MINUTES OF THE
SENATE COMMITTEE ON HEALTH AND HUMAN SERVICES

Eighty-second Session
May 2, 2023

The Senate Committee on Health and Human Services was called to order by Chair Fabian Doñate at 3:33 p.m. on Tuesday, May 2, 2023, in Room 2134 of the Legislative Building, Carson City, Nevada. The meeting was videoconferenced to Room 4412 of the Grant Sawyer State Office Building, 555 East Washington Avenue, Las Vegas, Nevada. Exhibit A is the Agenda. Exhibit B is the Attendance Roster. All exhibits are available and on file in the Research Library of the Legislative Counsel Bureau.

COMMITTEE MEMBERS PRESENT:

Senator Fabian Doñate, Chair
Senator Rochelle T. Nguyen, Vice Chair
Senator Roberta Lange
Senator Robin L. Titus
Senator Jeff Stone

GUEST LEGISLATORS PRESENT:

Assemblywoman Tracy Brown-May, Assembly District No. 42
Assemblywoman Selena Torres, Assembly District No. 3

STAFF MEMBERS PRESENT:

Destini Cooper, Policy Analyst
Eric Robbins, Counsel
Mary Ashley, Committee Secretary

OTHERS PRESENT:

Teresa Hayes, Health Program Manager, Division of Public and Behavioral Health, Nevada Department of Health and Human Services
Lauren Chapple-Love, Ph.D.
Sandra Leon-Villa, Ph.D.
Pat Kelly, Nevada Hospital Association
Cody Hoskins, Service Employees International Union 1107
Sheila Bray, University of Nevada, Reno

Blayne Osborn, Nevada Rural Hospital Partners
Deanna Hua Tran, Nevada Immigrant Coalition
Steve Messinger, Nevada Primary Care Association
Constance McMullen, Personal Care Association of Nevada
Diana Rovetti
Jack Rovetti
Catherine Nielsen, Executive Director, Nevada Governor's Council on Developmental Disabilities
Alysa Marquez, Intern, Nevada Governor's Council on Developmental Disabilities
Ellen Marquez, Self-Advocacy Coordinator, Nevada Governor's Council on Developmental Disabilities
Mary Bryant
Mary Pierczynski, State of Nevada Association of Providers
Lisa Holmquist, CEO, Founder, Down Syndrome Connections
Conor Slife

CHAIR DOÑATE:
We will open today's meeting with Assembly Bill (A.B.) 40.

ASSEMBLY BILL 40 (1st Reprint): Revises provisions related to inspections of food establishments. (BDR 40-223)

TERESA HAYES (Health Program Manager, Division of Public and Behavioral Health, Nevada Department of Health and Human Services):
We are the agency charged with implementing changes to *Nevada Revised Statutes* 446. I would like to provide you with a short description of A.B. 40. It requires an applicant for a permit to operate a food establishment to provide an email address for purposes of communicating certain notices. An email address will allow us to provide notices in an electronic format rather than a hard copy.

Our purpose is to be responsive to businesses. Paper-based inspections may result in delays for submitting inspection information to the operator who can promptly make necessary changes. Paper forms may be lost or damaged, leading to delays in the resolution of observed hazards. Also, corporate headquarters may be in another state or country.

The requested change will not prohibit us from providing a printed copy to the operator upon request. Official documents regarding enforcement accidents, such as suspension of a permit, will still be submitted on paper and could be hand-delivered to the permit holder or the person in charge. As an alternative, the document could be delivered by registered or certified mail.

The Nevada Department of Health and Human Services (DHHS) has had multiple requests from industry leaders to institute this change. Digital inspection reports allow field inspectors to upload their reports and allow operators to obtain results on the same days of the inspections. Immediate access results in faster identification and attention to the deficiencies. It will improve response times from the operator. An electronic submission provides a digital trail documenting when owners and managers were notified of existing problems.

While still in the Assembly, the bill was amended to change from “must submit” to “may submit” an email address. It was in response to those who do not have stable Internet access.

SENATOR STONE:
Does this bill apply to food trucks?

MS. HAYES:
Yes. They are food establishments.

CHAIR DOÑATE:
I have one document in support of A.B. 40 (Exhibit C). We will close the hearing on A.B. 40 and open the hearing on A.B. 267.

ASSEMBLY BILL 267 (1st Reprint): Revises provisions governing cultural competency training. (BDR 40-820)

ASSEMBLYWOMAN SELENA TORRES (Assembly District No. 3):
Thank you for allowing me to present A.B. 267. This bill establishes increased training requirements for certain employees of medical facilities and healthcare professionals on cultural competency, diversity, equity and inclusion (DEI). Cultural competency training focuses on skills and knowledge to value diversity, understand and respond to cultural differences, and increase the awareness of providers and healthcare organizations on cultural norms.

We know effective health communication is as important to health care as clinical skills. There is strong evidence that cultural competency training for healthcare professionals improves providers’ knowledge, understanding and skills for treating patients from cultural, linguistic and socioeconomically diverse backgrounds. To effectively serve diverse communities in Nevada, such as the Asian American and Pacific Islander community, Latinos and Native Americans, we need healthcare practitioners who understand, respect and value all the cultural differences and perspectives within our community.

Assembly Bill 267 will improve a patients' overall experience and reduce potential miscommunication or misunderstanding due to cultural differences that could lead to adverse outcomes. This bill reflects our State's commitment to fostering an inclusive healthcare environment catering to the unique needs of every patient regardless of background.

I have worked diligently on this bill, and it was amended significantly while in the Assembly. The amendments were adopted to make sure it made sense for hospitals, clinics and hardworking Nevada families. The amended bill in front of you is representative of a compromise and negotiation of what Nevadans need.

LAUREN CHAPPLE-LOVE, PH.D.:
I am a licensed psychologist who provides mental health services and have a private practice in Las Vegas. Cultural competency is viewed as building knowledge and skills relating to groups similar and dissimilar to your own. It is important to recognize these groups are not solely based upon the diversity that we can see.

This bill addresses populations like youth, the elderly, veterans and a host of others representing Nevada. Medical and mental health providers serve a growing diverse population across different spectrums and oftentimes multiple spectrums for one person. We have already started to establish an ethical as well as a professional requirement to improve skills to work with these populations. Continuing education must reflect the dedication to provide equitable care to these communities.

The term cultural competency can be seen as an inclusive umbrella. It is covering a network of educational tools, perspectives, evidence-based practices and patient symptoms or skills. How do we work with this population? The concept of cultural humility and responsiveness gives way to the notion that considering myself to be competent is not a research-based view. It is not a possibility that is realistic. Rather, professionals are tasked with continuing to improve their understanding of these competencies in the same manner they have continuing education for clinical skills.

Experiences or exposure to a particular population is not sufficient to imply a person has met a level of cultural humility with that population. For example, it will not suggest that a person is culturally competent simply because he or she identifies with a population or knows someone else who does. We need to recognize that many in our field have fallen short of inclusive or equitable care. At times, this has caused harm or increased healthcare disparities.

Apologies and acknowledgements pouring in from provider associations such as the American Psychological Association, the American Medical Association and the National Association of Social Workers is a shift as it relates to cultural humility. This came from the 2009 case for cultural competency and psychotherapeutic interventions paper.

In 1985, it was argued that cultural competency is an ethical obligation. Cross-cultural skills should be placed on the same level with other specialized therapeutic skills. In 2003, it was advocated that ethical standards require cultural competence through collaboration with, and sometimes deference to, ethnic minorities as well as communities and experts. In short, we now see that training within cultural competency is being mandated across a host of educational curriculums before a person can practice. This is something we would like to continue.

We need increased training and development of effective training opportunities. Contemporary research focuses on identifying methods to implement evidence-based strategies toward more effective cultural competency training. Training needs to be developed with the audience in mind. The training should have an accessible training curriculum, employ the most effective methods of delivery and have well informed trainers. Participants should be offered an opportunity to provide feedback on the training.

A 2022 paper developed standards for cultural competency training for healthcare providers. This paper is one of the ways to improve training and the quality of health care in Nevada.

SANDRA LEON-VILLA, PH.D.:
I am a licensed psychologist in Las Vegas and have been in the mental health field for nearly 15 years. With 50.3 percent of the State identifying as White, it must be noted that nearly 50 percent is comprised of Black, Indigenous and People of Color (BIPOC). According to DHHS, nearly 30 percent are Hispanic or Latinx; 9 percent are Black; 10 percent are Asian or Pacific Islander; and 1 percent identify as Native American or Alaska native.

The *Minority Health Report 2021* disclosed that health disparities continue to have a predominantly negative impact on BIPOC communities in all aspects of mental and physical health. The report stated Black individuals have the highest mortality rates across various health conditions, mental health and support among Black individuals. Native Americans have the highest depression rates, and Latinos, or Hispanics, continue to be impacted the greatest by COVID-19.

Nevada ranks thirty-fifth in the Country for health equity when it comes to minority or global majority health. This is concerning when we pair this with low levels of education and income, which describes most of Nevada's population. For example, LatinX families, the largest global majority population in Nevada, report that approximately 39 percent have a level of education lower than a high school diploma, while only 8 percent are college graduates. This is undoubtedly influenced and exacerbated by low socioeconomic status with more than 26 percent of the population reporting an annual income between $15,000 to $24,000.

Similarly, 32 percent of Black families have individuals with high school diplomas and approximately 41 percent have some college education. More than 40 percent of all Black families and individuals in Nevada report making less than $50,000 per year. These statistics are important because educational level and socioeconomic status influences access to services and contributes to the lack of health literacy. These numbers have some significant implications for health disparities and health literacy.

According to the Centers for Disease Control and Prevention (CDC), health literacy includes both personal and organizational health literacy. Personal health literacy is the degree to which individuals can find, understand and use information and services to inform health-related decisions and actions for themselves or others. Organizational health literacy is the degree to which organizations equitably enable individuals to find, understand and use information and services to inform health-related decisions or actions for themselves or others. The CDC emphasizes the importance of one's ability to use health information, but organizations have an obligation to address health literacy as the responsibility of health providers. However, to understand and address health literacy, it is important to also understand social and cultural factors that influence health providers, whether physicians, psychologists or healthcare workers who are predominantly white.

Research, treatment and interventions have historically been based on the perspectives of members of the global minority, which consequently impacts and contributes to health disparities. As evidenced by multiple national provider associations, various health fields have issued apologies for the harm against BIPOC communities. The current policy on continuing education hours is insufficient to make a significant impact on these statistics.

Psychologists, for example, are required to obtain two hours of training for diversity and cultural competency every two years for license renewal. This equates to one hour per year of training on cultural factors. Research indicates the lack of cultural responsiveness is going to result in lack of sensitivity to cultural differences and symptom presentation. This leaves providers vulnerable to their own implicit biases, stereotypes and other negative attitudes that they may have toward certain populations.

Increasing continuing education requirements will contribute to decreasing the health disparities; it is implicit bias by providers that contributes to these disparities.

ASSEMBLYWOMAN TORRES:
I can walk the Committee through the different parts of the bill.

SENATOR STONE:
Looking at sections 3 through 9, the bill has a varying number of training hours for different professions. For example, a nurse has a mandatory four hours, a social worker has six hours, and a counselor has three hours. First, are these hours of instruction per year? Second, why are there different number of hours for different medical specialties?

ASSEMBLYWOMAN TORRES:
I would like to give a bit of history on developing this bill. In 2021, legislation required two hours of cultural competency training. Licensing boards began to make sure this requirement was added. This equates to one hour a year which is insignificant. This legislation would raise it for most professions to six hours, or three hours each year. The one exception is for nurses, because it was recognized they are required to dedicate many hours each year to their facilities.

In section 1, the bill allows for the hours that the licensing board requires to be included as hours the hospital might provide. The employee can submit a training certificate to the hospital to show that the required training has been completed. For nursing, the hospital may still want nurses to take their own training. It would be at the discretion of the hospital.

SENATOR STONE:
If this is in conformance with certified medical education requirements, can the professional use this training as part of the educational requirement?

ASSEMBLYWOMAN TORRES:
Yes.

SENATOR TITUS:
I support all professions receiving education on diversity and understanding different cultures. It is not just applicable to healthcare professions. We need to be more than tolerant of somebody else's background, beliefs, religion or choices; we have to appreciate them.

I am concerned about the different hours depending upon the profession. We are basically teaching the same subject on the importance of understanding the needs of others.

ASSEMBLYWOMAN TORRES:
In 2021, this legislation was meant to cover mental health professionals. Cultural competency is critical to any practice or profession, but even more critical when you are talking about mental health. For professions like physicians or physicians’ assistants, the medical board has control of what they are required to take. While still in the Assembly, we amended the bill to address the issue of their training requirements.

Other professions, like nursing, have other issues. For example, some nurses work in mental health spaces, but others do not. Based on discussions with the Nevada Nurses Association, we agreed to four hours of cultural competency training. Mandating six hours of training is fair and makes sense for mental health professionals. This is core to their practice of treating patients.

SENATOR TITUS:
When I began to practice as a doctor, we did not receive any training on cultural competency. We did receive training on medical topics, but nothing on different cultures or how we should approach it. I practice in a rural area with many Native Americans, and I had to rapidly learn how to respect their privacy. I had to ask questions in a different way. I had to learn through practice to respect and have insight into different cultures, since I was not trained. Therefore, I am supportive of the training.

I am not sure how many communities of different cultural backgrounds are in Clark County. In addition, Las Vegas and Reno have visitors from all over the world. I worry about mandating cultural competency training regardless of the health professional. Perhaps we need to focus on the provider and recognize his or her individual biases. Providers cannot control who they are going to see in their offices. They cannot control the patients' backgrounds or lifestyle choices.

I am concerned about a statute for mandatory training with specific topics. We do not know all the topics, so it may be better to focus on the provider's bias. I know I have some biases but, as a provider, I have to work on overcoming them. For example, I have a bias about fat people. I need to control the bias when I walk into a room, and somebody is overweight. I need to stay professional and work past it. It may not necessarily be the patient's fault that they are overweight. It was a personal bias that I had to work through in my career.

I worry when we put into statute specific items that have to be addressed because we could miss other things. Training on understanding each healthcare professional's own biases in life is a better approach.

ASSEMBLYWOMAN TORRES:
I would like to address a couple of things. Cultural competency, as it pertains to the licensing boards, are two separate parts of this legislation. It is general and allows for a practitioner to have autonomy in choosing the areas he or she is

working on. For example, a mental health professional could work with people from various gender, racial, religious or ethnic backgrounds. They could also work with people from the LGBTQ+ community, children, senior citizens, veterans or people with mental illness. The bill has a general definition to allow choice.

DR. LEON-VILLA:
We all have implicit biases whether we are persons of color or not. To place the responsibility on providers to obtain training or some way to help them see their own implicit biases is difficult. I was a diversity chair for the Nevada Psychological Association for approximately two years, and I sent out a survey on interest in cultural competency training. The results revealed people do not want to attend this training. People do not want to attend ethics trainings either, but we are mandated to take them.

Cultural competency training is not necessarily to learn about individual cultures. Predominantly white spaces, like medicine or psychology, have disparities happening because of implicit bias. These trainings should include a component that helps people to understand how implicit bias can result in a white supremacy culture. We are talking about something different.

I do not think that we can absolutely rely on providers to sit with their own implicit biases unless they are participating in trainings. Ethics training is not exciting, but it is necessary and is mandated for a reason. Cultural competency is something that is not achievable because we cannot ever be fully competent culturally. However, it is a journey we need to take to continue to learn about disparities.

There is a reason why Black women are more likely to die giving birth or be less likely to be believed when they are in pain. We are now looking at historical context of why this is happening. It is imperative to mandate the training just like we do with ethics and suicide prevention training. We cannot rely on providers, as we have seen in psychology; they are just not willing to sit with their own implicit biases.

SENATOR NGUYEN:
In section 1, subsection 5, it states how a request must be approved or denied by DHHS no later than ten business days after the receipt of the application. How did you come up with a ten-day turnaround? Is it in existing legislation?

ASSEMBLYWOMAN TORRES:
During the development of this bill, one of the main complaints is the time it takes DHHS to approve the training. Stakeholders wanted a more consistent turnaround time for evaluating the training. I did speak with DHHS on a reasonable amount of time to approve those trainings. They responded two weeks or ten business days.

SENATOR NGUYEN:
In a previous hearing, we heard a bill presented by Senator Titus on how people would apply for programs to be approved. One organization would submit their cultural competency program and it was approved. A second facility would submit the same program and it was denied. Did the ten-day time frame come in combination with those kinds of conversations?

ASSEMBLYWOMAN TORRES:
This bill is intended to address some of those issues and concerns that I heard from providers. The ten days will prevent delays for implementing the training within some of these facilities. The bill has language that provides a clear outline of the training requirements. In addition, DHHS, Office of Minority Health and Equity, is required to post a list of qualifying cultural competency training courses. We are trying to streamline training while ensuring hospitals and facilities are providing culturally competent care.

SENATOR NGUYEN:
Have you taken any of these courses? Is there any component addressing an individual's implicit biases when treating a patient?

DR. CHAPPLE-LOVE:
In practice, the training is less about a particular population. It is more about how a person can institute knowledge relating to this population. It is coupled with the person's own biases and if it negatively impacts said population. How can I use the training in my work?

My private practice provides DEI consultation and training. It does not happen every time, but we do discuss implicit bias. To quote Maya Angelou, "When you know better, you do better." It is difficult to rely on internal pressure to learn more about a particular thing, especially when people start to consider DEI training. We need to address how your own histories or identities can impact a person and his or her ability to work with other people.

SENATOR STONE:
I want to return to the questioning about different hours for different professions. It would seem it could have the same type of cultural competency curriculum. Would it not be a course for cultural competency DEI training? Why would a nurse have two hours less training than a behavioral analyst?

ASSEMBLYWOMAN TORRES:
We are agreeable to make it a consistent six hours for all professions. However, it is important to note that each licensing board is separate. The training that is appropriate for nurses is going to be different than the training for psychologists or social workers. The training will be tailored for the profession and will need approval from the individual licensing board.

Since it requires each board's approval, we did not allow for the hospitals' training to be applied as the licensing hours. This training is different. We wanted it to be specific to the profession because social work is going to be covering different practices than a psychologist would.

SENATOR STONE:
Did you consult with the respective licensing boards? If so, did they advise what the appropriate number of hours are for the training? How did you arrive at the hours for each profession?

ASSEMBLYWOMAN TORRES:
We had many conversations with stakeholders on the appropriate number of hours. The four-hour requirement for nurses was at the request of the Nevada Nurses Association.

PAT KELLY (Nevada Hospital Association):
We support A.B. 267. We appreciate the Assemblywoman for bringing everyone together and for listening to our concerns. I would like to address the issue on the mandatory training hours for nurses. We also had requested two hours each year because nurses have many different training requirements. For example, a critical care nurse will need training on current techniques or other specialties.

We want to make sure that we address cultural competency, but we also have to address competency in the core areas in which the nurses practice. Initially, we had difficulties in setting the program up, but we are now ready to provide the training.

CODY HOSKINS (Service Employees International Union 1107):
We support A.B. 267. Our organization represents over 8,000 Nevada nurses and healthcare professionals. The cultural competency requirement is going to be important for our nurses.

SHEILA BRAY (University of Nevada, Reno):
We are in support of A.B. 267. As a higher education entity, we are supportive of continued education and training, especially when it strengthens the diversity of our State. Assembly Bill 267 provides an opportunity to ensure medical providers receive training to best prepare for serving their patients.

BLAYNE OSBORN (Nevada Rural Hospital Partners):
We support A.B. 267. We appreciate that this bill clarifies the requirements for the facilities.

DEANNA HUA TRAN (Nevada Immigrant Coalition):
We support A.B. 267. The Nevada Immigrant Coalition consists of diverse organizations from across the State. We work together to fight for immigration reform and justice. Cultural competency training is important for medical facilities and should be an ethical duty and a professional responsibility for healthcare organizations, agencies and providers.

Individuals come from unique cultural backgrounds with different beliefs or values that can influence their health behaviors and expectations of care. Cultural competency training can help healthcare providers and staff to understand and respect these differences. It can lead to better communication and culturally sensitive care. Healthcare providers may unknowingly engage in cultural misunderstandings or perpetuate biases, leading to reduced patient satisfaction with health outcomes and inequitable healthcare practices. We urge your support.

STEVE MESSINGER (Nevada Primary Care Association):
We represent the State's federally qualified health centers and operate Nevada Cultural Competency, a facility-licensing program for cultural competency. Originally, I was going to provide data on health disparities, but have dismissed it given the great presentation.

I would like to point out that federally qualified health centers have been addressing the needs of underserved communities since the 1960s War on

Poverty. I have seen firsthand many organizations doing incredible work in these spaces and communities across the Country. We can see better outcomes. We support A.B. 267.

CONSTANCE MCMULLEN (Personal Care Association of Nevada):
I met with the bill sponsor and informed her that this bill is a compromise that we can live with. Personal caregiver employees are not licensed professionals. However, we do provide training and will include cultural competency in our curriculum. We have been working toward a training plan that has yet to be approved.

As an alternative, we would rather have only the personal care agency administrators and owners be mandated for the training. We support A.B. 267.

CHAIR DOÑATE:
I have one document in support of A.B. 267 (Exhibit D). We close the hearing on A.B. 267 and open the hearing on A.B. 116.

ASSEMBLY BILL 116 (1st Reprint): Requires the provision of information and referrals concerning Down syndrome under certain circumstances. (BDR 40-569)

ASSEMBLYWOMAN TRACY BROWN-MAY (Assembly District No. 42):
We are excited to present A.B. 116. We will walk you through this bill quickly. It is intended to provide information about Down Syndrome and came from constituents. My copresenters are Diana Rovetti and her son, Jack Rovetti. They are going to provide some background on where this bill came from.

DIANA ROVETTI:
Everyone has a moment in life when time stood still. I can remember everything about my moment. It should have been a joyous occasion and I should have been celebrating. Instead, I was in tears, and I was scared. The moment came when my pediatrician told me that my baby boy has Down Syndrome.

In Nevada, this happens approximately 50 times every year. If I would have known in 1998 what I know now, I would have been celebrating this handsome young man sitting next to me, my son Jack. He has changed the course of my life and made it better. He has changed the course of my four daughters' lives for the better too. They are more compassionate, empathetic and just all around particularly good humans.

Many parents who have children with Down Syndrome are given grim outlooks for their babies and that is the reason for this bill. A family should be given hope and not fear. Good things can happen in their lives. I would never give up the opportunity to have a son with Down Syndrome. It has enriched my life. We are a family who loves Jack and believes he adds value to our community and to our State.

JACK ROVETTI:
I have a great life. I graduated from high school and have a lot of friends. I love my family. I have my own business, Jack's Popcorn Company. I am a volunteer and have been a barback. We should tell new moms that I am happy how I am, and I love having Down Syndrome. We need to tell a new mom that her baby is perfect.

ASSEMBLYWOMAN BROWN-MAY:
New babies are perfect even when they have Down Syndrome. It should not be something to be frowned upon. We understand the real capabilities of our citizens with Down Syndrome, and they are our equals.

Currently, 23 states have enacted Down Syndrome information bills. Most recently, the bill passed in Idaho and serves as our primary example for A.B. 116.

SENATOR STONE:
Jack, you are an inspiration for coming here with your mom to advocate for more information on Down Syndrome. We love our kids, even those with special needs. I have a special needs granddaughter who I am crazy about. These children bring out empathy, love and compassion that we are capable of having. I am happy that you are here.

I want to compliment the Assemblywoman for getting this information out to future moms and dads who are going to have Down Syndrome children. It is not the end of the world. We love these kids and want to show them that we love them. This information is going to help a lot of families.

SENATOR TITUS:
I have to question mandating what a provider does when they make a diagnosis. For example, when I diagnose someone with congestive heart failure, there is not a statute mandating what I am required to do. There is a standard medical practice, and it changes as new medicines or treatments come out. In my practice as a provider, the medications I prescribed when I graduated from medical school are practically not in existence today.

Although I am supportive of the information, I worry about legislating medical mandates. I understand you did not get information at the time of the diagnosis and the approach was disappointment rather than joy. I am thankful you are here today and every time you present; it is better for all of us. I just have concerns about legislating what a provider must do once he or she makes a diagnosis.

ASSEMBLYWOMAN BROWN-MAY:
I appreciate your concerns. We did walk this through in several different ways. A typical medical doctor does not diagnose a baby with Down Syndrome. Many times, it is an obstetrician, gynecologist or somebody who is going to do the diagnosis of pregnancy. These physicians already deliver multiple types of information.

We need to prioritize the fact that a baby with Down Syndrome is not a tragedy and can be a blessing. Parents need a referral source. Therefore, a medical office could have nothing more than a poster on the wall with a link to get a referral source. We are not mandating the information, only a referral.

Nevada 211 is an example that was used as a referral source. This website is a place Nevadans can go to when looking for help. We just want people who are receiving information about a diagnosis to be able to go somewhere to get current, accurate information. Ideally, it should be peer-reviewed based on science. It should not be "I am so sorry you are having a baby with Down Syndrome," which has been the experience of many parents throughout our State.

CATHERINE NIELSEN (Executive Director, Nevada Governor's Council on Developmental Disabilities):
I am with Alysa Marquez and will be helping her testify in support of A.B. 116.

ALYSA MARQUEZ (Intern, Nevada Governor's Council on Developmental Disabilities):
I have a service dog whose name is Girl. I like flag football and have testified in front of the Legislature three times. I love people and St. Gall Church. I am downright awesome.

MS. NIELSEN:
Informed choice occurs when people, with or without reasonable accommodation, understand all the options available to them, including the benefits and the risks of their decisions. The process of informed choice does not have an end and does not occur just one time. It is part of an ongoing process of engaging people in person-centered conversations about their goals. It allows individuals with or without disabilities to be in control of their life decisions and ensure they are making meaningful choices about what will impact their future.

This is where A.B. 116 comes in. When parents are having a child with Down Syndrome, they should be afforded the right to make an informed decision about their lives and their child's future. As you have heard today, people with disabilities, particularly those with Down Syndrome, bring purpose to this world.

Alysa is my intern. While she is my first intern, she is also my favorite. When I enter the office in the morning, my lights are on, the heater is going and the office is open for business. This is all due to Alysa. When people come into the office for information or resources, Alysa greets them and finds out their needs. She can alert the appropriate staff member.

We sent hundreds of health-information binders Statewide to help ensure the public is prepared for the next emergency. Alysa was the staff member primarily responsible for assembling and shipping the binders. She is valuable as a staff member, and she brings me joy as a person. She makes my life better. She makes me excited to enter the office in the morning and sad to leave at the end of the day.

While I am the executive director, I want you to know as a constituent, people with Down Syndrome are valuable. It is important to provide opportunities for families to make informed choices. Assembly Bill 116 will ensure this population’s value is finally upheld in Nevada statute.

ELLEN MARQUEZ (Self-Advocacy Coordinator, Nevada Governor’s Council on Developmental Disabilities):
I am also here as a proud parent of a young adult with Down Syndrome. Over 20 years ago, I had an amniocentesis procedure and was told my daughter would be born with Down Syndrome. There was no explanation or information provided. We were told to read some books to learn about it and to see what the future will look like. Those books were outdated and mostly explained all the medical issues she could be born with and institutionalization. As disheartening as this was, I looked forward to the day I would meet my precious girl.

My daughter was born on March 10, 2003. The doctor confirmed she had Down Syndrome but otherwise appeared healthy. Later that day, the hospital social worker came in with no compassion to ask if my daughter would be going home with me. I thought to myself, where else is she going? Is somebody coming to take her from me? The social worker gave us little information or resources to contact.

Assembly Bill 116 will give these parents the information and support services to understand Down Syndrome is not the end of their child's life. It is the beginning of a new and different adventure. It may be challenging at times. For example, my daughter had open heart surgery when she was two and a half months old. We are now part of a diverse and supportive community.

Our children go to school with their peers and learn alongside their friends. They can graduate with an alternative diploma, a parallel curriculum to the standard diploma. These children can be employed, attend college and are the future of our communities.

Parents need to be aware when they receive the diagnosis of Down Syndrome there is so much more. Knowing others with Down Syndrome provides encouragement for what others can aspire to become. We know people like Jack Rovetti, an entrepreneur and heartbreaker; Kailin Kelderman, a prep cook who lives independently; Kenley Casselman, a spunky elementary school student who knows no stranger; and Alysa Marquez, an intern and a beauty pageant queen.

MARY BRYANT:
I ask you to support A.B. 116. I live in Reno and have a beautiful 28-year-old daughter with Down Syndrome. She could not be here today because she is working.

My pregnancy with my daughter in 1994 was a surprise. I had recently had a miscarriage, so I underwent an amniocentesis because I did not want to take any chances. She was born two weeks late and I was fortunate to have a doctor who was sensitive and knowledgeable about Down Syndrome. About two minutes after she was born, he said, "I strongly suspect your daughter has Down Syndrome." He said it without acting like it was a death sentence. He was just very matter of fact about it.

Dr. Farringer shared resources with me that could help our daughter reach her potential. He told me that he had other patients who had children with Down Syndrome. He said the families got back to normal after the shock. He mentioned one family that liked to snow ski. At first, I thought how sad not to be able to ski anymore. He went on to tell me that the little boy started skiing as soon as he was walking.

The social worker came in shortly after her birth and gave us contact information for Nevada Early Intervention Services and the family organization associated with it. We were able to provide early intervention for our daughter and meet other parents through their network. They are now some of my best friends.

This might not sound like a life-changing interaction between the doctor, the social worker and our family. However, it was what we needed to avoid being completely devastated. It has been a lifetime of adjustments because every new age and situation can be challenging. When I compare this experience to other friends who have gotten the diagnosis, I feel fortunate. Their experience was like their family was given a death sentence or worse.

Families are getting the diagnosis with inaccurate and disturbing information, especially if they get a prenatal diagnosis. I want to mention that I am very pro-choice and believe women should have complete autonomy about their bodies and their health care, including abortion. However, women need to have accurate information to make informed choices.

My daughter is now 28 years old and lives in her own apartment. She works in retail at the mall. She was recently named employee of the month. My daughter graduated from the Path to Independence Program at the University of Nevada, Reno, which is an inclusive two-year program for students with intellectual disabilities. Her life has not been without challenges.

Her diagnosis has changed our whole family. My husband and I work for nonprofits. I started the Path to Independence Program, which is in its tenth year. Our other daughter got a master of social work degree and will be working with people with disabilities. The challenges presented by having a child with Down Syndrome are minor compared to the good she has done. There are no guarantees with any of our children. When a normal child is born, no one states any potential catastrophic events like cancer could happen. Why do we single out people with Down Syndrome to discuss how horrible life is going to be?

I want women to have the facts so they can make informed choices.

MARY PIERCZYNSKI (State of Nevada Association of Providers):
We support A.B. 116. The State of Nevada Association of Providers is an umbrella organization. The members provide services for intellectually challenged or disabled people, including those diagnosed with Down Syndrome. We are supportive of all educational materials offered to families who are looking for community and medical support.

LISA HOLMQUIST (CEO, Founder, Down Syndrome Connections):
I am here today with Hannah Huse. Our organization provides trained parent mentors to help people who have a new birth or prenatal diagnosis of Down Syndrome. It is a connection to our community and helps them answer questions.

We would like to present a video where Ms. Huse describes her life. She also addresses what you should tell someone with a baby who has Down Syndrome. Ms. Huse says the family should be happy and the baby is beautiful. The baby can do anything, including walk, talk and read. The family just needs to be happy. Please support A.B. 116.

CONOR SLIFE:
I am a father of three children and my youngest child, Annalise, has Down Syndrome. When we were told that she had Down Syndrome, we were devastated. We were concerned about a short life expectancy, mental disability, physical limitations and suffering for her and our family. We have discovered that most of our concerns are not true.

Annalise is the light of our family and our extended family. She is the light anywhere we go because she is an amazing little girl. I cannot imagine the world without her. It would have been beneficial to have someone to talk to when we received her diagnosis. I needed someone like me to explain exactly what Down Syndrome is and all the wonderful benefits. I support A.B. 116.

Remainder of page intentionally left blank; signature page to follow.

CHAIR DOÑATE:
I have three documents in support of A.B. 116 to put into the record (Exhibit E). We will close the hearing on A.B. 116. Hearing no public comment, we will adjourn the meeting at 4:45 p.m.

RESPECTFULLY SUBMITTED:

Mary Ashley,
Committee Secretary

APPROVED BY:

Senator Fabian Doñate, Chair

DATE:

EXHIBIT SUMMARY				
Bill	**Exhibit Letter**	**Introduced on Minute Report Page No.**	**Witness / Entity**	**Description**
	A	1		Agenda
	B	1		Attendance Roster
A.B. 40	C	3	Chair Fabian Doñate	Letter of Support
A.B. 267	D	14	Chair Fabian Doñate	Letter of Support
A.B. 116	E	22	Chair Fabian Doñate	Three Letters of Support