employees and the facility by giving them a broader scope of how to treat patients to avoid any harm that may come to a patient and, therefore, bring harm or threat to the facility. This can be looked at as a wise investment on risk control. As I said, this is a normal part of health care culture.

Assemblywoman Titus:
I certainly hear your concerns. I do need some clarification in section 2. You outline what a medical facility may or may not do based on color, religion, sexual orientation, gender identity, expression, HIV, et cetera. I certainly understand how important that is. However, section 2, subsection 2, states: "Prohibited discrimination pursuant to subsection 1 includes, without limitation . . . (b) Denying a request by persons to share a room. . . . (d) Restricting a person from associating with other persons, including, without limitations, engaging in consensual sexual relations."

I am the director of a long-term care unit in a very small hospital with 40-plus beds in long-term care and 8 beds acute. As a doctor for over 39 years, I have had couples who actually ended up in the hospital together, especially in the long-term care wing. One was there for pneumonia and the other fell and broke a hip. The husband wanted the wife in his room, but the wife said no. She was afraid she would end up taking care of him and did not want to be in the room with him. We did not put them in the same room, although he wanted that to happen.

I need some clarification because the facility has to make decisions based on the individual patient's best care. If we do that based on that reason, the only thing this would demand of us, I could not make that decision based on gender identity or race, but I could for medical reasons. I just want to make sure I am not restricted to making a health care decision when one patient wants one thing and the other patient wants another, based on this law, which would be in effect for all medical facilities. I need some clarification that it still allows me, as a physician, to make medical choices based on the disease process and not put us all in a corner where we do not want to be. Could you clarify that please?

Brooke Maylath:
The last thing we would ever want to do is confine what a doctor wants to do based on their experience and education in terms of medical necessity. Medical necessity is the primary decider for anything that we want a doctor to be able to do for us. Looking out for the individual patient's best interest always comes to mind. I would suggest that a scenario this would apply to is in a nursing home with two married gay men. If they choose to share a room, and the facility has no reason to deny them the same room if they are both willing, and if they do engage in an intimate action, the facility has no place to say they cannot do that, especially if there is a history of allowing a man and woman in a heterosexual relationship to be able to share the same room if patient care warrants. The same thing would be applied to a nonheterosexual couple in the same parameters. That is what the bill is saying; it would not take away your ability to make a decision as a physician. In absolutely no way would we want anything in this bill to restrict what you need to do to serve your patients in your best interests.

Chairwoman Cohen:
I had the same concern. I thought of someone in traction to whom the doctor said, "None of that," just because of the physical condition they were in. Some people do not want to listen to their doctor, so that was a concern.

Assemblyman Hafen:
I have a question in section 2 regarding some of the prohibited discriminations. I know this is probably going to sound really odd, but "restricting a person from . . . consensual sexual relations"—are we saying that a medical facility has to allow people to have consensual sexual relations in the facility or are we just trying to say we cannot discriminate based on sexual orientation?

Brooke Maylath:
We are saying we cannot discriminate based on sexual orientation. If you are prohibiting intimate relationships between anyone in the facility—which most facilities do not have anything written down about unless it is something that would endanger a patient's health—then that same nonrestriction must apply to other couples. That is all the bill says—we need to be treated equally. Nothing special, just equally.

Assemblyman Hafen:
Perhaps legal could help me with this. The way it is written, I think it is restricting the medical facility.

Karly O'Krent:
Section 2, subsection 5 of the bill states: "The provisions of this section shall not be construed to . . . (b) prohibit a medical facility . . . from adopting a policy that is applied uniformly and in a nondiscriminatory manner, including, without limitation, such a policy that bans or restricts sexual relations."

[Assemblyman Carrillo assumed the Chair.]

Vice Chairman Carrillo:
Are there any further questions from the Committee? [There were none.] I will open the hearing for those in support of S.B. 364 in Las Vegas and Carson City.

Briana Escamilla, Nevada State Director, Human Rights Campaign:
We are in support of S.B. 364 and would like to thank Senator Parks for bringing this forward, and Ms. Maylath and Ms. Scaffidi with TAG for all their work on this. We think it is very important. No one should face discrimination when they are seeking medical treatment.

Zachary Kenney-Sontiwun, Legislative Intern, Human Rights Campaign:
I am echoing the support. To shed some more light on the issue, according to the National Center for Transgender Equality, in 2015, 1 in 4 transgender individuals reported avoiding seeking health care because of some kind of mistreatment or discrimination, or the fear of mistreatment or discrimination. Nearly one-third reported negative experiences with various medical providers. Adopting this bill is definitely supported by the facts and will go a long way to not only making these facilities more receptive in practice to members of the LGBT community, but also alleviating some of that fear and encouraging more LGBT people to seek out health care which they do not have access to at a disparaging rate to other individuals.

Thank you to Senator Parks for bringing this bill, and thank you for listening.

[Assemblywoman Cohen reassumed the Chair.]

Chairwoman Cohen:
We will continue testimony in support of the bill for those in Carson City.

Vivian Leal, Team Leader, Indivisible Nevada:
I am part of the leadership team of Indivisible Northern Nevada. I am also the health care lead of Indivisible Northern Nevada. We want to express our support for this bill. We think it addresses a blind spot for when all human beings become vulnerable, in a sense, to their caregivers. We focus on having everyone treated equally—as Ms. Maylath so eloquently put it—regarding gender identity issues. This bill would apply to all other sorts of categories, whether it be religious or political. I know I have often thought about this as I age, and having gone through that process with my parents, and especially my grandmother in the way she wanted to be addressed at the care facility. They wanted to "honey" her. That was completely insulting and demeaning to her. It begins very easily and nonmaliciously, but it pervades everything. When evaluating the options as we go forward, Indivisible always stands with everyone being treated equally, especially when they are vulnerable. We are in full support. We hope you pass this bill and make the changes needed to express what the training requirements are.

Chairwoman Cohen:
Seeing no further testimony in support, is there anyone who would like to testify in opposition, either in Las Vegas or Carson City?

James L. Wadhams, representing Nevada Hospital Association:
Although we appear opposed, I would appreciate it if we could have the opportunity to visit with the sponsor to try to assuage any concerns on the medical privacy of this issue. The principal expressed by the proponents is certainly laudable, and that is not our concern, but making sure the opportunity and the need for the medical facility to protect the medical needs is paramount. If we could have the opportunity to work with the sponsor and address those issues and concerns, we would appreciate it very much.

Assemblywoman Cohen:
I am sure Senator Parks would be happy to meet with you. Seeing no further opposition, is there anyone present who would like to testify as neutral? [There was no one.] Are there any concluding remarks?

Senator Parks:
I would like to thank you for giving this bill a hearing. As was indicated, most of this language appears in other portions of state statutes. We just want it extended to our general care facilities, rehabilitation facilities, and the like.

Brooke Maylath:
We value being able to meet with concerned parties. However, I will also suggest that before we meet, they review the Joint Commission model policies for inclusive policy. The Joint Commission, for those of you who may not be familiar with it, is the primary credentialing organization across the country for hospitals. I believe all of the hospitals in Nevada are credentialed through the Joint Commission. That document is to specifically help hospitals navigate that interface between their policy and medical necessity.

I thank the Committee for listening to us and seriously considering the needs and the background of this bill and how it can positively impact our lives in the future.

Chairwoman Cohen:
I will close the hearing on Senate Bill 364. Is there anyone here for public comment, either in Las Vegas or Carson City? [There was no one.]

This meeting is adjourned [at 3:18 p.m.].

RESPECTFULLY SUBMITTED:

Christian Thauer
Recording Secretary

Lori McCleary
Transcribing Secretary

APPROVED BY:

Assemblywoman Lesley E. Cohen, Chairwoman

DATE: ______________________________

EXHIBITS

Exhibit A is the Agenda.

Exhibit B is the Attendance Roster.

Exhibit C is a document titled "Recommended Uniform Screening Panel Core Conditions (As of July 2018)," presented by Senator Julia Ratti, Senate District No. 13, in relation to Senate Bill 291.

Exhibit D is a document titled "Recommended Universal Screening Panel (RUSP) For Newborn Screening, regarding Senate Bill 291, presented by Trudy A. Larson, M.D., Dean, School of Community Health Sciences, University of Nevada, Reno.

Exhibit E is a pie chart titled "Identified Newborn Disorders July 2014-July 2018," obtained from the Nevada State Public Health Laboratory, Newborn Screening Advisory Committee meeting, August, 2019, presented by Trudy A. Larson, M.D., Dean, School of Community Health Sciences, University of Nevada, Reno, in relation to Senate Bill 291.

Exhibit F is written testimony in support of Senate Bill 291, presented by Trudy A. Larson, M.D., Dean, School of Community Health Sciences, University of Nevada, Reno.

Exhibit G is written testimony dated April 24, 2019, in support of Senate Bill 364 (1st Reprint), presented by Sherrie Scaffidi, Member, Transgender Allies Group, Reno, Nevada.

Exhibit H is written testimony in support of Senate Bill 284 (1st Reprint), submitted by Elisa Cafferata on behalf of Planned Parenthood.

Exhibit I is written testimony dated April 24, 2019, in support of Senate Bill 364, presented by Brooke Maylath, President and Advocate, Transgender Allies Group, and Sherrie Scaffidi, Director and Advocate, Transgender Allies Group, Reno, Nevada.