MINUTES OF THE
SENATE COMMITTEE ON HEALTH AND HUMAN SERVICES

Eighty-second Session
April 4, 2023

The Senate Committee on Health and Human Services was called to order by Chair Fabian Doñate at 3:33 p.m. on Tuesday, April 4, 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:

Senator Carrie A. Buck, Senatorial District No. 5
Senator Melanie Scheible, Senatorial District No. 9

STAFF MEMBERS PRESENT:

Destini Cooper, Policy Analyst
Eric Robbins, Counsel
Norma Mallett, Committee Secretary

OTHERS PRESENT:

Annette Logan-Parker, Founder and CEO, Cure 4 The Kids Foundation
Howard Baron, M.D., Sunrise Hospital & Medical Center
Stacie Weeks, Administrator, Division of Health Care Financing and Policy, Nevada Department of Health and Human Services
George Ross, Hospital Corporation of America, Sunrise Children's Hospital
Will Pregman, Battle Born Progress
Philip M. Paleracio, D.D.S., The Dental Center of Nevada

Susan B. Proffitt, Vice President, Nevada Republican Club
Erin Shaffer
Erik Jimenez, Chief Policy Deputy, Office of the State Treasurer
Santa Perez, Chairperson, Nevada Governor's Council on Developmental Disabilities
Marlene Lockard, Service Employees International Union, Local 1107
Kierra Capurro, Nevada Blind Children's Foundation
Eddie Ableser, Opportunity Village
Jonathan Norman, Nevada Coalition of Legal Services Providers
Steven Cohen
Christine Essex
Katrina Ojeda
Connie McMullen, Personal Care Association of Nevada
Catherine Nielsen, Executive Director, Nevada Governor's Council on Developmental Disabilities
Max Kim Lowe, Vice Chair, Nevada Governor's Council on Developmental Disabilities
Raquel O'Neill, President, Blindconnect in Nevada
Mindy Lokshin, M.D., Chair, Parkinson Support Center of Northern Nevada
Jefferson Kinney, Chair, Department of Brain Health, School of Integrated Health Sciences, University of Nevada, Las Vegas
Julia Peek, Deputy Administrator, Division of Public and Behavioral Health, Nevada Department of Health and Human Services
Charles Duarte, Alzheimer's Association
Ben Scheible
Julia Pitcher, Director of State Government Relations, The Michael J. Fox Foundation for Parkinson's Research
Blayne Osborn, Nevada Rural Hospital Partners
Cadence Matijevich, Washoe County
Dora Martinez, Nevada Disability Peer Action Coalition

CHAIR DOÑATE:
We will open with a work session on Senate Bill (S.B.) 41.

SENATE BILL 41: Revises provisions relating to child welfare. (BDR 38-392)

DESTINI COOPER (Policy Analyst):
I have a work session document (Exhibit C) describing the bill and its amendments.

CHAIR DOÑATE:
I will entertain a motion on S.B. 41.

> SENATOR STONE MOVED TO AMEND AND DO PASS AS AMENDED S.B. 41.
>
> SENATOR NGUYEN SECONDED THE MOTION.

SENATOR TITUS:
I will vote this out of Committee, but I am just now looking at these amendments. I want to make sure I agree with the amendments, so I will vote yes today, with the caveat that I will understand this amendment first.

> THE MOTION CARRIED UNANIMOUSLY.

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CHAIR DOÑATE:
Let us move on to S.B. 42.

SENATE BILL 42: Revises provisions relating to the funding of medical assistance to indigent persons. (BDR 38-398)

MS. COOPER:
I have a work session document (Exhibit D) describing the bill and its amendment.

CHAIR DOÑATE:
I will entertain a motion on S.B. 42.

> SENATOR STONE MOVED TO AMEND AND DO PASS AS AMENDED S.B. 42.
>
> SENATOR NGUYEN SECONDED THE MOTION.
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> THE MOTION CARRIED UNANIMOUSLY.

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CHAIR DOÑATE:
Let us move on to S.B. 109.

SENATE BILL 109: Revises provisions governing anatomical gifts. (BDR 40-453)

MS. COOPER:
I have a work session document (Exhibit E) describing the bill and its amendments.

CHAIR DOÑATE:
I will entertain a motion on S.B. 109.

SENATOR NGUYEN MOVED TO AMEND AND DO PASS AS AMENDED S.B. 109.

SENATOR LANGE SECONDED THE MOTION.

SENATOR TITUS:
I will be an absolute no on this bill. My concern with this bill is that it potentially does a disservice to the people we are trying to protect. Those would be the people who do not have identification, are undocumented or homeless. Those are the folks whom we may not be able to find out where they are from, or not able to reach the nearest family member. That is who we are really targeting in this bill and, unfortunately, I cannot support the bill.

SENATOR STONE:
Thank you to the proponents of this bill for coming in and exemplifying the importance of harvesting organs and getting more donors. We have people who cannot live because we are not getting the organs in time. I share some of the same concerns as my colleague, Dr. Titus. This could have a disproportionate effect on people who are not identified, namely homeless or undocumented because you only have a certain amount of time to harvest these organs. It is about 72 hours before the organs are no longer viable. That does not give enough time to locate the next of kin or someone who knew the unfortunate person that was brain dead to harvest their organs.

It also places us in a medical and ethical dilemma. Upon the request of the procurement organization for the organs of the brain-dead subject, every human being has the right to decide if he or she wants to give an organ. While the benefit of receiving organ donations is understood, every person deserves the right to affirmatively donate their organs. The absence of such documentation or knowledge should not default to a "yes." Hopefully, we can work with the proponents and better educate the public about the importance of organ donation so we can increase these important issues. The bill, in its present form, however, is something I cannot support.

THE MOTION CARRIED. (SENATORS STONE AND TITUS VOTED NO.)

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CHAIR DOÑATE:
Let us move to S.B. 177.

SENATE BILL 177: Imposes requirements governing Medicaid coverage of certain antipsychotic or anticonvulsant drugs. (BDR 38-82)

MS. COOPER:
I have a work session document (Exhibit F) describing the bill.

CHAIR DOÑATE:
I will entertain a motion on S.B. 177.

SENATOR LANGE MOVED TO DO PASS S.B. 177.

SENATOR STONE SECONDED THE MOTION.

SENATOR TITUS:
Unfortunately, I must vote no on this bill. The bill, although well intended, will have unintended consequences. If I have a patient who is on a medication that has worked for them and the formularies are changed, this bill should have said that they can stay on the original formula. Opening this up to allow and mandate that they must provide any other drug the prescriber may order when there are alternatives, that I cannot accept. The cost is going to be prohibitive, and although the bill is well intended, it is misguided.

THE MOTION CARRIED. (SENATOR TITUS VOTED NO.)

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CHAIR DOÑATE:
Let us move to S.B. 221.

SENATE BILL 221: Revises provisions relating to Medicaid. (BDR S-951)

MS. COOPER:
I have a work session document (Exhibit G) describing the bill.

CHAIR DOÑATE:
I will entertain a motion on S.B. 221.

SENATOR TITUS MOVED TO DO PASS S.B. 221.

SENATOR NGUYEN SECONDED THE MOTION.

THE MOTION CARRIED UNANIMOUSLY.

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CHAIR DOÑATE:
Let us move to S.B. 237.

SENATE BILL 237: Revises provisions relating to crisis intervention. (BDR 39-312)

MS. COOPER:
I have a work session document (Exhibit H) describing the bill and its amendments.

CHAIR DOÑATE:
I will entertain a motion on S.B. 237.

SENATOR NGUYEN MOVED TO AMEND AND DO PASS AS AMENDED S.B. 237.

SENATOR LANGE SECONDED THE MOTION.

SENATOR TITUS:
I was okay with this bill until the amendment. Originally, it was stated that it made no changes other than a clarification on what lines could be billed. With this amendment, you are now adding a provision for an adjustment in the surcharge every five years. I protest that without it being a two-thirds bill, I am going to vote no on this bill.

THE MOTION CARRIED. (SENATORS STONE AND TITUS VOTED NO.)

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CHAIR DOÑATE:
We are going to move on to S.B. 297.

SENATE BILL 297: Provides for the establishment of the Nevada Memory Network. (BDR 40-298)

MS. COOPER:
I have a work session document (Exhibit I) describing the bill and its amendment.

CHAIR DOÑATE:
I will entertain a motion on S.B. 297.

SENATOR NGUYEN MOVED TO AMEND AND DO PASS AS AMENDED S.B. 297.

SENATOR LANGE SECONDED THE MOTION.

SENATOR TITUS:
I am going to vote no on this one. Although I appreciate the clarification on what a community-based dementia care navigator is, I remain concerned about the ability to create this clinic. The lack of resources is going to be draining our resources, not augmenting them. Unfortunately, I must be a no.

THE MOTION CARRIED. (SENATORS STONE AND TITUS VOTED NO.)

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CHAIR DOÑATE:
We will move on to the final work session bill, S.B. 239.

SENATE BILL 239: Establishes provisions governing the prescribing, dispensing and administering of medication designed to end the life of a patient. (BDR 40-677)

MS. COOPER:
I have a work session document (Exhibit J) describing this bill and its amendments.

CHAIR DOÑATE:
I will entertain a motion on S.B. 239.

> SENATOR NGUYEN MOVED TO AMEND AND DO PASS AS AMENDED S.B. 239.
>
> SENATOR LANGE SECONDED THE MOTION.

SENATOR TITUS:
I am going to vote no on this bill for several reasons. As a provider, what I document on the death certificate is the definition of end of life. It should be part of the documentation if the person chooses to take their own life. You can also add the underlying disease process, but it tends to skew outcomes and some of that data. That is only one of the reasons I will vote no on this bill.

SENATOR STONE:
As a healthcare provider, the last thing that Dr. Titus or I want to do is make anybody suffer, but we have medical resources available for treating illnesses that can alleviate suffering when administered by the appropriate medical personnel. This is not my first rodeo with this bill. This is something that I studied intently in my prior tenure as a California State Senator.

What I discovered are things that I brought up during the hearing. I want to summarize that there were many botched suicides where a physician was not present; family members were there and sometimes the suicide took days to accomplish. It also may give insurance companies a reason not to cover an expensive drug that may have some efficacy in treating some cancers. I was witness to some letters, and I would be happy to give them to the Committee for documentation. Those were letters from an insurance company that said to a lung cancer recipient, we are not going to pay for this expensive medication, even though it could give you 30 percent potential efficacy of living. But we will pay for the suicide cocktail. That was alarming.

If you look at section 35 in the bill, it says death resulting from the self-administration designed to end the life of the patient is not suicide or assisted suicide. My question is, if it is not that, then what is it?

One thing I mentioned during the hearing is that there were many instances of coercion. One of the proponents of the legislation that was testifying said that, in 25 years, there was not any documentation of coercion, but I can tell you that there is. I will mention one case and I am not going to go into a lot of details. Ms. Kate Chaney had a terminal illness, but she also had dementia. Her own psychiatrist said that she was unable to decide. The daughter shopped for a doctor until they found a doctor who said Ms. Chaney could be cognizant of agreeing to physician-assisted suicide. But there was significant coercion by her daughter that is also in the public record as well. I do not think there are enough protections in place. We have the medical resources to take people out of their misery and, for those reasons, I cannot support the legislation today.

CHAIR DOÑATE:
During the hearing, I shared some alarming remarks as to how the bill was structured and how it did not make sense to our State. We wanted to ensure the amendment was reflective of that. It is an important conversation for all of us. There were portions of the bill that did not make sense, but the bottom line and where we philosophically stand, is that it is important to ensure this is done in a controlled and right way. The bill will go through other iterations as well. I thank my colleagues for any input, either for or against any circumstance, and am appreciative of all their sentiments.

THE MOTION CARRIED. (SENATORS STONE AND TITUS VOTED NO.)

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We will now move on to S.B. 255 and welcome Senator Buck to present the bill.

SENATE BILL 255: Makes various changes relating to services provided for the treatment of diseases that predominantly affect children. (BDR S-646)

SENATOR CARRIE A. BUCK (Senatorial District No. 5):
This bill requires the Nevada Department of Health and Human Services (DHHS) to identify services that treat diseases that predominantly affect children, including pediatric cancers, and seeks an increase in Medicaid reimbursement rates. Pediatric physicians, like many other physicians in the State, are facing increased patient volumes and challenges getting children and families in need access to quality and timely health care.

These shortages force families to travel long distances and join waitlists that can sometimes be months long or avoid getting care or treatment altogether. For example, according to the American Academy of Pediatrics, about 21 percent of Nevadans must drive at least 80 miles to get to the nearest pediatric subspecialty for adolescent primary care. About 23 percent of Nevadans must drive at least 80 miles to reach a pediatric allergy or immune specialist, whereas nationwide, this is only true for only about 6 percent of the population. The American Board of Pediatrics states that there is roughly 1 developmental-behavioral pediatrician for every 698,748 children, about 0.10 per 100,000 children.

One potential barrier is that we do not have enough pediatric specialists in our State to provide care, and the ones who are here can only provide limited services due to the low Medicaid reimbursement rates. Medicaid reform is the top priority on the healthcare financing agenda. Medicaid reimbursement continues to be a barrier to equity and access for low-income families. Medicaid reimburses at rates lower than Medicare and commercial rates, deterring providers from caring for lower income families.

Over 191,000 low-income children in Nevada rely on the Children's Health Insurance Program for access to quality health care. When pediatricians and Medicaid have a disconnect, the consequences fall on the children, creating additional barriers to quality health care at an affordable price. With low Medicaid reimbursement rates in place, the burden not only falls on children seeking care but also on the providers who are expected to provide the care. These low reimbursement rates continue to cause physicians to turn away Medicaid patients due to one simple fact—their practice cannot afford to provide expensive services for such low rates. Fewer physicians mean increased wait times for urgent appointments, sometimes even pushing families out of the State to get the care they need. More reasonable provider payments for care are necessary to ensure that low-income children in our State have the same access to health care as those with Medicare or commercial insurances.

This bill will increase the rate of reimbursement for specific diagnoses and services by 10 percent for each service. Not only will this benefit the youth in our State, but it will also increase the number of pediatric specialists practicing in our State, fueling the healthcare workforce.

Section 1 of the bill requires DHHS to determine which services under the Nevada State Plan for Medicaid are provided to children with rare diseases or pediatric cancer. Section 1 also requires that DHHS appeal to the U.S. Secretary of Health and Human Services to amend the State Plan. This would increase the rate of reimbursement by at least 10 percent for the services identified in the first part of section 1.

Section 2 makes the bill effective upon passage and approval. The brief conceptual amendment (Exhibit K) will require DHHS to determine which diseases impacting children have a significant shortage of specialists, broadening it from the original bill that only applied to rare diseases and pediatric cancer. The patient-to-specialist ratio is to be included in this report along with wait times. The Medicaid payment rates for these shortages will be increased by 10 percent.

ANNETTE LOGAN-PARKER (Founder and CEO, Cure 4 The Kids Foundation):
It is an honor for me to represent the medical needs of Nevada's children. I am the founder and CEO of Cure 4 The Kids Foundation. I am also the chair of the Rare Disease Advisory Council (RDAC).

I will give you some background on Cure 4 the Kids Foundation in my presentation (Exhibit L and Exhibit M). We were established in 2007 as a 501(c)(3) tax-exempt organization, primarily to recognize children battling cancer and other rare diseases and the lack of services available to them 17 years ago in southern Nevada. We have a multidisciplinary approach, and we employ many pediatric subspecialists. We primarily offer pediatric oncology, hematology, orthopedic surgery and genetics. We have a pediatric physical therapy program, many different bleeding and clotting disorder clinics, and specialty clinics for sickle cell patients. We are adding a pediatric rheumatology program soon. So, we have a robust program and see about 125 kids a day, which equates to roughly 6,000 unique patients every year. It is a very large organization, and we treat many children in Nevada that have cancer and other rare diseases.

For anyone unfamiliar with the RDAC, it was established through S.B. No. 315 of the 80th Session. The RDAC was established to help bridge policymakers' gaps in knowledge regarding rare diseases. There are over 7,000 identified rare diseases that impact approximately 10 percent of the American population. We serve as an advising body and liaison between the rare disease community and State government.

I am here in support of S.B. 255 with the purpose of amending the *Medicaid Services Manual* as described by Senator Buck. I want us to focus on and understand that having Medicaid coverage does not always translate into getting the care needed in the Nevada pediatric subspecialty environment. It is no secret that for many years, families with children enrolled in Nevada Medicaid have experienced difficulties finding pediatric specialists willing to accept them into their practice. The subspecialty physician offices in Nevada have cited the only reason for limiting or not accepting children with Medicaid is consistently inadequate payment for services.

Children with cancer and other rare diseases and serious conditions, particularly the fee-for-service piece of the Medicaid product, have serious access to healthcare challenges. The overall supply of physicians participating in Medicaid is not keeping up with the pace of growth within enrollment. As Senator Buck had described, Medicaid does not reimburse sufficiently to cover the actual costs of providing care for children with cancer and other rare and serious conditions. The physician payment rates for Medicaid have only increased approximately 5 percent over the last 20 years. Yet, many studies prove that the cost of delivering health care has increased as high as 195 percent. That study was at the University of Southern California, School of Public Health.

What we need to talk about here is not just a reduction in fees; providers are being paid less than the cost of providing the care. That is increasing more with our current staffing situation in Nevada. For example, I can tell you that at Cure 4 The Kids Foundation, we are paying healthcare professionals 35 percent more today than we did just five years ago. Pediatricians simply cannot afford to see Medicaid patients—it has the potential to bankrupt them.

What is happening with Medicaid beneficiaries is challenging when the reimbursement rate is 30 percent to 35 percent less than Medicare's reimbursement. The pediatric medical subspecialists who care for these patients require a considerable amount of additional training and that training is not cheap. Since these highly specialized physicians are in short supply, children and families face challenges in accessing timely health care and often, do not get the care that they need. Research has found that most pediatric subspecialists, including those practicing oncology, neurology, pulmonology, genetics and gastroenterology, do not see a financial return from the additional training that is required for the credentials they need to care for these children. That is associated with the delay in receiving increased compensation and repayment for educational debt. To put it in simple terms, the juice is just not worth the squeeze.

The practice of medicine is a business and, in this case, it is bad business. Physicians simply cannot stay in the environment providing care when the cost of providing it is too high. I can share with you that Cure 4 The Kids Foundation was established as a tax-exempt medical facility, primarily because we knew that we needed to rely on philanthropy to raise the funds required to provide the level of care that these children deserve. We cannot expect all pediatric specialists to start a tax-exempt organization because they cannot afford to practice medicine any other way. There is a direct correlation between physician payment and access to care. There are multiple studies that the American Medical Association has provided, and I can provide a link to the robust list of those studies.

Just today, we had a 26-year-old patient who is posttransplant from a form of leukemia, who needed photopheresis due to renal failure. She will need to have this done four times consecutively, approximately four times a year for the rest of her life. She has a Medicaid product and today, the hospital informed us that she will no longer be able to receive these services due to financial reasons. The cost of the service is $3,000 plus three hours of nursing care and supplies and the administrative team required to schedule billing, collection and coordination of all of this. The reimbursement rate from Medicaid is $500. This patient will be required to seek care out of state, and it is unlikely that we can identify a facility, let alone get her there. Without the treatment that she needs, she will end up in kidney failure. Unfortunately, her current medical condition is a direct result of childhood cancer treatment and will keep her from that kidney donor list.

That is just one example of things that we face every day. Another example would be when we attempt to refer Medicaid patients out into the community for services that we do not offer at Cure 4 The Kids Foundation. For example, concurrent care with the cardiologist, pulmonologist and gastroenterologist are specialists that children with cancer and other rare diseases need to address the toxicities of their treatments or comorbidities associated with their conditions. We always get resistance and often a straight refusal to accept the patient because our colleagues simply cannot afford to care for these patients and keep their practices open.

When the cost to provide the care is greater than the reimbursement received for that care, it is no longer discounted care; it is not even free care. It is an expense, and it is an expense that our local healthcare system cannot afford. These children might as well be undocumented. We have the same access to care issues with Medicaid patients as we do with undocumented children. The State must fund its Medicaid program—it is literally crumbling before our eyes.

We will not see a robust and thriving pediatric healthcare delivery system in Nevada until we pay our physicians living wages, which are earned through adequate reimbursement for the services they provide. It is unreasonable to expect physicians and the facilities they work at to pay for these services as a cost of doing business. This bill is seeking a 10 percent increase for providers who care for our State's most vulnerable children. They deserve it and so much more. Please support an increase in fees for these providers and facilities—the children of Nevada are depending on you.

HOWARD BARON, M.D. (Sunrise Hospital & Medical Center):
I am a pediatric gastroenterologist in private practice in Las Vegas and have been treating children for over 30 years. I support S.B. 255 with the proposed amendment and appreciate the sponsor for expanding the bill to consider all pediatric subspecialists. This Committee is fully aware of the lower rates of Medicaid reimbursement and the extreme physician shortages in Nevada for pediatric specialists. The situation is dire compared to the national average of 8 pediatric subspecialists per 100,000 population. Nevada has 3.3 pediatric subspecialists per 100,000 population.

As a pediatric gastroenterologist, I treat children with Crohn's disease, cystic fibrosis, cancers and genetic disorders—children who are dependent upon feeding tubes, parental intravenous nutrition at home and a wide variety of different disorders. Today, a family member of one of my patients with celiac disease called my office complaining that they could not get into any local pediatric endocrinologist for three to six months. This child has known Hashimoto thyroiditis; I made her diagnosis. I had to make a call to one of three colleagues in southern Nevada to try and get this patient in within the next couple of weeks so that she could get appropriate treatment for her thyroid condition. That happens every day.

As one of only ten pediatric gastroenterologists in the entire State, there are two in Reno and eight in Las Vegas, I see firsthand the long wait times for parents to get their kids in to see us. Because most of the pediatric subspecialty services are provided to Medicaid recipients in our State, we often fail to compete with cities outside of Nevada when it comes to recruiting talent to the State. My practice is essentially 60 percent Medicaid. It took us over ten years to recruit a fourth physician willing to come to Nevada to join our practice.

Senate Bill 255 would provide a thoughtful review of the pediatric specialists that are in short supply in Nevada and help to ensure that Medicaid rates are adjusted to continue to serve Nevada's most vulnerable population with the quality and timeliness all Nevada patients deserve.

SENATOR LANGE:
When you talk about pediatric care, what is pediatric care? Is it aged 18 and younger? What is the age range?

DR. BARON:
In our practice, it is 18 years old and younger. Cure 4 The Kids can testify that they follow their pediatric cancer patients well into their twenties because there are certain tumors that are pediatric-specific. An example would be Ewing sarcoma, which is a bone tumor. If one of the adult oncologists in Las Vegas gets a patient with Ewing sarcoma, they refer them to Cure 4 The Kids because they have the expertise in that facility to treat that particular bone tumor.

SENATOR LANGE:
Dr. Baron, I really appreciate your care as you took care of my son. Does this include hospitals? We heard testimony about hospitals and their Medicaid reimbursements. Would they be included in this bill or is it just for physicians?

SENATOR BUCK:
It is just for physicians; however, I am willing to expand that if the Committee wishes.

SENATOR LANGE:
We heard testimony earlier this week about how important it was that hospitals are not getting the reimbursements they need. That is something that you should consider.

SENATOR STONE:
Senator Buck, thank you for bringing this bill forward. Ms. Logan-Parker, I am always amazed when you speak and when I see your dedication to Cure 4 The Kids. I was fortunate to take a tour there and the number of kids you take care of is incredible. I applaud your efforts. This bill is going to increase the Medicaid payment by 10 percent. What percentage of your clientele coming in now is either Medicaid or going to be Medicaid-referred to another physician?

MS. LOGAN-PARKER:
Our patient population of Medicaid is between 50 percent and 55 percent. Sometimes it is as high as 60 percent of our entire patient population.

SENATOR STONE:
You are taking a lot of patients. You have had some national celebrities come to Nevada and do concerts giving a portion of the proceeds to your organization, which shows that there is not only Nevada support from the philanthropic community but a lot of national philanthropic organizations and people. You are saving kids' lives. Nothing could be more important than that.

Dr. Baron, thank you. You are not only a physician but a humanitarian because 60 percent of your clientele is Medicaid, and we have one of the worst Medicaid rates in the entire Country. I support this bill. It seems like a lot of the bills we are hearing deal with this low Medicaid rate and, Chair Doñate, that is important to you in covering populations as well. What is interesting is that for every dollar that we invest as a State, we get three more back from the federal government. I like that multiplier effect.

We have limited resources in the State but, hopefully, it is a bipartisan desire to pump a bunch of money into Medicaid so we can get that federal match. In turn, we can pay our hospitals and pediatric oncologists more so that we can attract more physicians to Nevada, and they can make a living taking Medicaid patients. The bill enhances health care from Elko to Laughlin, from the top to the bottom of this wonderful State. This is a good start and thank you for bringing it forward.

I am one of the biggest cheerleaders for Cure 4 The Kids, and one of the areas they really need help with outside of this bill is the 420(b) program. There are many hospitals that can buy oncological drugs for 10 percent of what this wonderful organization has to pay because they do not qualify for the 420(b) program. We need to find a way to get them qualified so they can continue to give low-cost chemotherapy to their kids.

SENATOR LANGE:
Dr. Baron, if we raise these rates, would they be competitive with other states around us? Do you think it increases the number of physicians that we can attract to Nevada?

DR. BARON:
Yes, to both questions. A 10 percent increase on 60 percent of our patient population would allow us to recruit one or two more specialists into our practice and cut our waiting times from currently six weeks down to probably two weeks. I have a pet project which is to provide telehealth specialty care to some of the rural areas, which we have not really been able to develop because we are so clinically busy with patients in the big city. There is simply no workforce to do that.

SENATOR LANGE:
I really like this bill.

SENATOR NGUYEN:
You have talked about the wait times. How would we be able to pull that data on wait times and specialists to patients? Are the providers providing that data for us?

DR. BARON:
I am a member of the Network Adequacy Advisory Council. We have been asking for that data from the staff of the Division of Insurance for the last eight years, and we are always told that we cannot get wait time data. The group has a hard enough time obtaining and meeting the Centers for Medicare &

Medicaid requirements for time and distance, which are how network adequacy is currently identified in our State. Ms. Weeks would tell you that the Council does not have access to that data through our Division of Insurance.

STACIE WEEKS (Administrator, Division of Health Care Financing and Policy, Nevada Department of Health and Human Services):
In Medicaid, we could get access to data that we could try and make conclusions about. We can look at referral dates for services and how long it takes for a child to get a billable service. I am not sure about the Division of Insurance but, in Medicaid, we do have claims data that we can look at and try to make some inferences about wait times.

SENATOR NGUYEN:
Is it accessible or would it be burdensome and require multiple data people we obviously do not have?

MS. WEEKS:
This is something we could do, but it would take us some time; however, we do have data analytics and an Office of Analytics team. This looks like one study, not an annual study. It would take us some time to do it, but, I do not think it will be a massive undertaking.

CHAIR DOÑATE:
I would like a quick clarification in the amendment about wait time. When I hear wait time, I think of how many minutes that patient waited in the waiting room. What is the specification you are setting for parameters?

DR. BARON:
It is about the time from the initial referral for a subspecialty appointment to being in the office for that referral.

MS. LOGAN-PARKER:
We do have wait-time statistics at Cure 4 The Kids that is available for a variety of different categories. For example, we currently, as of this morning, had 49 patients on the waitlist who have not even made it to the scheduling queue for newborn screening evaluations. Our genetics program has a yearlong waitlist. Currently, we have 49 patients on the waitlist to even be screened at Cure 4 The Kids Foundation to be assigned to a physician. This is one snapshot

in time, but that is a significant number of potentially very ill children waiting for appointments.

SENATOR NGUYEN:
I really like this bill. This is something that is important across the aisle and to our State. An increase in the Medicaid reimbursement rate of 10 percent would make a significant difference. Would that bring us to a competitive rate? How did we land on that percentage?

DR. BARON:
When I last looked at the statistics on a heat map of the entire U.S. state by state, states with our provider-to-patient ratio—such as Alaska and Montana for Medicaid reimbursement—were averaging 1.16 times Medicare rates. Nevada currently provides about 0.8 to 0.85 times Medicare rates. A 10 percent increase gets us closer, not quite to Medicare rates, but gets us closer. Medicare rates at the hospitals will tell you that is the breakeven point in providing care. For us, it is a little better than that.

GEORGE ROSS (Hospital Corporation of America, Sunrise Children's Hospital):
We support S.B. 255. Many of you have visited Sunrise Children's Hospital and have seen the neonatal intensive care unit, pediatric intensive care unit and the serious illnesses those kids have. Most of them, or a great many of them, are uninsured or on Medicaid. We strongly support this bill and the 10 percent increase. We strongly support the calculation to figure out where the shortages are and what we can do to add 10 percent more to their reimbursement.

At the Medicaid meeting, Administrator Weeks pointed out there are 920,000 people in Nevada on Medicaid. Forty-four percent of those are aged 0 to 18. Another way to look at it is that 55 percent of Nevada's births are Medicaid kids and that does not count the undocumented. This is a tremendously horrible problem, and I encourage you to pass this bill.

Senate Bill 255 is a strong first step in trying to address this. We have a gigantic problem with a two-class medical system. Many of us are lucky enough to have insurance with relatively full networks. But we have a large portion of the population on Medicaid, and it is incredibly inequitable. Both I and the Health Care Education Association are incredibly encouraged to hear so many of you in support of this bill. We strongly urge its passing.

WILL PREGMAN (Battle Born Progress):
We support S.B. 255, to amend the State Plan for Medicaid to increase the reimbursement rate for children with cancer and other diseases. We support measures that generally increase access and help Nevadans afford critical medical care. We think no child and their family should be left confused or doubtful that Medicaid can cover the illness their child is experiencing.

PHILIP M. PALERACIO, D.D.S. (The Dental Center of Nevada):
I support Senator Buck and would also like to express my concerns about the lack of limited access to healthcare services for Nevadans. This problem is compounded by a lack of available physicians, dentists, nurses and other healthcare providers. The retention of providers could be attributed to low fees or subminimal reimbursement for services rendered. In this manner, it will affect the quality and access to health care in our State.

We all know that going to medical and dental school is cost-prohibitive. Young generations do not wish to start life with a half-million-dollar student loan. With the present reimbursement status for providers, this becomes an unattractive State to make a living for doctors and other allied healthcare providers. Many physician friends expressed their dismay about the $20 to $30 reimbursement per patient visit. The same situation applies to us as dental practitioners in Nevada working under Medicaid programs. From low reimbursement to increased patient load wrapped by our litigious society, the quality of our health care undeniably will suffer. I ask all of you to support our healthcare workers. We want to have healthy Nevadans. Always remember, healthcare providers save lives regardless of the reasons. Healthcare providers make a great difference in our lives.

SUSAN B. PROFFITT (Vice President, Nevada Republican Club):
Senator Buck, this is a good bill, well written and much needed. I agree with everything Dr. Baron said. I have firsthand experience with our medical facilities and what is available. I am not indigent, but I was assigned to a pediatrician when I went on Silver States Insurance because there was not a doctor that could take care of a senior citizen with disabilities. I would like you to address those issues because we have a real lack there.

SENATOR BUCK:
My son had bloody noses and was sent to Cure 4 The Kids. I was scared to death, looked around the waiting room and thought how lucky I am to have

insurance and the means to take care of him. But what if you do not? I want to be a champion for these children, so they can get the necessary care they need. Thank you so much and the rest of the Committee for hearing and considering my bill.

CHAIR DOÑATE:
We appreciate you joining us, and we know this is an important issue. Hearing no one in opposition or neutral, we will close the hearing on S.B. 255.

We will now move on to S.B. 315. We have with us, Senator Scheible to present the bill.

SENATE BILL 315: Makes revisions relating to the rights of persons with disabilities and persons who are aged. (BDR 38-808)

SENATOR MELANIE SCHEIBLE (Senatorial District No. 9):
I am presenting S.B. 315, which establishes the Bill of Rights for Persons with Intellectual, Developmental or Physical Disabilities or who are Aged. I have brought three other presenters who will explain the bill. My intern, Erin Shaffer, will walk us through the bill, followed by Eric Jimenez, who will provide background and details, and last will be Santa Perez to speak on the importance of the bill.

ERIN SHAFFER:
I am an intern to Senator Scheible providing background information and amendments to this bill. This bill takes tremendous steps in protecting the rights of people with disabilities and people who are aged by establishing the Bill of Rights. It ensures the right to bodily autonomy by protecting individuals' ability to make decisions that affect their lives, including decisions regarding personal property and finances, location of residence, and the development of a home- and community-based care plan.

While receiving services from a home- and community-based services waiver, this bill also guarantees that an individual is treated with dignity and respect; lives in a safe and sanitary environment with reasonable privacy and independence; has access to adequate nutritious food; practices the religion of choice or abstains from the practice of any religion; receives timely health care; has access to educational, rehabilitation and recreational opportunities; and selects a family member or advocate to enter into a supported decision-making agreement, among other things.

This bill also establishes the Bill of Rights for Pupils with Disabilities. With many of the same guarantees from the aforementioned Bill of Rights, this section also provides assistance and counseling for higher education, allows for education in financial literacy as well as the Nevada Achieving a Better Life Experience, ABLE savings program. For pupils with disabilities who are enrolled in public school or are receiving special education services, this Bill of Rights guarantees autonomy and equal opportunity in all aspects of life.

Within this bill is a proposed amendment (Exhibit N) from Erik Jiminez at the Office of the State Treasurer. The amendment clarifies section 1 of the bill, which only applies to existing services provided through the home and community-based services waiver.

Section 1, subsection 2, paragraph (g) is revised to clarify the extent that certain ancillary services would fall under the provisions of this bill. It refines section 3, thereby establishing the Transition Bill of Rights for Pupils with Disabilities. This would apply to older children with disabilities who are also receiving transition services through an individualized education plan (IEP), also known as an IEP. Lastly, this amendment makes various changes in section 3, subsection 2 to outline the various rights afforded to individuals under the new Transition Bill of Rights for Pupils with Disabilities. This Bill of Rights guarantees autonomy and equal opportunity in all aspects of life.

CHAIR DOÑATE:
Is the amendment that you reference the one sponsored by the Nevada Governor's Council on Developmental Disabilities?

ERIK JIMENEZ (Chief Policy Deputy, Office of the State Treasurer):
No. It is the one proposed by me in Exhibit N.

I will provide you some background on how we got to this bill over the last decade. I have been an advocate on how to strengthen existing programs and services and to advocate for systemic change for Nevada's largest minority group, which is people with disabilities. While we care about them, they tend to be forgotten in some of these important conversations because they do not have lobbyists. We have tremendous federal laws like the Americans with

Disabilities Act (ADA) and the Individuals With Disabilities Education Act (IDEA) that provide baseline federal protections for people with disabilities. Often, when it comes to our federal agencies, those become box-checking exercises and paperwork exercises; they do not consider the monumental strides that we have made in disability rights over the last 40 or 50 years. This bill came from the community. It came from a promise I made to Regent Sam Lieberman, who sadly is no longer with us, that we would find ways to strengthen the services that are provided through Medicaid, home- and community-based services waiver and for our kids in the school system.

This bill is modeled after two states. The state of Ohio has a Bill of Rights for People with Developmental Disabilities, and the state of Massachusetts has furthered that. Thanks to the work of many State agencies and stakeholders, the amendment we are presenting to you today goes a long way in helping to advance these rights for folks. It increases the person-centered rights that are provided through the Medicaid home- and community-based services waiver. There has been robust conversation this Legislative Session and in sessions past about how we can move people with disabilities out of institutionalized settings, have them obtain competitive integrated employment within the community, pursue higher education, join a trade or graduate with an alternate high school diploma. Some of our Medicaid services do not take these into account.

This bill would provide a prominent statement from the Legislature that says when we are providing Medicaid services under the waiver, we are going to keep the person in mind first. That may differ from the things we have done in the past. It will go a long way in improving services and telling people they do not have to be institutionalized or settle for less. They can choose what kind of care they get and can voice grievances if that care is not what they think it should be. They and their families can rest assured that they can have a little more ownership in what that care looks like.

Section 3 differs from some of the other states that have a similar Bill of Rights. If we are providing this new kind of concept in how we provide disability services in the State, how can we start that conversation earlier with kids? We have federal protections, such as IDEA, which are available to parents since young kids in the school system cannot make decisions for themselves. In conversations with the wonderful team at the Nevada Department of Education, Office of Inclusive Education, we have produced a Transition Bill of Rights. The idea is when children reach about aged 14, they start to think about what to do with their lives. Maybe they want to go to college; or perhaps the traditional education model is not working for them, and they want to work with their IEP team to figure out a different path going forward. How can we strengthen the students' rights and provide them with some ownership in what they want life to be like?

We have not done this before. This is one of the largest disability bills ever considered by our State, even though it is only five sections. It would have monumental effects on how kids and their families can start to move forward to a more independent future. The importance of this bill became even more apparent with a recent U.S. Supreme Court decision, where the Supreme Court unanimously said that parents and students with disabilities do not have to go under the lengthy IDEA process to sue for grievances. If parents believe that their children are not getting all the rights and services that are protected under IDEA, they can instead sue upon the ADA standard. This bill is important because it shows the federal government that our State would take action for our waiver and that we take IDEA services 100 percent seriously and that we are working with families to help them live independently.

SANTA PEREZ (Chairperson, Nevada Governor's Council on Developmental Disabilities):
I encourage you to approve this bill. The ADA gave the disability community a great springboard to ensure our rights as American citizens, but we need more. As a person with a significant disability, I need my Medicaid waiver to survive, but that does not mean I have to give up my human rights. I like having choices regarding my life; they may be right, or they may be wrong, but it is my life. When we receive waivers through Medicaid, there is so much that is out of our control. The Bill of Rights for people with disabilities will ensure that we have a say in navigating our lives. We want the same things as everyone else. We want the right to choose the way we live, love, play and work in our communities.

We want our students to be informed about the services in our communities so that when they are adults, they can be informed citizens and contribute to society. We want the best for our kids, but they need to know every available option. Please support S.B. 315.

SENATOR STONE:
Could you please just elaborate again on that U.S. Supreme Court decision and what was the name of the case?

MR. JIMENEZ:
It is a new U.S. Supreme Court decision, so we are all digesting it. The case is *Perez v. Sturgis Public Schools*, and it was a 9-0 decision. The IDEA allows a lengthy grievance process for families and students if they have a perceived violation of their rights protected under federal law. The U.S. Supreme Court case involved a blind student who was not given accessible resources through the school district for most of his schooling, namely interpreting services. The Court said that they could then sue under the ADA, which is a much faster and a stronger process. While the intent of S.B. 315 is not to sue anyone or our government agencies, it is about how we can strengthen our programs now to avoid potential litigation in the future.

CHAIR DOÑATE:
I have one question regarding your comments about your coordination with Regent Lieberman. He was my Regent when I was at the University of Nevada, Las Vegas (UNLV), and he was a guiding light for many of us. To now see this bill is a good moment. Have you introduced this legislation before? Is this the first time the State is looking at it? It would be great if you can give us some context.

MR. JIMENEZ:
This is the first time we are introducing this concept. We had some advocates come to us and say they were doing this in other states. We had conversations with Regent Lieberman before he passed away about structural changes that could take place, and this is the synthesis of that. We have made a lot of progress over the last couple of sessions. I do not want to diminish that progress, but this is a whole new way to look at services and better provide them.

MARLENE LOCKARD (Service Employees International Union, Local 1107):
We support S.B. 315 and the Bill of Rights that it provides in special new services for students. I, too, am honored to support a bill that Regent Sam Lieberman would have loved to see come forward.

KIERRA CAPURRO (Nevada Blind Children's Foundation):
We support S.B. 315 and believe it will improve the livelihoods, education and services for disabled and blind Nevadans. Recently, some of the Nevada Blind Children's Foundation members visited the Legislature and were introduced on both the Senate and Assembly Floors. Hearing their stories eliminated the disparity between disabled children and constituents in our State. Nevada is one of seven states in the Country without a school for the blind, making Nevada one of the most underserved states for the blind in the entire Country.

Some children who are blind in the public school system get placed in special education classes. While the only disability they have is blindness or visual impairment, it can take years for these students to get out of these classes, limiting their educational growth and lowering their chances of going to college, a statistic that is already so low for those who are blind.

We support the bill and the proposed language and the added amendment by Mr. Jimenez and especially on the extensive rights afforded to those who are disabled and respect their IEP within this bill. By recognizing and addressing these needs, you will help these individuals become more self-supporting and independent and will save State revenue in the long run.

EDDIE ABLESER (Opportunity Village):
We support S.B. 315 and are thrilled that a bill such as this is brought forward for so many individuals—on waivers, with intellectual developmental disabilities, on the physical disability and age waiver who have so many needs every day. A bill such as this codifies those needs and the rights embedded in them through the State to ensure that they are being served in appropriate ways and their voices are being heard. This bill is so important and brings to light the needs of our students in the education system, particularly the transition system.

We support the bill and the amendment. We appreciate Senator Scheible and Erik Jimenez for working so diligently on this bill and bringing all the stakeholders to the table.

MR. PREGMAN:
Battle Born Progress is in support of S.B. 315. Persons with intellectual, developmental or physical disabilities, who are receiving home or community care, deserve to live with dignity and respect.

We want to recognize that part of the inspiration for this bill was the titan of education advocacy and former Battle Born Progress Board Chair, Regent Sam Lieberman. Those who were privileged enough to know Sam understand that he faced unique challenges from his own struggle with a disability. Throughout his life, he blazed a trail for the rights of people with disabilities that inspired this legislation you see before you today.

People with disabilities who receive care should have the ability to manage their own finances, have personal records handled with confidentiality, be treated as equal citizens and have access to the education that they wish to pursue.

The rights of people with disabilities are fundamental just as any other civil rights. We urge you to support S.B. 315, in the memory of Regent Lieberman and for the people of Nevada.

JONATHAN NORMAN (Nevada Coalition of Legal Services Providers):
Before I was in my current position, I represented families in IEP and Section 504 due process cases with the Clark County School District, ensuring that they were receiving the education they were entitled to under federal law. When I read this bill, it was exciting, not only for the statements about the rights they have but also as a tool. When you can point to documents like this, that show they are thought of and have the same place and rights as everyone else in our society, it is powerful. I represent foster kids and the foster care Children's Bill of Rights. They are powerful messages in addition to what they substantively do.

STEVEN COHEN:
I support S.B. 315 and have submitted my written testimony (Exhibit O).

CHRISTINE ESSEX:
I support this bill. I have a disabled son who is incarcerated and has several of these issues. If this bill is taken into consideration, I can better advocate for him and his rights. That is why I am supporting this bill.

KATRINA OJEDA:
I support this bill. My son is on the autism spectrum. We need more funding for families on the spectrum and more respite and therapy for my son. Therefore, I am supporting this bill.

CONNIE MCMULLEN (Personal Care Association of Nevada):
We would like to go on record in strong support of S.B. 315.

CATHERINE NIELSEN (Executive Director, Nevada Governor's Council on Developmental Disabilities):
I have submitted my written testimony (Exhibit P) in support of S.B. 315. Our friendly amendment (Exhibit Q) adds our Nevada Governor's Council on Developmental Disabilities, along with the Aging and Disability Services Division and vocational rehabilitation. We are the entity that has been identified by the Developmental Disabilities and Bill of Rights Act to provide these tasks.

MAX KIM LOWE (Vice Chair, Governor's Council on Developmental Disabilities):
I support S.B. 315 because our rights are fundamental freedoms guaranteed under the U.S. Constitution and the right to life, liberty and the pursuit of happiness regardless of who we are. This is especially important to those with a disability.

Those who utilize services through social service agencies, both in the public and private sector, have had their rights continually violated. For example, recently the U.S. Department of Justice reported on an investigation into Nevada's violation of the ADA Title II, 42 USC section 12132, by denying children with behavioral health disabilities, treatment in the least restrictive environment within their communities and homes. Without S.B. 315, the State will continue violating the rights of those with disabilities. As a person with a disability, on the community home-based waiver program and a client with Desert Regional Center, I have had experiences with this situation. Even as an adult, I am lucky to have an advocate, which is what people do not realize they have the right to. Therefore, I support S.B. 315.

RAQUEL O'NEILL (President, Blindconnect in Nevada):
Blindconnect is a small nonprofit that has striven to provide gaps in services for newly blind adults in Nevada since 1998. We have provided these services for many years because, unfortunately, in the U.S. when you lose something as vital as your eyesight, you are typically not sent to a rehabilitation hospital, but you are sent home. This leads to a lot of misconceptions.

There is a lack of awareness surrounding vision loss in and of itself. The fear continues in individuals, by the time they start receiving our vital services to regain independence, it is typically six months to three years of staying within their own homes, often described as "being a prisoner of their own homes" due to the fear involved in losing eyesight.

We are in full support of S.B. 315. We would like to see section 1, subsection 2, paragraph (g) of this bill include ancillary services for individuals who are blind to receive blindness-related orientation, mobility services and vision rehabilitation therapy. We want to draw attention to the specific specialized needs of individuals with blindness in Nevada. Without your support and your help, individuals experiencing vision loss will continue to stay at home and not realize their potential or their capacity for independence.

SENATOR SCHEIBLE:
We are here to expand services for people with disabilities, to strengthen the rights and protections that they have under law and to provide more programming in Nevada. This bill sets up the legal foundation to do that. This bill does not actually mandate that any State agencies provide additional services that they do not already provide. But it sets up the foundation to ensure that the services provided are done in a person-centered manner and that the people provided with services are involved in making decisions about their own lives and their own services. It creates a platform for future legislation to expand the services that we are able to offer to people with disabilities and students with disabilities in our community.

CHAIR DOÑATE:
I will close the hearing on S.B. 315. I will now open the hearing on S.B. 390.

SENATE BILL 390: Enacts provisions relating to neurodegenerative diseases. (BDR 40-135)

SENATOR MELANIE SCHEIBLE (Senatorial District No. 9):
Senate Bill 390 enacts provisions and creates a registry for people with neurodegenerative diseases. I am joined today again by my intern, Erin Shaffer from the University of Nevada, Reno, as well as Dr. Mindy Lokshin, Chair of the Parkinson Support Center of Northern Nevada. We also have Dr. Jefferson Kinney from UNLV, Department of Brain Health joining us on Zoom. I will briefly review the background and purpose of this bill.

The purpose of this bill is to create a registry that allows people with Parkinson's disease, Alzheimer's and other neurodegenerative diseases to opt into research opportunities to allow us to better understand these illnesses and conduct further medical research so that we can start diagnosing and treating people earlier. In the future, we might even prevent or cure Parkinson's, Alzheimer's and other neurodegenerative diseases.

Dr. Lokshin can tell you more about how and why we connected over this bill a few weeks ago. We have been collaborating diligently with several stakeholders, including the UNLV Brain Health Department, Nevada Department of Health and Human Services and other people who are passionate about taking care of those in the community who struggle with chronic illnesses like Parkinson's. Through those conversations, we have discussed several different approaches to creating such a registry.

There would be an amendment before a work session to conceptually address questions about where this registry is going to be housed, what it is going to do, and how it is going to work. As we learned in this process, there are several different ways that a registry can function and can provide some real benefits to the State. With this registry, the goal is to ensure that we have a process, an avenue for communicating with people who are affected by neurodegenerative diseases, to connect them with resources and with those research opportunities.

MS. SHAFFER:
Sections 3 through 8 of this bill define terms such as healthcare facility, medical laboratory, neurodegenerative disease, Parkinsonism, among other definitions relevant to sections 2 through 17 of this bill.

Section 9 requires the Chief Medical Officer to establish and maintain a system for reporting information on Parkinson's disease, Parkinsonism, Alzheimer's and other neurodegenerative diseases as prescribed by regulations adopted by the State Board of Health. Sections 9 and 10 require hospitals and certain other facilities and/or providers of health care to report certain information as prescribed by the Board of Health regarding cases of neurodegenerative diseases diagnosed and/or treated at the facility.

Section 11 defines the procedures by which a patient may opt out of having information regarding their neurodegenerative information reported, other than the diagnosis. Section 12 of this bill requires the chief administrative officer of each hospital or other facility in the State to submit records to the Chief Medical

Officer. These are records for certain cases of neurodegenerative diseases, for the abstraction by the Division of Public and Behavioral Health (DPBH) of the DHHS. This section also provides the penalty against an entity that fails to make these records available for abstraction.

Section 13 states DPBH shall publish these reports and use the information to report and assess trends in the use of healthcare services and by neurodegenerative patients. This report must also include the locations where patients with neurodegenerative diseases reside and information on patients diagnosed over the age of 60, among other provisions.

Section 14 provides that the Chief Medical Officer, or other qualified person assigned by the administrator of DPBH, is to analyze the information to determine any trends in the usage and access to healthcare services. If the administrator or designated individual determines that a trend exists, they shall work with the appropriate governmental, educational and research entities to investigate the trend, advance the research and facilitate the treatment. Section 15 requires DPBH to apply for and accept gifts, donations and/or grants to carry out the provisions of this bill.

Sections 10, 16 and 18 provide confidentiality of the patient's information along with that of the provider and/or healthcare facility. Section 17 provides immunity from liability for any person who discloses information in good faith to DPBH in accordance with the requirements of sections 9, 10 and 12.

MINDY LOKSHIN, M.D. (Chair, Parkinson Support Center of Northern Nevada):
I am a family physician with over 30 years of experience in medicine and education advocacy with a master's degree in public health. I am also the family member of several people with Parkinson's disease. My father, my mother's sister, and my mother-in-law passed from Parkinson's, and my sister-in-law developed Parkinson's in her late thirties while working as an optometrist.

Over the past several years, I stopped practicing medicine and have become involved with the Parkinson's community. I have also become better self-educated in many aspects of the disease. Several key points have become clear to me—the Parkinson's community is severely under-recognized and underserved. Most people with the disease are not diagnosed for many years and then they still have trouble finding a neurologist with expertise in the field. Although new research seems to suggest that someone is diagnosed with

Parkinson's disease every six minutes in the U.S., there are not good numbers of how many people are living with the disease. Parkinson's disease does not necessarily shorten your lifespan, it simply presents more challenges for that life. Although there are officially 10,000 people with Parkinson's disease in Nevada, we estimate there are at least 3 times that number who have not been properly diagnosed and not properly treated. There is a severe shortage of neurologists with proper subspecialty training.

Without good epidemiologic records, it is hard to properly allocate resources for research, public health and medical care. As we know, Nevada is one of the fastest-growing states in the Nation, particularly in the older population. Parkinson's disease can affect people in their twenties to their nineties and affects both men and women. At least 10 percent of people with Parkinson's disease have symptoms before the age of 50. That means it affects our workforce, parents of young children and our veteran population. Nevada has a large veteran population. Parkinson's is associated with toxic exposures, such as Agent Orange and burn pits. It is associated with head injuries; Muhammad Ali is a classic example, and head injuries are frequent among veterans. It affects our rural and Hispanic/Latinx communities due to pesticides and other chemical exposures.

When someone has symptoms of Parkinson's disease and they are not properly diagnosed or treated, they feel scared, frustrated and all alone. Parkinson's is a disease that is visible with tremors, slowness of movement and sometimes depressed facial features. It makes it hard to go out and socialize, hard to eat in public, and social isolation leads to other illnesses.

Senate Bill 390 attempts to address the issues of Parkinson's disease, but it is expanded to other neurodegenerative diseases such as Alzheimer's and other dementias, such as Lewy body dementia, frontotemporal lobe dementia and other chronic problems like multiple sclerosis (MS), Lou Gehrig's and Huntington's diseases. All these neurologic diseases are chronic and progressive diseases of the brain. They affect people of all ages, their families, coworkers and their businesses. The goal is to create a research registry that would help determine the numbers and demographics of people diagnosed with these diseases. This would allow people to opt in or opt out of participating in research, so that we can find a cure or find ways to prevent all these illnesses. Only with good epidemiologic data can we hope to find ways to prevent and treat these terrible, debilitating and isolating conditions. I urge you to support S.B. 390.

JEFFERSON KINNEY (Chair, Department of Brain Health, School of Integrated Health Sciences, University of Nevada, Las Vegas):
My specific area of expertise and research is the investigation of neurodegenerative diseases. Primarily, what we focus on is biomarkers of diseases to better identify, diagnose and track treatment efficacy. We partner with several clinicians and other researchers to develop a cohesive group of researchers who can investigate these debilitating diseases.

I offer my support for S.B. 390 because the creation of a voluntary registry provides benefits in the advancement of research, which is desperately needed for all these neurodegenerative diseases. It also provides a tremendous benefit for the participants who sign up for the registry and agree to be part of the process. Several other states have established registries like this, where information is distributed, and people are able to opt in to participate in the registry. It can connect them to resources and support groups. It can provide information to people who are not sure whether they should be seeing a physician. Nevada is the second-fastest growing state in terms of population over the age of 65. You have heard the phrase "a neurology desert"—we simply do not have enough specialists in this field. There is a gap to seek out and find information about what is available in specific communities. There is a much larger gap in terms of the availability of treatment.

A research registry provides the opportunity for what we call citizen scientists, for people to opt in to participate in research. Even if they do not want to participate in the research, they have access to information about support, community organizations, and ways to learn more about Alzheimer's, Parkinson's or MS. We do work related to traumatic brain injury, so there is a connection between all of these.

The best examples I can provide are Emory University in Georgia, which has developed a registry like this, and a similar system in North Carolina that has been particularly productive. It is also worth mentioning that Nevada is a unique place based on our demographics. There is such a good diversity of individuals in Nevada. This is a tremendous strength in the research that will help us try and answer these questions. It is also an opportunity for us to engage communities across the State from rural to urban where there are several extremely important questions that need to be asked. There are also many people who want to be involved in the process of asking those questions.

Our group here, as well as several other collaborators we work with, welcome the opportunity to work on and develop this registry because it provides an opportunity for our research. It provides an opportunity to connect with people throughout Nevada. It also gives us the opportunity to compare Nevada to what is happening in other states that have similar registries. We can collect epidemiologic data about incidents and locations. There are details about specific studies and, most importantly, the availability of information to participants on what is available here, the progress that is being made and a way to weave this all together into something that advances the science. It also advances the community in a State that has so many individuals who are at risk for these neurodegenerative diseases.

CHAIR DOÑATE:
Is this modeled after other states? I know California just did this in 2021.

SENATOR SCHEIBLE:
It is both modeled after other states and other registries within Nevada, including the Cancer Registry and the Lupus Registry, although our vision for it is a little bit different from those registries—less focused on statistical data or numerical data and more focused on the research side of it. We have also been working with The Michael J. Fox Foundation to ensure that the kind of information that the registry would be obtaining would be useful in a multistate effort to coordinate Parkinson's research.

CHAIR DOÑATE:
It is not just collecting who gets diagnosed with this disease, but it is also providing the research services that could be available to them. So, it is kind of both?

SENATOR SCHEIBLE:
Yes, that is correct.

CHAIR DOÑATE:
How many registries do we have in the State right now?

JULIA PEEK (Deputy Administrator, Division of Public and Behavioral Health, Nevada Department of Health and Human Services):
Nevada has four registries of this type: cancer, lupus, sickle cell and, if this bill is passed, neurodegenerative diseases. It is an incidence registry but also initial treatment registry in the way it is drafted in the bill.

CHAIR DOÑATE:
When it comes to tracking diseases nationally, is there a means of also supporting public health infrastructure that must come with this disease tracking? In general, it is important to have registries like this for certain initiatives. Therefore, we want to ensure, as Senator Scheible mentioned, that when someone gets diagnosed, it is not just keeping track and reviewing why the statistics occur, it is also providing services for when the diagnosis comes. Are there certain parameters that we should be focusing on for other legislation, as to what our public health mechanism can do for disease tracking? Is that the capability that we have right now? What does the future look like for infrastructure for this particular subset?

MS. PEEK:
Any registry should develop some level of infrastructure. We would have a fiscal note on this to ensure that it is staffed to collect the data and provide other data that is helpful. It should never be collected and put into a black hole. What we need is to make it actionable, based on this information. What should we do? Is there prevention or intervention that needs to occur along with this? It does not necessarily need to be DPBH that is doing that intervention. We have many experts in Nevada who would use that data in various ways.

As far as general public health registries, the Centers for Disease Control (CDC) is really trying to push for registries such as this. They typically come with grants that are very competitive. Two sessions ago, development of a registry for sickle cell was passed, and we are just now getting the opportunity to apply for grants to make the registry more robust, using that information for interventions and telling the patients' stories.

The benefit of a registry such as this is to understand how patients navigated through the system, which is more important than incident data because we often hear from diagnosed patients and have challenges accessing care. An all-payer claims database would help us see how they access care over time. Sometimes, you develop a specific incidents registry. Sometimes, we utilize other data sources and provide information. There is great opportunity whichever path is chosen.

CHAIR DOÑATE:
You answered my follow-up question, which was how does this all relate to when people get diagnosed and go through the segments of our healthcare system? How does that get collected and how do we differentiate between what this registry would collect versus the all-payers claim database? The greater question is, if only there was a hub to collect and review what this all looks like in the long term.

CHARLES DUARTE (Alzheimer's Association):
On behalf of the more than 50,000 Nevadans living with dementia, their families and care partners, I support S.B. 390, as amended, which establishes a disease registry for neurodegenerative diseases including Alzheimer's disease.

Nevada has the third-fastest rate of growth of Alzheimer's disease in the Nation. This bill will allow the State to collect information on these diseases for further research, including research that may lead to potential treatments and cures.

BEN SCHEIBLE:
I am in favor of S.B. 390. I love this American democracy in action. I am a retired real estate professor at Truckee Meadows Community College and a recovering attorney. Most relevant is that I have Parkinson's disease. I did not know this until I got it, but it affects my voice—not always, but it is a raspy voice. Parkinson's disease affects that.

If you are familiar with my last name, it is because Senator Scheible is my daughter. It is appropriate that we consider this right now because this is Parkinson's Awareness Month, and my presentation has changed based on two things I heard today. I believe the doctor in Las Vegas said something about opting into this program. That is not what the bill does. The healthcare provider is required to provide the information to the registry. That caused me concern except that there is an opt-out provision. An opt-in traditionally, in any kind of system, results in much more data. Very few people are anticipated to opt out.

The second thing, the Alzheimer's Association says there are approximately 49,000 people in Nevada with Alzheimer's over the age of 65. The Parkinson

Support Center of Northern Nevada says approximately 15,000 have Parkinson's. We have a dispute on that because 10,000 was quoted a little while ago.

If we could have a registry, I could provide you with more accurate and precise information on that. So, those are the two things I noticed today. First, this is a data-driven model for research, and problem solving requires us to gather the right data. Second is that we know the data is accurate and is interpreted properly. The first two are served by the registry; the centralization of the data and making the same data collected will be helpful in that regard.

The third one, I am not sure how to handle. The classic example of misinterpretation of data was a serious crime rate in Brooklyn, which for many years was directly correlated to a rise in ice cream sales. Well, you would be a little remiss to sigh "we got it, we can reduce the crime rate by simply prohibiting those damn ice cream sales." It would be doing damage to correlation versus causation. There is no error-proof system, but the centralization and consistency in the way the data is gathered will help with those first two criteria. I urge you to vote in favor of S.B. 390.

MS. PROFFITT:
I support this bill and like what you are doing here; we need it. I had to wait six months to see a neurologist, and now my husband is having some dementia issues. We desperately need to find some solutions, and I commend you all for making this bill possible. I have some questions that may put me in the neutral zone. I have an issue with HIPAA laws. There are people that really need to protect their identity and when you say they can opt out, there are a lot of times that information does not get passed on to the people that should know that. So, when you talk about a hub, how are you going to be putting that information out there?

I have a suggestion and I am curious how you are going to plan to do that. I would want to opt in but would not want my name shared in a big database. I would want a number, a case number, something like that, that really does protect the identity of the patient. You would get 100 percent participation if you did something like that. Thank you for addressing this. We need more medical services in the State, and I see that you are trying to do that. Another way to get more medical doctors to come to the State is to improve the schools quickly because they are not coming here if their children are not going to get educated.

JULIA PITCHER (Director of State Government Relations, The Michael J. Fox Foundation for Parkinson's Research):

I am thrilled to join you all on the phone tonight. I do wish I were there in person, but I am coming from the Washington, D.C., area, and am home with my children on spring break. Normally, I have a structured presentation, and everything that has been said this evening by Dr. Lokshin, Dr. Kenny and Senator Scheible has been spot on. There is every reason why we have made this the No. 1 priority for State legislation for The Michael J. Fox Foundation.

I will answer a few questions I heard through testimony, and you all have my written testimony (Exhibit R). I have a document on our initiative to answer questions about registries (Exhibit S). There are confidentiality provisions provided in the bill to mask the identify of patients. Any names would be concealed; they would become a number that would then be part of the data set. As Ms. Peek from DPBH stated, the job is to get the information and publish incidents and prevalence, then figure out ways that we can connect with the community in Nevada.

There was a Senator who asked a question about a hub. Our longer term goal is to connect with multiple states and with the CDC. There is a hub that was passed by federal legislation about eight years ago, and it is known as the National Neurological Conditions Surveillance System. Their pilot project is with Parkinson's and MS. The goal with the federal government is to add Alzheimer's into that program. That will be a national hub for researchers to do patient contact surveys, clinical trials and other research in this Country and potentially abroad. The guidance we have been given from the CDC is to get as many states as we can online this year. We currently have this exact bill running in nine states, which are Oregon, Colorado, Nebraska, Missouri, Ohio, Maryland, New York, Massachusetts and Hawaii.

Now we have added Nevada and are hoping to pass it in as many states as possible this year and get as many online by 2024. Then we would go back to the CDC and flip the switch over the next year or two as you come online and start to collect the data in the national hub to better give more substantive data for Parkinson's research. We support The Michael J. Fox Foundation, we support the bill and are thankful to Senator Scheible for putting the bill forward and hopefully have a favorable vote.

BLAYNE OSBORNE (Nevada Rural Hospital Partners):
We are here in neutral today but appreciate and support the need for this bill as I lost both of my grandfathers to Alzheimer's and dementia. Senator, we appreciate your suggestions on getting a data hub that could house all these registries. We would certainly support that as well because Nevada Rural Hospital Partners has taken the time to list all these registries and all the public health-reporting requirements on our critical access hospitals on which there is a fairly good burden now.

If you will go to <data.nhrp.org>, you can see the full list. It includes abuse, neglect, behavioral health, blindness, burns, cancer, communicable diseases, community, paramedicine, controlled substances, COVID-19 deaths, devices, drugs, epilepsy, finance, firearm wounds, healthcare-associated infections, hospital administration, immunizations, infectious diseases, knife wounds, lab reporting, lead licensing, long-term care, lupus, meaningful use, macro and equipped quality obstetrics, OSHA overdoses, patient safety checklists, pediatrics, pharmacy, radiology, restraints, central events, sexual assaults, sickle cell, state of an emergency syndrome, surveillance trauma, vital statistics and workplace violence.

So, there is already a significant effort underway. Our rural hospitals struggle with that as we often charge individual nurses with being the ones to report these items. As we move forward throughout this process and acknowledge that, it is our hope that we can reduce regulations, streamline this reporting and get this data to where it needs to go.

CHAIR DOÑATE:
I reiterate my commitment and think I speak for all of us when I say our commitment is to working with the stakeholders to ensure that this registry is feasible in Nevada and make it a reality.

We will close the hearing on S.B. 390 and move on to our last bill, S.B. 317. I will go ahead and open the hearing on this bill.

SENATE BILL 317: Establishes provisions relating to resources for persons experiencing homelessness. (BDR 38-981)

SENATOR MELANIE SCHEIBLE (Senatorial District No. 9):
Senate Bill 317 is a short bill that does something especially important. It allows people who do not have a permanent address to use the address of a provider of services to the homeless as their permanent address for purposes of applying for a job, benefits or identification (ID). These are things that get in the way of people who are unhoused to contribute in the way that they want to. Our society prohibits them from getting back into stable housing. This addresses one small piece of the puzzle to hopefully help several folks throughout Nevada get back on their feet. That is the purpose of the bill.

MR. JIMENEZ:
This bill is the product of something we heard on the Nevada Recovers Listening Tour. You may remember when the federal government stepped up, your U.S. Senators Catherine Cortez Masto and Jacky Rosen delivered $6.7 billion in federal aid through the American Rescue Plan. Over $2 billion of that was more flexible dollars that the Legislature has prioritized. We conducted a listening tour. Nevada State Treasurer Zach Conine and former Governor Steve Sisolak held 123 events over 82 days across the State. We met with constituents across the State to hear and listen to problems that they were facing and many of those requests were funding-related.

We made a commitment to folks that if there were good ideas that we heard that needed legislation, we would pursue those ideas in this Legislative Session. In one of our Reno meetings, we had meetings with homeless service providers on housing in homeless shelters. We heard one of the barriers for folks who are experiencing homelessness is often for certain things like enrolling their child in education, getting a job and applying for benefits. Sometimes you need an address to help streamline that process. When you do not have an address or just have a post office (PO) box, sometimes that can get in the way of this process.

There are limited circumstances under which the U.S. Postal Service (USPS) will authorize an individual to use a PO box. If you think I did not call my regional postmaster, you would be mistaken and that is an arduous process. Sometimes, PO boxes cannot be used for the same purposes. This bill is meant to solve a very simple problem. It is a voluntary solution to allow people who are experiencing homelessness and receiving services from one of our nonprofit providers to temporarily use an address for limited purposes, which are outlined in section 7.

SENATOR NGUYEN:
I had an office that was in downtown Las Vegas, and it was near the post office. Whenever I went to the post office to mail things, there were quite a few unhoused population that would go there and receive what looked like social security or disability checks, or other benefits. Do you know how they were or are doing that?

MR. JIMENEZ:
The USPS allows for the limited use of free PO boxes for unhoused individuals. Unfortunately, sometimes that can only take place at certain post offices and then there is a form you must complete. It is a lengthy process. While we are appreciative that the USPS does that sometimes, it does not meet the immediate needs for folks applying for a job tomorrow and not wanting it to show that they have no address on their resume. Hopefully, this bill will help meet people where they are and still allow them to use that USPS process.

SENATOR NGUYEN:
My question has to do with section 3, the definition of a Nevada resident. Can you describe how that is? I have concerns in my private professional world outside of the Legislature, about IDs, receiving IDs and getting all that. We have bills here every session about aiding individuals to get their license or ID card. Is there any reason that was included in this bill and how we came up with six months? I do not even think it is six months for other types of residencies. I am curious about what the thinking was behind both of those provisions.

MR. JIMENEZ:
We modeled this after something that is being done in our larger cities across the Country. Notably, Los Angeles has a robust process in place which you will see. That is why we have asked the Division of Welfare and Supportive Services to publish a list so we can have people understand where they can go to utilize the services. We are open to what would meet the requirements of the Nevada resident. We are trying to figure out the sweet spot of how long someone has been here. We recognize the barriers to getting IDs, which is in section 3.

CHAIR DOÑATE:
My only suggestion for an amendment would be in section 3, which says "a valid driver's license or identification card issued by the Department of Motor Vehicles." I would instead indicate that if they do not have that, they should offer to provide services or documentation from wherever they are from.

You would work with the consulate to make sure that people from another country can still receive the appropriate documentation, but maybe it is not recognized by the State, but it is still official documentation from somewhere else. That is my only recommendation. This is a good bill and is something that folks can utilize. Does the provider still have to agree to allow folks to do this?

SENATOR SCHEIBLE:
Yes, they would have to agree to allow people to use the address. To clarify again, in section 3, because of the "or" language, what we are saying is that somebody does not have to have an ID to utilize a nonprofit's address as their address. But if they have not been residing here for six months or to qualify as a resident, would show their Nevada ID or driver's license. Then it does not matter how long you have been here.

CADENCE MATIJEVICH (Washoe County):
We support this bill. I am pleased to share with the Committee that at our Nevada Cares Campus in Washoe County, we already offer the service to anyone in our community who needs an address and needs to receive mail. The mail is available for pickup Monday through Friday during regular business hours at the mail center at the front of the Campus. We appreciate that is available for everyone and, hopefully, anyone that needs it will take advantage of it.

We think that this bill provides options for those who are not in the most convenient location and may be receiving services from other providers in our community. We support this expansion and urge your support of the bill.

MR. PREGMAN:
Battle Born Progress supports S.B. 317 and thanks Senator Scheible for bringing this forward as well as the Office of the State Treasurer for hearing Nevadans during the State Listening Tour. This bill allows a person experiencing homelessness to use a provider of services as a temporary mailing address. Currently, people experiencing homelessness can face major difficulty applying for jobs, housing, education, receiving mail and other basic functions of living that most of us take for granted.

However, these social amenities are key to someone who is unhoused making the transition to get back on their feet. We should be doing everything we can as a State to facilitate this transition in a positive way, especially as the economic fallout of the pandemic continues.

DORA MARTINEZ (Nevada Disability Peer Action Coalition):
We support S.B. 317. As a blind mom with five children, when I first came to America, we found ourselves homeless ten years ago, and we needed a physical address. One of the Native homes provided us with the letterhead, and we brought it to the services that we needed and received support from that. This is a commonsense bill and a long-time-needed bill for the State.

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CHAIR DOÑATE:
There being no further testimony in opposition or neutral, we will close the hearing on S.B. 317.

There being no public comment or further business, the Senate Committee on Health and Human Services is adjourned at 6:01 p.m.

RESPECTFULLY SUBMITTED:

Norma Mallett,
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
S.B. 41	C	2	Destini Cooper	Work Session Document
S.B. 42	D	3	Destini Cooper	Work Session Document
S.B.109	E	4	Destini Cooper	Work Session Document
S.B.177	F	5	Destini Cooper	Work Session Document
S.B. 221	G	6	Destini Cooper	Work Session Document
S.B. 237	H	6	Destini Cooper	Work Session Document
S.B. 297	I	7	Destini Cooper	Work Session Document
S.B. 239	J	8	Destini Cooper	Work Session Document
S.B. 255	K	11	Senator Carrie Buck	Proposed Amendment
S.B. 255	L	11	Annette Logan-Parker / Cure 4 The Kids Foundation	Presentation
S.B. 255	M	11	Annette Logan-Parker / Cure 4 The Kids Foundation	Summary
S.B. 315	N	22	Erin Shaffer	Office of the State Treasurer’s Proposed Amendment
S.B. 315	O	27	Steven Cohen	Support Testimony Proposed Amendment
S.B. 315	P	28	Catherine Nielsen / NV Council on Developmental Disabilities	Support Testimony

S.B. 315	Q	28	Catherine Nielsen / NV Council on Developmental Disabilities	Proposed Amendment
S.B. 390	R	38	Julia Pitcher / The Michael J. Fox Foundation	Support Testimony
S.B. 390	S	38	Julia Pitcher / The Michael J. Fox Foundation	Parkinson's Research Registries