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

Eightieth Session March 29, 2019

The Committee on Health and Human Services was called to order by Chairwoman Lesley E. Cohen at 12:58 a.m. on Friday, March 29, 2019, in Room 3138 of the Legislative Building, 401 South Carson Street, Carson City, Nevada. The meeting was videoconferenced to Room 4406 of the Grant Sawyer State Office Building, 555 East Washington Avenue, Las Vegas, Nevada. Copies of the minutes, including the Agenda (Exhibit A), the Attendance Roster (Exhibit B), and other substantive exhibits, are available and on file in the Research Library of the Legislative Counsel Bureau and on the Nevada Legislature's website at www.leg.state.nv.us/App/NELIS/REL/80th2019.

COMMITTEE MEMBERS PRESENT:

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

COMMITTEE MEMBERS ABSENT:

Assemblyman John Hambrick (excused)

GUEST LEGISLATORS PRESENT:

Senator Julia Ratti, Senate District No. 13 Assemblywoman Dina Neal, Assembly District No. 7



STAFF MEMBERS PRESENT:

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

OTHERS PRESENT:

Dorothy Edwards, Coordinator, Washoe Regional Behavioral Health Policy Board Charles Duarte, CEO, Community Health Alliance; and Chair, Washoe Regional Behavioral Health Policy Board

Jamie Sellar, Chief Strategy Officer, RI International

Brian O'Callaghan, Government Liaison, Office of Intergovernmental Services, Las Vegas Metropolitan Police Department

Dan Musgrove, representing The Valley Health System of Universal Health Services, Inc.; and WestCare Nevada

Sandra K. Stamates, Program Manager, National Alliance on Mental Illness, Northern Nevada; and Member, Washoe Regional Behavioral Health Policy Board

Kevin Dick, District Health Officer, Washoe County Health District; and Member, Washoe Regional Behavioral Health Policy Board

David Marlon, President, State of Nevada Association for Addiction Professionals Mackenzie Baysinger, Intern, Human Services Network

Kendra G. Bertschy, Deputy Public Defender, Public Defender's Office, Washoe County

Debra Rilea, Board President, National Alliance on Mental Illness, Northern Nevada Robin V. Reedy, Executive Director, National Alliance on Mental Illness, Nevada William Blume, Private Citizen, Carson City, Nevada

Amber L. Howell, Director, Human Services Agency, Washoe County

Michael D. Hillerby, representing Renown Health

Sharon Zadra, Executive Director, Truckee Meadows Healthy Communities

Joanna Jacob, representing Dignity Health-St. Rose Dominican Neighborhood Hospitals

Gary Snelson, Private Citizen, Zephyr Cove, Nevada

Joan Hall, President, Nevada Rural Hospital Partners

Laura Hale, Private Citizen, Reno, Nevada

Karla Sue Brune, Private Citizen, Reno, Nevada

Alex Ortiz, Assistant Director, Department of Administrative Services, Clark County

Ryan Black, Legislative Liaison, Office of Administrative Services, City of Las Vegas

Nik F. Abdul Rashid, M.D., Pediatric Hematologist/Oncologist, Cure 4 The Kids Foundation

Linetta Barnes, President, Sickled Not Broken Foundation of NV

Georgene' Glass, Founder/President, Dreamsickle Kids Foundation

> Don Gallimore, Private Citizen, Reno, Nevada Pamela White, Private Citizen, Las Vegas, Nevada Ingrid Williams, Private Citizen, Las Vegas, Nevada

Sondra Williams, Private Citizen, Las Vegas, Nevada

Zavier White, Private Citizen, Las Vegas, Nevada

Tina Dortch, Program Manager, Office of Minority Health and Equity, Department of Health and Human Services

Chike M. Nzerue, M.D., Chief Medical Officer, Dignity Health-St. Rose Dominican Hospitals

Erica Edden, Private Citizen, North Las Vegas, Nevada Barron D. Hall, Private Citizen, Las Vegas, Nevada

Esperanza Brooks, Private Citizen, Las Vegas, Nevada

Chairwoman Cohen:

[Roll was taken. Committee rules and protocol were explained.] We are about to start doing our work sessions more frequently. If you have a bill that needs an amendment or you are still working on one, please get the amendment to us and let us know if there are any issues with it.

We are now going to our work session for <u>Assembly Bill 169</u>. Our Committee Policy Analyst will walk us through the bill.

Assembly Bill 169: Establishes the Maternal Mortality Review Committee. (BDR 40-712)

Marsheilah Lyons, Committee Policy Analyst:

[Marsheilah Lyons read from the work session document (Exhibit C).] Assembly Bill 169 establishes the Maternal Mortality Review Committee within the Department of Health and Human Services (DHHS). The bill was heard on March 22, 2019. The director of the Department is required to appoint various persons who are interested in maternal health and welfare as members of the Committee. The Committee is required to:

- 1. Review incidents of maternal mortality and, to the extent that resources are available, severe maternal morbidity in this state;
- 2. Disseminate findings and recommendations concerning maternal mortality and severe maternal morbidity to providers of health care, medical facilities, other interested persons, and the public;
- 3. Publish an annual report consisting of data relating to maternal mortality and severe maternal morbidity; and
- 4. Submit to the Legislature a biennial report containing a description of incidents reviewed by the Committee and recommendations to reduce maternal mortality and severe maternal morbidity in Nevada.

The bill authorizes the Committee to take measures necessary to perform their duties, including authority to access certain records. The measure provides that meetings of the Committee are closed to the public; their records are confidential and are not public records.

An amendment was proposed at the hearing by Catherine O'Mara on behalf of the Nevada State Medical Association [page 2, (Exhibit C)] that was agreed to by the sponsor. In addition, representatives of DHHS indicated that Nevada is preparing to apply for Centers for Disease Control and Prevention funds to implement Preventing Maternal Deaths: Supporting Maternal Mortality Review Committees, also known as CDC-RFA-DP19-1908. The application period closes on May 8, 2019. If the Maternal Mortality Review Committee is created prior to the deadline, Nevada is able to apply for the funding.

Chairwoman Cohen:

Thank you, Ms. Lyons. I will entertain a motion to amend and do pass A.B. 169.

ASSEMBLYMAN THOMPSON MADE A MOTION TO AMEND AND DO PASS ASSEMBLY BILL 169.

ASSEMBLYWOMAN TITUS SECONDED THE MOTION.

Chairwoman Cohen:

Do we have any discussion? [There was none.]

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

We will give the floor statement to Assemblywoman Monroe-Moreno and Assemblywoman Titus will be our backup.

With that, we will move on to the hearing on Assembly Bill 66.

<u>Assembly Bill 66</u>: Provides for the establishment of crisis stabilization centers in certain counties. (BDR 39-486)

Senator Julia Ratti, Senate District No. 13:

I am here to introduce a bill that a lot of other folks have done a lot of work on. I was appointed as the legislative member to the Washoe Regional Behavioral Health Policy Board, Division of Public and Behavioral Health, Department of Health and Human Services. During the 79th Session of the Nevada Legislature, testimony was provided to members of the Legislature and the public in support of <u>Assembly Bill 366 of the 79th Session</u> which supported the creation of four regional behavioral health policy boards. Those boards led to a discussion by a diverse group of legislators and members of professional and public behavioral health disciplines and included the opportunity that these boards would provide for improvement in Nevada by giving local leaders a more active voice in the decisions that are made as they pertain to behavioral health.

Presenters agreed that all regions of the state are facing unique challenges, especially in behavioral health issues, and generally agreed that each region is best qualified to address their respective issues. The Washoe Regional Behavioral Health Policy Board, along with the other three regional boards, is charged with the responsibility specified in *Nevada Revised Statutes* (NRS) 433.4295. One unique aspect of <u>A.B. 366 of the 79th Session</u> was the opportunity for each regional policy board to request the drafting of one legislative measure which relates to matters within the scope of the policy board. This session, there are four such pieces of legislation being presented on behalf of each board.

Since its inception, the Washoe Regional Behavioral Health Policy Board has met with county leadership, public and private agencies, and stakeholders to assess the needs of the county; prioritize and strategize those needs; and coordinate efforts statewide. We know that resources are limited and we do not want to be duplicative. Based on results of the research by our board, it was recognized that certain areas require policy development and/or enhancements. While several areas emerged as priorities, it became clear that there is a critical need in our community for crisis stabilization services, and ultimately, this issue became the subject of the bill draft request which resulted in <u>Assembly Bill 66</u>.

I am very proud to be a member of the Washoe County policy board. It is a very dedicated board with a wide variety of representation, really good stakeholder engagement, and really good discussions. I am very proud of the work that the board did to put this bill forward. I will turn this over to others who will present the crisis stabilization model and walk through the bill and proposed amendments.

Dorothy Edwards, Coordinator, Washoe Regional Behavioral Health Policy Board:

Our policy board has been busy collaborating with behavioral health experts in an effort to identify and understand regional needs and gaps in services that address substance abuse and mental health concerns. An issue that continued to emerge in discussions and in our research was the challenge to provide adequate and appropriate stabilization services to individuals who are experiencing a mental health and/or a substance abuse crisis, but for whom diversion to jails or hospital emergency rooms (ERs) is not necessarily appropriate. As you will see in the presentation to follow, these individuals can be better served in an environment that is designed to treat their conditions.

The Substance Abuse and Mental Health Services Administration states that research based on the effectiveness of crisis services is growing. There is evidence that crisis stabilization can divert individuals from unnecessary hospitalizations to ensure the least restrictive treatment option is available to people experiencing these crises. Additionally, a continuum of crisis services, which we propose, can assist in reducing costs for psychiatric hospitals without having an impact on clinical intervention, services, and outcomes.

The Washoe policy board began to explore best practices and successful programs in other states dealing with the subject of behavioral health. Through meetings with our state partners, the Division of Public and Behavioral Health in the Department of Health and Human Services (DHHS) introduced and supported the "Crisis Now" model which we will

be introducing today. We believe this piece of legislation is a strong step in the direction of advocacy for Washoe County. Our policy board strives to increase awareness of mental health and substance use disorder. We strive to promote emotional health and wellness, address prevention of substance use disorders and mental illness, and increase access to effective treatment and support recovery. We view this piece of legislation as an opportunity to partner with our other local resources to ensure a comprehensive approach to behavioral health crises, and we are committed to continuing our work with state, county, and other local agencies to address these issues.

Charles Duarte, CEO, Community Health Alliance; and Chair, Washoe Regional Behavioral Health Policy Board:

[A PowerPoint presentation accompanied this testimony (Exhibit D).] With me at the table today is Jamie Sellar to my left. He is the chief strategy officer for RI International, a nonprofit organization that provides crisis services in five states as well as in New Zealand. I will do a short presentation on the work of the policy board and give an overview of crisis services and the intent of A.B. 66. I will then turn it over to Mr. Sellar to discuss the work of RI International. Finally, I will go over the proposed amendments to A.B. 66.

Page 2 (Exhibit D) shows the current members of the Washoe policy board. The members include a diverse group of advocates, policy makers, and representatives of behavioral health provider organizations. Assembly Bill 366 of the 79th Session established the regional health policy boards [page 3]. As a part of the work of the Washoe policy board, we invited experts in the field to present information on behavioral health programs and needs. We conducted surveys and also held focus groups in order to determine what the need really was in Washoe County. At one of our meetings, DHHS staff presented information on the Crisis Now model, a model of crisis care that saves lives and money in other communities and is becoming the standard for crisis services across the nation. The need for crisis stabilization facilities, a central component of a robust system of crisis care, emerged as a top priority for the policy board.

We all know the problem. For people in crisis, hospital emergency rooms have become a choke point [page 4]. Patients are dropped off by police officers or they are referred by crisis call lines. Mobile outreach teams drop people off, families drop their loved ones off, or people just walk into ERs or are referred by primary care or social service providers. The bottom line is that they stay in hospital ERs and wait for behavioral health services. Because of this, hospital staff struggle daily to get patients into behavioral health beds or referred to outpatient programs. Often, patients get discharged with nothing—no therapeutic support—which can lead to the street, jail, or worse.

This is data from the Office of Analytics at DHHS [page 5]. What it shows is that, on any given day, there can be more than 100 patients in hospital ERs waiting for behavioral health services. This is a huge misuse of health care resources, and it keeps hospital ERs from doing their jobs to serve patients experiencing medical emergencies.

This page [page 6] shows the components of the Crisis Now model that include the crisis call center as well as steps in between outpatient and inpatient care. The key component of the system is a crisis stabilization facility. These are short-stay, subacute intake, and observation units with 16 or fewer crisis stabilization beds. In essence, they are psychiatric emergency rooms. These facilities are an alternative to hospital emergency departments (EDs) and are central to the system of care. This model is also supported by a number of national professional and advocacy organizations.

Crisis Now has achieved some very impressive results [page 7]. It not only saves lives, but it makes great business sense. A 2016 study out of Maricopa County, Arizona, reported it saved an estimated 37 full-time-equivalent law enforcement officers by allowing 5-minute drop-off and turnaround of clients. No clients were rejected, so any time an officer had someone who needed services, they bypassed the ER and went right to the crisis center. These crisis centers were open 24/7. It reduced an estimated 45 years of hospital boarding—patients waiting in hospital ERs for behavioral health services. This created an estimated \$37 million in hospital ER savings. It also avoided \$260 million in inpatient psychiatric care after the investment in the crisis stabilization centers.

Our goals for this legislation are fourfold [page 8, (Exhibit D)]. One thing we struggled with as a policy board was the fact that there are statutes on the books for crisis triage centers, but during the years those statutes have been on the books, we have never seen them utilized in a way that could effectively deal with the crisis needs of our communities. Our goals are: Number 1, elevate the community's understanding of, and appreciation for, a robust system of crisis care; Number 2, set a standard for crisis services by defining Crisis Stabilization Facilities (CSFs) in statute; Number 3, require DHHS to establish CSFs as Medicaid "essential community providers." This would require DHHS and the Medicaid managed care organizations that work with DHHS to contract and negotiate in earnest with essential community providers—which would include CSFs. Number 4 would require DHHS to make all the necessary changes to the State Plan for Medicaid and associated Medicaid regulations to pay for CSF services.

I would like to turn this over to Jamie Sellar who can provide information on the programs they run in multiple states which will help clarify what this model really looks like.

Jamie Sellar, Chief Strategy Officer, RI International:

[Jamie Sellar read his testimony from prepared text (Exhibit E)]. Thank you, Senator Ratti, Dorothy [Edwards], and Mr. Duarte. Good afternoon, Madam Chairwoman and members of the Committee. My goal today is to provide an overview of the Crisis Now model of services and I will do that by talking a little bit about the agency I work for.

RI International is a large behavioral health care nonprofit with a presence in five U.S. states and New Zealand. Our business lines revolve around outpatient behavioral health services, peer-supported recovery services, and consulting. Our biggest service line is in the area of behavioral health facility-based crisis services. We operate 14 different crisis programs across the country ranging from short-term crisis housing to 24/7 mental health urgent care

centers, to crisis receiving facilities like the ones that I will describe today, to a locked inpatient hospital that is used as a diversion from the state hospital in the state of Washington.

Aside from our reputation as a crisis service provider, what has set RI International apart is our work as a crisis services thought leader. Our Chief Executive Officer was the co-lead on the *Crisis Now* paper with Dr. Mike Hogan. Dr. Hogan is a former mental health commissioner in Ohio, New York, and Connecticut. The National Action Alliance for Suicide Prevention's Crisis Services Task Force oversaw the writing of the *Crisis Now* paper. It brought in over 30 leaders in the field of behavioral health from such backgrounds as funding, government, direct care providers, and consumer organizations. The goal was to review the best practices across the country and create a roadmap for sustainable and effective crisis services. The Arizona model for facility-based crisis services was the consensus-based best practice for facility-based crisis services. RI International is one of three providers in Arizona that has decades of experience in utilizing this model.

The Crisis Now model is the only overarching model of crisis services currently endorsed by the National Association of State Mental Health Program Directors. It is a model that is built on the assumption that a community has enough resources to adequately support those in crisis if those who are in need have access to the right level of care and are not overprescribed hospitalization or underserved in an outpatient setting when they require a higher level of support.

If we look at the traditional model of behavioral health care, we generally see two types of care: traditional outpatient services where people who are not in crisis have access to therapists, counselors, and psychiatrists to support them in their journey to recovery; and traditional inpatient programs where people could be kept safe and given treatment to address their full psychiatric needs.

If we look at the continuum of services as a ladder, it is a ladder with two rungs and a lot of space in between those rungs. Those two rungs are made up of inpatient and outpatient treatment. In this common scenario, people are often placed in inpatient hospital services when an intermediary level of care better addresses their needs; or frequently, they are tragically underserved in outpatient programs when a higher level of care is needed to keep them stable. In fact, based on patient placement criteria using the level of care utilization system, over one million times in Georgia, the Crisis Now business case proposes that the majority of patients in an inpatient hospital bed would have been better served initially on an intermediary rung.

Crisis Now is a tried-and-true model that bridges the gap between inpatient and outpatient services. It provides the right response to a crisis at the right time. The additional rungs in the ladder involve crisis call centers, mobile crisis outreach teams, and facility-based crisis services. For the purposes of today's conversation, I will talk about facility-based crisis services.

In the Crisis Now model, facility-based crisis programs are facilities that divert people with behavioral health issues away from EDs and jails into care by behavioral health professionals. To do this, it is imperative for a crisis facility to be able to take any person in a behavioral health crisis regardless of his mental health acuity, substance abuse status, or voluntary treatment status.

This is called the "no wrong door" approach in the Crisis Now model. What it allows is guaranteed access to behavioral health crisis services 24 hours a day, 7 days a week, for everyone. An example of the community impact of a true crisis facility is how the no wrong door approach is utilized by law enforcement personnel. Law enforcement personnel need a good disposition every time they encounter someone in a behavioral health crisis. Without this level of care, the choices faced by an officer are to take them to an ED where they may wait hours or days to get behavioral health help; find a legitimate reason to take them to jail to support getting them off the street; or leave them in the community without appropriate care. None of these options are ideal.

In a Crisis Now system, an officer always has a great disposition ready by utilizing a facility-based crisis program. In this type of program the patient is accepted 100 percent of the time and the officer is back on the street attending to public safety within ten minutes of ringing the doorbell. Experience shows us that when an officer is turned away, or it is easier and quicker to drop a person off at an ED or book him into jail, those options become more utilized. The Crisis Now model gets behavioral health professionals treating behavioral health issues at the first possible intercept point.

A difference between a traditional psychiatric hospital and a crisis facility is that the goal of facility-based crisis services is to stabilize the presenting crisis and return the person back into the community for additional support on their path to recovery, and to do this quickly. Crisis stabilization in a crisis facility is much more focused than a traditional psychiatric facility and it is reflected in shorter average lengths of stay. I will go more into that in a minute.

A facility-based crisis center, in general, has two levels of care. The initial level of care resembles a psychiatric emergency room. This level is the admission point for all patients. In this level of care, multiple services are provided, beginning with evaluation. These evaluations include a thorough risk assessment, psychiatric evaluation, as well as an evaluation by nursing and counseling staff. In parallel with evaluation is targeted treatment designed to alleviate the crisis that the patient presented with. Additionally, discharge planners begin to work on establishing a safe and effective aftercare plan from the moment of admission. This plan helps to ensure that a patient has the community support needed to avoid a relapse of the crisis. What is important is that these programs cannot cherry pick patients. They accept 100 percent of the patients who present for services. If there is a need for transfer, they will set up the appropriate transfer. RI International's historical data shows that only between 1 and 2 percent of those admitted will need a transfer to a medical facility for medical care after the initial nursing assessment. The best working crisis facilities are

able to reconnect patients back into their community about 70 percent of the time within the first 24 hours. Those who cannot be stabilized move into the second level of care.

This level of care has different names in different states. In the *Crisis Now* paper, it is referred to as subacute treatment. However, recently it has become obvious that calling it subacute is a misnomer. The care needed in this level is anything but subacute. It must be designed to address the needs of the 30 percent of patients who could not be stabilized in the psychiatric emergency room. This means that it serves the most acute patients. These patients include those with active psychosis, suicidal or homicidal intent in both voluntary and involuntary statuses. These units must include all antiligature fixtures and provide a staffing pattern that is equal to or exceeds traditional inpatient psychiatric hospitals. We now believe that the best term for this type of program would be short-term hospitalization. Historically, 75 percent of patients in this level of care should be discharged back into their community within two or three days. The remaining 25 percent would be those patients who have treatment-resistant symptoms, and they would be identified and transferred to a longer-term traditional inpatient setting.

As the math shows us, about 8 percent of the total patients admitted to a true crisis program require a transfer to an inpatient psychiatric hospital. These types of programs lessen the demand on inpatient psychiatric hospitals. In Arizona, the results have been exceptional. It is no secret that many states have issues with psychiatric patients languishing in EDs and jails due to a lack of psychiatric beds. The Treatment Advocacy Center has published that a state needs 50 psychiatric beds for every 100,000 in population to avoid psychiatric boarding in EDs and overuse of jails for those with mental illness.

At RI International, we feel that without adequate rungs in the ladder, that number is probably right. However, currently in Arizona based on a report by the Open Minds Organization called *State-By-State Guide To Psychiatric Bed Distribution* published in May 2017, Arizona only had 14.4 beds per 100,000 population which, according to this report, ranked lowest in the US. In comparison, the same report identifies Nevada as having 26.2 beds per 100,000 in population. What is remarkable is not that Arizona had the lowest number of beds, but that we were not seeing the levels of psychiatric boarding or jail issues that many other states were witnessing. We were not hearing concerns from large metropolitan police departments that the system was broken and not meeting their needs. In fact, the opposite was true. According to Detective Sabrina Taylor who is the Crisis Intervention Team Training Coordinator and CIT liaison for the Phoenix Police Department, in 2017 more than 23,000 people were connected by Maricopa County law enforcement personnel to a behavioral health solution, and those people were accepted 100 percent of the time. This demonstrates that increasing psychiatric beds is not the answer to crisis services. Increasing crisis services is the answer to psychiatric beds.

How did this come about? Arizona has spent the past two decades focused on creating a true crisis system that offers multiple rungs in the behavioral health ladder. These additional rungs address crises and ensure people are getting the care that most fits their needs. This means utilizing inpatient psychiatric hospitals only for those who require the most care and

treatment to resolve their behavioral health emergency and spending that savings to ensure the types of programs that match up with the level of crisis a person is in. Many communities see that spending one dollar on true crisis services saves two dollars in overprescribed inpatient care.

It is the matching of the need to the best service that eliminates waste and makes the system truly sustainable. As a national and international consultant, I have seen firsthand in multiple states the type of legislation that drives successful crisis services as well as hinders them. I support the work being done in regards to this bill and believe it will strengthen the current system in northern Nevada.

I would like to thank Madam Chairwoman, Senator Ratti, and members of the Committee. I will now step aside to let Mr. Chuck Duarte discuss proposed amendments to the bill and how it will help create an environment that will allow for the creation and maintenance of a true crisis system that benefits everyone.

Charles Duarte:

We have a list of proposed amendments to the bill (Exhibit F). As a policy board, we were really just learning about the Crisis Now model and what would be necessary from a legislative perspective to make this happen in Nevada. After we submitted the proposed legislation, we learned quite a bit, which is why we have come back with some proposed amendments. We are looking to amend A.B. 66:

- 1) To eliminate the requirement that the Division of Public and Behavioral Health establish a crisis stabilization center within each county whose population is 100,000 or more [section 1, subsection 1]. Rather than establish population criteria for this, we want to do this on a statewide level.
- 2) Establish crisis stabilization facilities (CSFs) as licensed psychiatric hospitals, pursuant to NRS 449A.068.
- 3) Establish that a psychiatric hospital may be endorsed as a CSF. To receive such an endorsement, the psychiatric hospital must:
 - a) Be accredited by the Commission on Accreditation of Rehabilitation Facilities or by the Joint Commission on Accreditation of Healthcare Organizations;
 - b) Not exceed a maximum of 16 beds;
 - c) Not exceed 5-day patient stays;
 - d) Take all patients regardless of their ability to pay;
 - e) Be nonprofit;
 - f) Be willing to take involuntary and voluntary patients; and
 - g) Perform medical clearance (diverting the need for emergency department admissions).
- 4) Require the Department of Health and Human Services to:
 - a) Recognize CSFs as "essential community providers" and to revise the State Plan for Medicaid accordingly;

- b) Ensure that CSFs are not classified as an institution for mental disease for Medicaid payment purposes; and
- c) Make all appropriate changes to the State Plan for Medicaid and associated regulations to fund CSF services.

Assemblyman Thompson:

Can you tell me who in southern Nevada does what you just described?

Charles Duarte:

I do not believe this is currently being provided in the form we just described in either southern or northern Nevada. The closest example would be a crisis triage center. The difference between a crisis triage center and what we are describing—crisis stabilization facility—is that the stabilization facility is a locked facility and could appropriately be licensed as a hospital. A crisis triage center is not a locked facility; it cannot take 100 percent of patients regardless of their mental health status or diagnostic acuity, whereas a crisis stabilization facility can because they are staffed and developed as psychiatric emergency departments on the front end and small psychiatric hospitals on the back end. It is a higher level of care than what I would consider a crisis triage center to be.

Assemblyman Thompson:

Why the restriction? If we do not have it in the most populated areas, why in areas above 100,000 in population?

Charles Duarte:

When the bill was drafted the criteria was added, but I am not sure why. From a market perspective, these facilities need a population base that is significant enough that they can get an adequate number of patients through the facility so they can bill for services and be sustainable. That is why having these types of facilities in urban centers makes sense and they may need to be different in rural settings.

Jamie Sellar:

We have been able to operationalize the types of crises that a community would experience, so the level of care utilization system is a patient placement tool that is widely known and evidence-based and widely used in Georgia. When people are in crisis, what level of care placement will they need? We have looked at data from Arizona, and for every 100,000 folks in a population, you are going to have about 200 crisis events. Those 200 crisis events are going to be things requiring police intervention, emergency departments, crisis facilities, and mobile crisis outreach teams—more than talking with family and friends, more than something that can resolve itself. Out of those 200 episodes per 100,000, when we start putting a patient placement tool against it, about 14 percent are going to need to be inpatient; about 54 percent will benefit from a crisis facility that will begin triage; and about 20-plus percent will benefit from a mobile crisis outreach team. We have been able to calculate and do some predictive modeling. What the records tend to show is that if you have a population of over 200,000 in a centralized location, you need about 16 beds.

As someone who operates crisis facilities, I could not open an 8- or 10-bed psychiatric receiving facility or psychiatric emergency room because of the staffing pattern I need to ensure that I can take 100 percent of the patients—that I can take that violent and aggressive person and have enough staff to handle that situation. I cannot do that profitably if I only have 8 or 10 beds, so we look at 16 beds as being about the sweet spot. You can have more beds, but you cannot have fewer beds and have any economy of scale that will allow you to staff it appropriately.

Assemblyman Carrillo:

There have been discussions in Clark County around the inability of psychiatric hospitals to medically clear patients. Looking at number 3 of your amendments, how do you see that issue being addressed?

Jamie Sellar:

It goes back to what the term "medical clearance" actually means. In 2017 in Maricopa County, Arizona, at a facility like ours, a police officer dropped someone off 23,000 times. What we initially do is a medical screening with a registered nurse. We discovered that 1 percent or 2 percent of the time, someone has a medical condition that will require a transfer to an emergency department for what we would consider medical clearance. That means 98 percent of the folks would be able to be treated with the level of care that provides 24-hour nursing staff and 24-hour doctor coverage either by phone or in-house. For us, medical clearance is not a requirement. If anything, we would consider it to be a roadblock. We need to have a quick nursing assessment within the first 5 minutes upon admission to a facility and a protocol in place that would allow that 1-2 percent of patients to be quickly and effectively transferred.

Assemblywoman Munk:

Being a retired mental health specialist, I think this is a great start. What type or level of staff would be working in the crisis stabilization center? Would you be using case managers, would you be using social rehabilitation workers; who exactly would compose the staff?

Charles Duarte:

The goal would be to make sure that we have appropriate staff to take care of the medical and behavioral health cases that come in the front door—that would be 100 percent of the cases except those that need medical clearance in a hospital ER. The other component of it, which is essential, is to look at some of these programs, including the ones that are run by RI International in other states. There are a lot of peer support workers in those facilities. The first person they see and the last person they see is a peer supporter, and that is a good way of describing how these programs work.

Another thing that is essential is to make sure there is ongoing case management; that these patients are not just discharged and let go on their own recognizance and resources, but that there is some follow-up with them.

Jamie Sellar:

Staffing models can vary from state to state and regulation to regulation. A standard operational model for a 16-bed facility has 24-hour registered nursing staff present. During busy times, you might have an additional licensed practical nurse or licensed vocational nurse—depending on licensure—who is there to provide and administer medication. In our Peoria, Illinois, facility, there is a psychiatric provider who is there 24/7. In some of our smaller 16-bed facilities in other states, we will have a provider, nurse practitioner, or psychiatrist 10 hours a day but available the rest of the time by phone to give admission and discharge orders. We also have a licensed professional counselor, licensed therapist, or licensed marriage and family therapist—someone who is a qualified mental health professional—who is able to do assessments, start treatment planning, and be able to work through some of those crises. We also have a discharge planner who will usually work 16 to 24 hours a day. Their focus is to start discharge upon admission.

At RI International, our preference is for certified peer support specialists, and as was mentioned, the goal is peer support, both first and last. When you are looking at having a faster throughput, when you are looking to help stabilize a crisis, it is all about engagement. We have found that certified peers tend to engage a little faster and deeper. Generally, for a 16-bed facility we would have about three of those, and if we had high acuity, we would call someone else in. At any given time to be able to say we will accept 100 percent of cases coming in, I generally need at least six or seven people in the facility.

Assemblywoman Munk:

We have peer support workers in Nevada, but what type of certification do they have and how many hours do they need?

Charles Duarte:

I am not familiar with peer support requirements in our certification, but I would be happy to follow up with you on that.

Assemblywoman Munk:

I would appreciate that.

Chairwoman Cohen:

I am interested in the consumer-operated services and peer support. A 14-day turnaround might be difficult, or am I misunderstanding what the process will be?

Charles Duarte:

We are proposing to amend the bill and limit the 14-day stay language in the legislation to no more than 5 days. As Mr. Sellar indicated, the average length of stay in these facilities is less than 3 days. That was a lesson we learned after we submitted the original bill. Our amendment limits the length of stay to something close to 5 days.

Chairwoman Cohen:

Within that 3- to 5-day period, will you be able to provide the peer support?

Charles Duarte:

Mr. Sellar can speak to that because that is their model of care and it has been very effective in multiple states.

Jamie Sellar:

The difference between a traditional psychiatric hospital and crisis-receiving facilities for folks on crisis stabilization is that when someone comes to a crisis facility, there is a presenting problem. There is a presenting problem; a reason life started to fall apart for that individual on that day. The reality is that the goal of a good crisis-receiving facility is to be able to resolve what that crisis is going to be. We have seen that 70 percent of the folks can get that crisis resolved in the first 24 hours. Those folks who cannot get it resolved generally have some other underlying issues and deeper mental health issues that require a little bit more attention. For those folks, the majority of them will have those issues resolved to the point where they can move back into the community in about 3 or 4 days. From a time frame, we are talking about an aggregate. When we are talking about people, it is a little tougher to say that everyone will be gone in 3 days. What we can say is that, on average, people are going to be gone in 3 days. That may mean someone in their first episode of psychosis might take 5 or 6 days, but, on average, in our facilities it is as low as 1.5 days in certain states that have a robust outpatient system to which we can get same-day appointments and discharge people into. Our longest stay, on aggregate, would be 3 days in our longer-term inpatient program outside of our psychiatric ERs.

Assemblywoman Titus:

You are eliminating the 100,000-or-more population requirement, so are all counties doing this? Are you eliminating the Division of Public and Behavioral Health's (DHHS) requirement to do any of this?

Charles Duarte:

The restriction to counties that have populations higher than 100,000 would be eliminated. There is the potential that this type of facility could be established elsewhere, depending upon population size and need. The best example is the Mallory Behavioral Health Crisis Center in Carson City. If this legislation is passed, I am hoping it will be able to set a standard for the Mallory Center that they can utilize to make their programs sustainable. By establishing some of the payment criteria in statute, and also the requirement that it be identified as an essential community provider, they could be more sustainable long-term.

Assemblywoman Titus:

You are not intending to mandate that a county, regardless of size, establish a crisis center.

Charles Duarte:

We are not intending that.

Assemblywoman Titus:

I want to thank you for all your hard work. I sit on the Northern Nevada Regional Behavioral Health Policy Board, and I know hundreds of hours and much thought have gone

into this. I understand your intent. Originally you were looking to establish crisis intervention centers throughout the state so people could be averted and kept from tying up the ERs. It now seems this has morphed into inpatient treatment centers—now psychiatric hospitals and not just crisis stabilization centers—which are more of a temporary fix. Are you looking at creating psychiatric hospitals throughout the state?

Charles Duarte:

We intend to create marketplace conditions so these types of facilities can be sustainable; and to establish, from a market perspective, that these would be reimbursable services and could be established wherever it makes sense for a provider to do that.

We are proposing to amend the legislation because originally it was based off of what we knew, and the only things we knew at the time were residential programs. What we know now is that residential programs have not been sustainable, particularly because it is difficult to get paid for those services by Medicaid or some of the managed care companies. In working with RI International, looking at some of their facilities, and talking with them, we learned that the level of care we are talking about is higher. It is really a short-stay hospital. If you look at the videos about these types of facilities, while they may be licensed as psychiatric hospitals or a small psychiatric hospital facility, they have the look and feel of a residential treatment program. The architecture, the staffing, and the level of peer support there makes it less clinical and more residential, but they are staffed to take the level of acuity that is necessary to make sure that law enforcement and emergency medical services do not get turned away when they attempt to drop someone off, regardless of that individual's psychiatric condition.

From a licensing perspective, we have been talking to DHHS's Bureau of Health Care Quality and Compliance about this, and they feel that a model that might work is to license them as psychiatric hospitals. As such, it would create the conditions for proper reimbursement. As Mr. Sellar said, the staffing levels required go well beyond what money is available for residential treatment. You really have to staff up as though these were psychiatric facilities or psychiatric ERs.

Assemblywoman Titus:

Your amendment also mentions "perform medical clearance." I absolutely agree that medical clearance in many situations is a roadblock to getting patients transferred or treated in the appropriate manner. Our state demands medical clearance, but in order to do the medical clearance it requires laboratory tests and other things to make sure there is not some alternative disease that is creating the crisis in this patient, and that it is truly a mental health crisis and not a medical crisis. Your proposal is that you could do a rapid drug screen, laboratory tests, and those types of things—a basic physical on the person—to be sure he or she does not need to be transported for a different level of treatment.

Charles Duarte:

Yes, I believe that is correct.

Jamie Sellar:

It comes back to what medical clearance is and what it entails. We know that about 98 percent of the time there is really no issue going on with the person that requires treatment in an ER. Between 1 percent and 2 percent of the time, there is. When you function as a psychiatric ER or psychiatric hospital as opposed to a residential treatment facility, your staff will include registered nurses and they will have a certain skill set. We are able to immediately discern whether someone coming out of a police car needs further clearance. If that is the case, we are always going to err on the side of caution. We will put that individual in an ambulance and have him or her transported.

In Washington State, we had a lot of back-and-forth with the emergency departments related to what research says needs to be medically cleared and what does not. We have come up with collaborative protocols. For example, if someone's blood sugar is at a certain point, we will send that person to the hospital, and the hospitals agree with that. The same with blood alcohol levels. We have been able to really define what is medically unable to be treated in one of our facilities and what requires an upper level of care. If someone comes in with an open wound, we will send that person out. If a breathalyzer test is at 4.0 and a coma is impending, we are going to send that person out. If they have not been on their diabetes medication, we do a blood sugar test. If it is within the realm we feel we can handle, we will keep that person. Generally, the vast majority of times we keep the patient. In those one or two other instances, at least the person has seen us and we are going to arrange appropriate transport. We feel the 1-2 percent we deal with is better than the 98 percent it is unnecessary for the EDs to deal with.

Assemblywoman Titus:

I do not see aftercare in the conceptual amendment. The bill states [section 1, subsection 1, paragraph (f)] that you are going to provide "Comprehensive services to intervene effectively when a behavioral health crisis occurs and address underlying issues that lead to repeated behavioral health crises" and make sure there are "Aftercare services for persons who have received services." Would your psychiatric hospital offer services further identified as "basic needs, including . . . housing, food and primary health care"? Would you be making sure those arrangements have been made as opposed to just crisis stabilization? I see it is really expanding what this facility would be obligated to do.

Charles Duarte:

In terms of providing wraparound support, it was our intent to keep that language in the bill. Hospitals deal with this all the time. Case managers struggle with providing for all the needs of patients. Our intent is to provide that wraparound support and aftercare to make sure that patients are established with appropriate outpatient programs and that resource needs are identified. There is no guarantee that we will be able to solve all their housing problems, but the hope is to provide that level of aftercare so that we can help support them in the community.

Assemblywoman Titus:

I was worried you would never be able to discharge anyone because of the extent of your obligations to them after discharge.

Chairwoman Cohen:

Are you asking for new services to be covered in this new setting?

Charles Duarte:

It is a nexus of issues. We know there is coverage, but it has not been done in a manner to support the entirety of services we are proposing. Psychiatric inpatient hospital care is obviously paid for by Medicare and Medicaid, as well as by a number of insurance companies. However, it has not been dealt with in a manner that is sustainable for programs like this—short-stay psychiatric stabilization facilities. By licensing these facilities as small subacute hospitals, we can align existing reimbursement policies with these programs to make them sustainable in the long run.

Something that is still an open question is whether the Department of Health and Human Services has policies in place that can adequately and appropriately reimburse for all the services we are talking about at the level of reimbursement necessary to support the staffing needs. I would not want to put this bill out there without some assurance that there is going to be adequate revenue to support the staffing needs—that would be a recipe for failure. There probably needs to be a part of this that needs to be negotiated because it may require changes in Medicaid regulations and the State Plan for Medicaid to be sure that these facilities and services are adequately reimbursed so these types of programs can be established in Nevada.

Chairwoman Cohen:

Seeing no other questions, we will move on to support.

Brian O'Callaghan, Government Liaison, Office of Intergovernmental Services, Las Vegas Metropolitan Police Department:

The reasons why we need this have been well laid out because we do not have those types of services at this time to that extent.

Dan Musgrove, representing The Valley Health System of Universal Health Services, Inc.; and WestCare Nevada:

I have been working on this issue in this building since 2001. A number of things have led up to this point. A couple of things Mr. Duarte said are key to what this bill and the amendment do—creating a marketplace condition for sustainability of these kinds of facilities. When the WestCare Community Triage Center was created in the early 2000s, we did not have Medicaid expansion, so to get a program like this funded, we had to ask private hospitals to kick in their own money and we had to ask local governments to kick in their money. It was not until 2005 that the State added General Fund money, but it was not sustainable because there was not enough money and there were not enough facilities.

Let me give you a perspective on what happens in southern Nevada every day. I contacted the head of emergency medical services at The Valley Health System. Today at noon, we have 117 patients in our hospital EDs—systemwide, every hospital in southern Nevada—on mental health holds, sitting, waiting for treatment. That is just today. There are 179 people in acute care beds who have some kind of mental health issue. The trouble with that statistic is that it blends a lot of things. It could be someone who is experiencing substance abuse overdose, so that number is not quite as accurate; but the 117 people on mental health holds in southern Nevada is an absolutely accurate number, and that is our trouble.

The reason hospitals are the front door is because in southern Nevada they are convenient for first responders. There are 14 hospitals strategically placed all over the valley. We need multiple front doors like Crisis Now, and they are willing to show us how they would be sustainable. We have never before had anyone willing to come up with a sustainable model who was willing to enter into a market like southern Nevada and be able to last and handle these types of folks. We know his statistics are correct; we know that 2-3 percent of the people do not need any medical care beyond that medical clearance—that first, initial evaluation by someone licensed to get those folks where they need to go.

However, hospitals are the worst, most expensive places, to have these folks. When your family needs true emergent care, they are going to be lucky to find a gurney in a hallway that is not next to someone who has mental health issues. That is what is so scary about our current system. The hospitals have been the heroes for the past 20 years that we have been working on this issue. The hospitals are stuck with these folks; they are the ones probably putting in the majority of resources to take care of those folks because there is no other option. When Medicaid expansion came along, that gave us the first opportunity to cover this population of 19- to 64-year-old single, childless, adults who do not have insurance who now can at least access services. However, there is still a large part of that population who will never qualify for Medicaid. The state will tell you that 11 percent of our folks are uninsured, but in this population, it is closer to 20-25 percent.

This is an incredible first step to putting in place the framework and structure we need to get these services paid for. Unless someone can survive and open this kind of facility, they are not going to last, they are not going to come here, so kudos to the Washoe Regional Behavioral Health Policy Board that did the work, to Mr. Duarte and his team, Senator Ratti, Mr. Sellars and his group who showed that there is a sustainable model. We would love to have ten of those facilities in southern Nevada.

Sandra K. Stamates, Program Manager, National Alliance on Mental Illness, Northern Nevada; and Member, Washoe Regional Behavioral Health Policy Board:

I am a member of the Washoe Regional Behavioral Health Policy Board. I am also the program manager for NAMI Northern Nevada which is the National Alliance on Mental Illness in Washoe County. I strongly support <u>A.B. 66</u> to establish crisis stabilization facilities in Nevada.

I have an adult loved one who lives with mental illness. In the summer of 2010, he was in a manic phase of bipolar illness. I called the Sparks crisis call center from Ohio where I lived at the time. They were supportive but could not provide any options to get the help my loved one needed. He pulled a fire alarm and was arrested. In the Washoe County jail he was placed in the mental health unit and given medication. He was in jail for approximately 18 days, and when released, he continued to take the medication although he was still in a manic phase. Less than a month later, he was ordered back to jail for 6 days and he was not given any medication during those 6 days. A crisis stabilization facility would have made a difference. He could have been taken there by police and been given medication and time to stabilize, or been transferred to a more acute facility for additional treatment.

Families in Washoe County continue to struggle with how to get their loved ones the help they need. I take calls on our helpline and do not have many options to suggest when a family is dealing with a crisis. Police and emergency rooms have become the largest providers of crisis services, and they are not always equipped or well trained to handle the issues. Crisis stabilization facilities will fill a gap in the services we offer those dealing with a mental health or substance abuse crisis. With the support and approval of this Committee, I believe this bill can move forward and help provide much-needed services in a state ranked 51st in behavioral health care. I am encouraged, as I believe we are on the cusp of rising from the 51st ranking because of the commitment of many providers, legislators, families, and citizens to improving behavioral health care in Nevada.

Kevin Dick, District Health Officer, Washoe County Health District; and Member, Washoe Regional Behavioral Health Policy Board:

Passage of this bill was a legislative priority for the Washoe County District Board of Health. I am here today to speak on their behalf and on behalf of the health and well-being of the over 460,000 residents of Washoe County. We conducted a community health needs assessment and identified behavioral health and access to behavioral health care as a top priority for our community. This is integrated into our community health improvement plan we are currently working to implement.

In 2018 the Washoe Regional Behavioral Health Profile was developed in conjunction with our regional policy board, and it provided a more detailed compilation of data for our area. Some of this included data on emergency department visits for behavioral health conditions. The top behavioral health conditions were drug-related, alcohol-related, anxiety, and depression. In general, Washoe County had a higher rate of ED visits for behavioral health needs than the state as a whole. Our crude rate of behavioral health emergency department visits for anxiety in Washoe County was 2,353 per 100,000 population. Drug-related visits were 1,538 per 100,000; alcohol-related were 1,377 per 100,000; and visits for depression were 1,333 per 100,000 population. We have heard how the ED is not the place for these people to receive appropriate care.

The crisis stabilization services proposed in <u>A.B. 66</u> provide an alternative to this ineffective provision of mental health care which is provided at the highest cost when delivered in the emergency department. The bill provides for immediate and appropriate mental health crisis

care to these individuals and care that is best designed to meet their needs, to stabilize them, de-escalate them, and step them down to lower levels of care and a continuum of continuing care to appropriately address their mental health needs. It will provide improved care at lower costs than our existing systems, and has been shown to reduce Medicaid costs and the costs for law enforcement to respond to these individuals. For that reason, I urge you to pass A.B. 66 with the proposed conceptual amendments to provide the appropriate licensing and reimbursement structure to allow these facilities to be established in our communities.

David Marlon, President, State of Nevada Association for Addiction Professionals:

I recently retired after running the largest drug and alcohol treatment center in Nevada. I would like to offer complete support for A.B. 66. Yesterday I was at the Attorney General's Substance Abuse Working Group, where I have served for over 12 years. I want to share two statistics. At the local needle exchange, the numbers have been increasing. We distributed 480,000 needles in southern Nevada as part of a harm reduction effort. Legislation from the last session has reduced opioid prescription counts. They are running about 46,000 prescriptions a month per 100,000 population, which is down from approximately one prescription for every man, woman, and child in Nevada, per month, for the prior year. So I appreciate that there has been a reduction, but we still have a very serious problem, and these crisis stabilization facilities could be an efficient way to expeditiously help this problem.

Mackenzie Baysinger, Intern, Human Services Network:

Year after year the top priority continues to be access to health care and mental health for the Human Services Network. Not only would this expand access, but it would save the state millions of dollars. As we heard in the presentation, in Arizona's Mariposa County where similar programs are in place, \$37 million was saved by hospitals in one year. On top of that, they saved the time equivalent of 37 full-time police officers and reduced hospital wait times by 45 years. According to Nevada Medical Center, we rank 41st in death rate by suicide. This is a necessary change and it will help save money and keep people in Nevada safe. We urge your support.

Kendra G. Bertschy, Deputy Public Defender, Public Defender's Office, Washoe County:

In Washoe County we struggle with options for individuals who are in crisis. The individuals do not know where to go, their families do not know whom to turn to, and law enforcement often does not know where to take the individuals in order to protect them—except to jail. This bill provides an absolutely necessary and important step in helping our communities find answers and fix issues. This would allow members of our community who are in crisis to have a stable place to go that is an alternative to jail. We appreciate the Washoe Regional Behavioral Health Policy Board for bringing this bill forward and urge your support.

Debra Rilea, Board President, National Alliance on Mental Illness, Northern Nevada:

As a member of NAMI, I take phone calls from the public; I teach a family education class; and I cofacilitate a family support group. One of the subjects that always comes up in every

discussion is a lack of adequate services for our loved ones who are in crisis. At this time, many of those loved ones will enter the jail or the prison system, or they will cycle in and out of emergency rooms. This type of proposed center will not only help families and people living with mental illnesses, but as you heard, it will also save money. From my own personal experience, this type of crisis stabilization center would have helped my daughter. She was in an emergency room for over four hours in 4-point restraints while we waited for a bed in a mental health facility. Our story is not unique. I ask for your consideration in supporting this bill for our community and for our loved ones.

Robin V. Reedy, Executive Director, National Alliance on Mental Illness, Nevada:

I want to applaud the foresight shown in the previous legislative session for setting up these regional boards. They have come up with plans and solutions. While they do not fix everything, they are pieces of a puzzle that, if put together, eliminates some of the huge gaps in the state. This plan sounds like heaven to me. We take calls; we have to say that we do not know where to go—go to the emergency room, go to your general practitioner. We utilize ERs and the prison systems as our source of care for those people who are living with a mental health condition. This type of facility throughout our state will not only help save lives and money, it will create an environment in which a sustainable business can thrive in our community. It also helps those families who do not know what to do or where to go. I strongly support this bill. Dan Musgrove was correct. It has been years trying to get something like this done and we are on the precipice of doing that because of you.

William Blume, Private Citizen, Carson City, Nevada:

I am a member of Protection and Advocacy for Individuals With Mental Illness, Nevada. When I had my mental health crisis a number of years ago, I was in a state and county that did not have these types of stabilization facilities, so my condition deteriorated. I was not triaged properly. As a result, I spent six months in a county jail and five years in a state hospital at a cost of at least \$2 million. I am in support of this bill and I urge you to pass it.

Amber L. Howell, Director, Human Services Agency, Washoe County:

I want to put on the record that we are in strong support of this legislation. We are responsible for child welfare, adults, and seniors in Washoe County, and this is a much-needed resource that would fill a large gap in our community. I am extremely proud of the work the policy board has done and the steps they have taken to get us here today.

Michael D. Hillerby, representing Renown Health:

I have a written statement by Dr. Kristen Davis Coelho, Director of the Behavioral Health and Addiction Institute at Renown:

As a clinical psychologist practicing in northern Nevada for 20 years, I have seen the impact of a lack of behavioral health crisis services on our community members. Emergency rooms are the best place for someone experiencing a stroke or acute injury. They are the worst place for someone experiencing their first episode of psychosis or reaching out for help due to

thoughts of suicide. In my opinion, expanded options for crisis care are one of the highest priority needs for behavioral health in northern Nevada today.

We support the bill. As Dan Musgrove said earlier, our emergency rooms are the right places to go for an acute injury, a stroke, a heart attack; they are the wrong places to go for mental health needs.

Sharon Zadra, Executive Director, Truckee Meadows Healthy Communities:

I repeat the gratitude that has been stated for your work. Having served 12 years on the Reno City Council and having been faced with lots of people expecting you to make the right decision, I really respect the time and energy you have put into this project.

Truckee Meadows Healthy Communities is a network of networks within the Truckee Meadows. Three weeks ago we teamed with Renown to host a behavioral health forum. We had 60-plus providers attend that day. Five teams voluntarily agreed to take on many of these issues. The first step needed to make their work successful is a stabilization center, and we encourage and request your support.

Joanna Jacob, representing Dignity Health-St. Rose Dominican Neighborhood Hospitals:

I am here on behalf of our seven acute care hospitals. We are in support of this bill. I spent a lot of time with our ER nurses and with our physicians and others who work in our ERs every day. Throughout the years, I have asked them what they would do if they could do something about behavioral health in southern Nevada. Over and over, I have heard that what we need is short-term crisis stabilization services in the state. As their advocate, and having just heard from them this morning, I want to urge your support for this bill.

I also want to thank the people from last session who put these regional policy boards together. Dignity has participated—not only with the Southern Nevada Regional Behavioral Health Policy Board, but also with the northern board working on Legal 2000, and with the Washoe board. The work they have done coordinating with one another has been amazing. I want to thank Mr. Duarte for allowing us to work with him on this. We also look forward to working on the Legal 2000 issue from Assemblywoman Titus's regional policy board. Our doors are open. We have people walking in off the street because they do not know where to go. We will always be there, but we know the ER is not the best place to serve patients who are in mental health crisis, so we urge your support.

Gary Snelson, Private Citizen, Zephyr Cove, Nevada:

We have two sons with severe mental illness. They are both adults. One came up to visit with us awhile back. He ended up in crisis and needed hospitalization. He went to the ER. The ER was not the place for him. They sedated him in the ER and sent him home. His psychiatrist was very upset because it completely threw his medication regime off. The ERs are not the places for these patients. We strongly support this.

Joan Hall, President, Nevada Rural Hospital Partners:

Our current behavioral health system and our laws are not only outdated, but not functional. I so appreciate the Washoe Regional Behavioral Health Policy Board for all their hard work and for bringing this very important bill. It shines a light on an important issue that needs fixing.

Laura Hale, Private Citizen, Reno, Nevada:

I am one of 1,595 members of Indivisible Northern Nevada. We support the bill. I also have testimony from Heidi Howe, who is a retired captain from the Washoe County Sheriff's Office (Exhibit G). I will just read some highlights:

I do not know a single person who has not been impacted by mental health, behavioral health, or substance use crisis. These events can strike us without notice and when they happen, we are desperate: we need to know where to turn. When we reach out for help, we are looking for solutions which typically do not include criminalizing our loved ones.

My experience with behavioral health connects to my 30-years' experience in law enforcement, specifically interacting with those arrested and placed into Washoe County's regional jail. When things go wrong, and people are in crisis, law enforcement is called to solve the problem. Our lack of resources limits options; therefore, jails and prisons have become the largest mental health facilities in our state. Although there are times when the criminal justice system is the correct place for individuals, this is not usually the case.

... forty-four percent of all jail inmates and 37 percent of prison inmates have been told by a mental health professional in the past they have had a mental health disorder. . . . The National Association of Drug Court Professionals state 80 percent of offenders abuse drugs or alcohol, and nearly 50 percent of inmates are clinically addicted. Sixty to 80 percent of those with substance use disorders will commit a new crime after release from prison. Approximately 95 percent will return to drug abuse after release from prison. . . .

Assembly Bill 66 focuses on crisis stabilization. This stabilization is not limited to mental health, but includes also behavioral health and substance use disorders. A crisis stabilization center is part of a larger process, diverting individuals away from the criminal justice system and emergency rooms, making our communities healthier and safer. . . .

I urge your support of <u>A.B. 66</u> and thank the board and this Committee for their work.

Karla Sue Brune, Private Citizen, Reno, Nevada:

I am a member of the National Alliance on Mental Illness (NAMI) Nevada and the Depression Bipolar Support Alliance. I participate as a facilitator for the public and meet people with disorders. Many times I am asked if I know where they can go or to which doctors. There are not enough psychiatrists, and there is not enough help in the ERs. Please, we have to help these people.

Chairwoman Cohen:

Seeing no one else in support, we will move to opposition in Las Vegas or in Carson City. [There was no one.] Seeing no opposition; we will move to neutral testimony in either southern Nevada or in Carson City.

Alex Ortiz, Assistant Director, Department of Administrative Services, Clark County:

We are supportive of this concept, the goal of <u>A.B. 66</u>, and of the crisis stabilization facilities. However, we are here in neutral only because we are unsure that multiple providers are able to bill for and offer these services in Clark County—even those who are nonmedical providers. We have a great need in southern Nevada, and across the state as well, but we want to ensure that everyone has an opportunity to provide these services if they so choose. We also want to thank the Washoe Regional Behavioral Health Policy Board for bringing this forward today.

Ryan Black, Legislative Liaison, Office of Administrative Services, City of Las Vegas:

We are also in support of the concept of this bill, but we share the same concerns expressed by Clark County. We understand the need for mental health services. There is currently a huge shortage of mental health services in Clark County. The lack of mental health services also clogs up our criminal justice system and has an effect on our homeless population, which is on the City's priority list. We are neutral but in support of the concept.

Chairwoman Cohen:

Seeing no other neutral testimony, I will invite the presenters up for a brief closing statement.

Charles Duarte:

I want to thank you for your time, patience, and questions. I want to assure you that we understand there is some work we need to do on this bill. The conceptual amendments are concepts, and as a part of that, we have identified a work group to work through some of those conceptual amendments and, hopefully, make them final amendments for your consideration.

[(Exhibit H), (Exhibit I), (Exhibit J), and (Exhibit K) were submitted but not discussed and are included as exhibits for this meeting.]

Chairwoman Cohen:

We will close the hearing on A.B. 66.

I will now open the hearing on Assembly Bill 254.

Assembly Bill 254: Revises provisions relating to sickle cell anemia. (BDR 40-20)

Assemblywoman Dina Neal, Assembly District No. 7:

Thank you for hearing this bill. I will be working off the amendment (Exhibit L) and not the original bill. I want to give some opening remarks about what sickle cell is. There are two acronyms: SCT and SCD. Sickle cell trait is SCT, which is an inherited condition that affects the hemoglobin in the red blood cells. It is considered to be a mild condition. Hemoglobin is the iron-containing protein that transports oxygen in the red blood cells to the rest of the body. Sickle cell trait is considered to be the carrier state, meaning that an individual may never develop sickle cell disease (SCD) but has the potential to have children who are either going to have the trait or are going to develop the disease.

Sickle cell anemia is an inherited red blood condition in which an individual inherits two abnormal hemoglobin genes. The mutation in the hemoglobin genes results in abnormal hemoglobin protein which leads to the distortion of the red blood cell from a round shape to a crescent shape, which is what we call sickle shape. These sickle-shaped red blood cells break down and cause anemia and they obstruct the blood vessels, leading to recurring episodes of severe pain and multiple organ damage. I wanted you to understand what sickle cell anemia is.

In Nevada, on average, about 15 to 20 babies a year screen positive for sickle cell. The data you received (Exhibit M) shows that in 2017 there were 1,107 Medicaid enrollees with a sickle cell diagnosis who had related claims [page 2]. When I talked to the state biostatistician, she stated that, on average in any year, 1,000 people may get sickle cell. This is a small population, but it is a population that has significant needs. This bill will help assist with some of the issues encountered within this group. I have been working with a southern Nevada planning coalition. These are families who have a child or other family member with sickle cell. I have also been working with Cure 4 The Kids with Dr. Nik Abdul Rashid. During the interim I had several meetings with managed care organizations (MCOs). We gave them a laundry list of concerns and issues that sickle cell patients wanted addressed. There were a series of things one of the MCOs said it could do, but they are now fearful of being mandated to do those same things. We will work to figure that out.

Section 4 is supposed to be the definition of sickle cell disease. I will make sure that is added as we go forward. Section 5 is the definition of "provider of health care." The meat of the bill is between sections 6 and 30. In section 6, the issue here is being able to prescribe by regulation a list of prescription drugs for sickle cell patients. In the lifespan of a patient, they are not always given the option for other drugs, and there is more than one drug on the market. We wanted to make sure that the Pharmacy and Therapeutics Committee in the Division of Health Care Financing and Policy, Department of Health and Human Services, would review the necessity of the drugs and their composition. In section 6, subsection 3, we added supplements. When one has anemia, there is a need for vitamin D, PediaSure, and other supplements that may not be covered under Medicaid. These are available over the counter, but they are needed by the patient for a total package of care.

In section 6, subsection 4, we request the Pharmacy and Therapeutics Committee "Review and determine the need and access to opiate." There is significant pain management that comes with a sickle cell patient. Right now they are being given a 14-day supply, but they may need a 30-day supply. This language came from the patients who are encountering this issue. Sometimes the 14-day supply runs out, or the person could be dealing with a pain episode and needs that 30-day supply. The same situation arises in subsection 5 that covers antibiotic coverage—allowing the Pharmacy Committee to determine the necessity of a 30-day supply versus a 14-day supply.

In section 7, we want the State Board of Health to start maintaining a system to report information on sickle cell disease. We have some information but not enough, so we need to start collecting and producing a database similar to the Nevada Central Cancer Registry. Section 7 lists what information we would like collected.

Section 8 prescribes the form and manner in which information on cases of sickle cell disease must be reported. When we see this report, we want to see age, ethnicity, the variation of the sickle cell disease, opiate usage and access, age at death, and length of life. We need to know what is happening with these patients. Even though they are a small number, we need to know more about the variant diseases and how they are functioning so doctors can better manage and treat sickle cell patients. In section 8, subsection 3, abstracted health information should be kept confidential.

Section 9 discusses abstracting health information and that the State Board of Health shall assess fees to a health care facility so that information can be retrieved. Section 10 states that "The Division shall publish reports" related to provisions under sections 7, 8, and 9. Under section 11, the Chief Medical Officer will analyze the information obtained pursuant to sections 7, 8, and 9. Under section 12, the identity of any patient, physician, or health care facility involved in reporting may not be revealed. Section 13 is a liability provision.

Section 14 deals with adopting regulations concerning examinations and tests. Currently, we have newborn screening. What is missing in the process is screening of the parent at the same time so we can figure out who has the trait. We had this conversation with the MCOs about the cost to test the parent at the same time. Otherwise, the parents walk away wondering where the child got the trait from. We are trying to solve the problem all at once. If we all know at the same time, it helps with education, access to care, and all parties involved would be able to proceed with the best care for the child or adult who has been identified.

Section 18 relates to what should be included in the State Plan for Medicaid and makes sure that we are going to get "Case management services for a participant in Medicaid who has been diagnosed with sickle cell disease." Case management matters because typically you might have pediatric care, but once they become 18, there is no more care, it is not consistent, or knowledgeable providers are limited. We wanted to build continuity through the system so that when a participant turns 18, the care is continued. We want to develop a pathway and a model within the system so that they can be taken care of. We also

recommended at least two visits per year to a comprehensive clinic, and there is also a provision dealing with prescriptions. Section 19 concerns *Nevada Revised Statutes* (NRS) Chapter 689A.

Section 20 relates to NRS 689A.330 which covers insurance policies written by a domestic insurer who may have a policy for delivery to a person residing in another state. Section 21 amends NRS Chapter 689B to cover sickle cell disease in group and blanket health insurance. This is health insurance that may cover two or more persons. Section 22 relates to NRS Chapter 689C which covers health insurance for small employers. Section 24 involves NRS Chapter 695A which covers benefit societies because there may be circumstances where fraternal benefit societies may be offering a health plan. If they have one or two individuals who have sickle cell, we are asking for that to reach into those spaces. Section 25 amends NRS Chapter 695B which covers nonprofit corporations that provide health care, so similar language is applied there. If you go into section 26, NRS Chapter 695C covers health maintenance organizations. In section 30, NRS Chapter 695G covers the managed care organizations and is a repeat of the same information making sure we have case management services, comprehensive care for an insured under and over the age of 18 who has been diagnosed, and making sure there is an evaluation. I found out that mental illness may come with being a sickle cell patient, so counseling and education are included. One of the biggest things is trying to make sure that doctors, nurses, and any providers who come into contact with a sickle cell patient understand the disease so they can appropriately treat and deal with what is going on. This is a small, specialized population that needs focused attention and care.

Assemblyman Thompson:

I want to thank my colleague for bringing such a comprehensive bill. We can all see that you put your heart into it. To the parents and patients in the audience, this is a true advocacy bill. I know that sometimes there are challenges with MCOs, and now that things have turned a little hairy, I would hope that the MCOs who were at the table with you two weeks ago will be more inclusive. If you are open to it, I would also like to sign on to the bill.

Assemblywoman Neal:

We had a series of meetings and phone calls in September and October. When we gave the MCOs a laundry list of things we wanted them to look at to see what they could internally change, there was one MCO—Anthem Blue Cross—that took our information and implemented it. They saw what they could do just through our conversation. Other MCOs were at the table and they were always included in the emails, so I do hope we can work this out. I mentioned that I intended to codify some of the changes because I did not want those changes to fall by the wayside along with the work the parents put into this. Administrators of MCOs change, human beings come and go, so I wanted to make sure there was a standard in the statutes. Hopefully, we will find a way. I want to make sure to acknowledge Commissioner Lawrence Weekly [Vice Chair, Board of Commissioners, Clark County]. He came to me right after the 2017 Session and said he needed me to bring a bill because there was no care model helping the parents. I started on the journey and met all these individuals. I found out that there was a planning coalition and there was a regional coalition

that covered ten states. I met all these individuals who were doing the work in a silo and I jumped into their circle and said I was doing a bill. This bill represents their input.

Assemblywoman Titus:

I really appreciate your initial statements and the way you presented the medical definitions and explanation of the disease process. It is rather complicated, but your overview was well thought out, so thank you for that. You are really a community advocate, and thank you for bringing this bill forward.

My question regards what other states do and the information gathering you are seeking in this bill. Is there a template other states are using? What is required of those other states?

Assemblywoman Neal:

Tennessee and North Carolina tried to pass legislation that dealt with collection of data. The Centers for Disease Control and Prevention (CDC) got involved with a screening and preventative measure. They identified two states—California and Georgia—that started a screening and prevention pilot program. They are going into communities so they could document the sickle cell patients and the variations of the disease, the disorders or other diseases that are accompanying the disease. Also, a bill [the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2018] moved out of Congress—a reauthorization and reappropriation for sickle cell prevention and screening. It allows states that have a sickle cell policy to look for grants. It also allowed for a global data template for states to start collecting and beginning to curate a registry about sickle cell patients.

Assemblywoman Titus:

I was looking to have a partnership nationwide on possible grants. If there are programs out there that have grants, I would want to make sure we could still apply for a grant.

Assemblywoman Neal:

The Pacific Sickle Cell Regional Collaborative created through Dr. Rashid and the stakeholder group in southern Nevada has been moving the needle and trying to equal what is happening in the South, where most of the cases are. The cases are predominantly among African Americans, but there are Latinos and whites who also have sickle cell disease; however, they do not have the disease in the numbers that African Americans do. They wanted to create a state plan, but I jumped into the middle of what they were doing and brought this bill.

Assemblywoman Titus:

You have acknowledged the opioid problem. In our zest to get control of the opioid crisis in our state, we have, unfortunately, harmed several subsets of folks who have chronic disease—diseases like sickle cell. I have had patients with sickle cell. It is an incredibly painful experience for them. It is unpredictable, they cannot always get back in to see their providers in a set amount of time to refill the necessary medication, so I appreciate that you put into the bill the expansion of being able to write a prescription for them. This is not the

only subset, however. Hopefully, as we clean up that particular legislation, we can acknowledge that there are many different patients with other health problems who do not fall under that 7- or 14-day mandate. Thank you for adding that to your bill.

Chairwoman Cohen:

Has there been any research about medical marijuana and if it can provide relief to some of the patients?

Assemblywoman Neal:

I think Dr. Rashid would be better able to answer that question. I have to tell you about this woman. She is small but amazing. While we were working on this legislation, she got a cancer diagnosis. She would still come to our meetings. She found the time to talk about sickle cell while she was going through chemotherapy. She is a true advocate. Their center is the only one taking care of sickle cell patients in the south. She is awesome.

Chairwoman Cohen:

Thank you, Dr. Rashid, for the work you are doing for our communities. Would you mind addressing the question about medical marijuana and pain management for sickle cell?

Nik F. Abdul Rashid, M.D., Pediatric Hematologist/Oncologist, Cure 4 The Kids Foundation:

We are the only pediatric center for hematology/oncology patients in Nevada. I am also director for the sickle cell program at our center, and I am the primary investigator for the Pacific Sickle Cell Regional Collaborative, the group mentioned by Assemblywoman Neal. They receive a grant from the Health Resources and Services Administration through the Sickle Cell Disease Treatment Demonstration Regional Collaboratives Program.

Yes, there has been a lot of research about the positive effect of marijuana compared to opiates, and there is a big study going on in California right now. They have shown there are benefits in terms of calming effects, pain control, and fewer side effects compared to opiates; however, we have not prescribed it to our pediatric patients.

We are very grateful to Assemblywoman Neal for championing this bill. It has been a long time coming. I was trained in New York City at Montefiore Medical Center. We had a good sickle cell program there, so when I moved to Nevada in 2005, I was appalled at what was lacking here and what little understanding physicians had about sickle cell disease, the crises patients go through, and all the medical complications. There was a lot of misunderstanding about our patients when they go through a pain crisis and seek pain treatment. When a lot of them go to the emergency rooms, they are labeled as drug seekers because they know so much about their medications and the dosages. What they do not understand is, as pediatricians, we train our patients. We come up with pain plans and recommendations. When the CDC did their study in California, they found that there was a significant health disparity for patients with sickle cell disease. A lot of it is due to not understanding the disease and misconception about the patients.

With this bill, we were hoping to collect data. If it is mandated for hospitals to collect certain data, then we can understand what our patients are going in for, what their complications are, and how hospitals are managing these complications. If they are not managing them correctly, is there a way we can come up with policies or procedures on how to manage these patients through the ER as well as when they are admitted into the hospitals. There have been too many cases of complications that occur that could have been prevented in which the outcome was death. There are also cases where patients call us for help because they are not being managed correctly or are not being heard by their providers.

Another thing I want to stress is that there are certain medications that we know help our patients. I have had some problems getting those medications because of the insurance coverage or insurance not covering certain ways of giving these medications. Hydroxyurea has been around since the 1990s and has helped hundreds of sickle cell patients. It only comes in 500 milligram capsules, so for pediatric patients, it has to be compounded down to a smaller dose, but compounding is not covered by Medicaid. So we have patients who are on Medicaid but now they have to pay \$30, \$50, or \$90 for compounding by the pharmacy.

Access to care is lacking here for our adult patients. The pediatric patients have us, and we advocate for them. When they are in the hospital, we make sure to visit and be certain they are getting the right care; however, once they are adults, if they are admitted to the hospital, they are usually admitted under a general hospitalist. That person must decide whether to call a hematologist for a consultation. Sometimes I feel they mismanage some of our patients. If that can be improved and this bill can help us at least recognize the problems they have in the hospitals, that will be a big step toward improving the care for our patients.

Linetta Barnes, President, Sickled Not Broken Foundation of Nevada:

[Linetta Barnes provided a letter and supplemental information (Exhibit N).] I am an adult critical care nurse and the mother of a 13-year-old sickle cell warrior. I want to educate about sickle cell. I fully support A.B. 254 which would address some of the health care disparities that the sickle cell populations face every day. For Nevada, I see this as a way to decrease the costs associated with ER visits and hospitalizations. Up to this point, a lack of legislative support has denied the people of Nevada the right to know the prevalence of sickle cell disease in our state or to receive basic resources as well as standard of care.

Recently my son was in the hospital. Bloodwork was done and they asked him if he was really having pain. His blood levels were high. They did not understand that with the type of sickle cell he has, his blood levels are generally higher, but he still has the same excruciating pain. As an advocate, I was recently with a mother whose baby was crying in her arms. She was venting that she could not get her prescription filled because it was \$95 and she could not afford that. She was upset because it had been almost a month and a half since her child had been given one of the two medications proven for sickle cell anemia. Recently, I was with a provider who stated that a patient recently died from a complication that is well documented for sickle cell anemia. I talk to many adults in the community who say they hate going to the hospital, they hate going there for their pain management or for their bloodwork,

but there is nowhere else to go. There is no competent provider to help with their pain or care for them.

I want Nevada to be a state that is proactive and preventative for sickle cell anemia versus reactive. A place where, if a patient goes to the hospital because they have to, they will go in not feeling as though they are drug seekers, and they will come out alive. They will not die from a complication that is documented for sickle cell anemia due to lack of knowledge and standard of care. So I would love for this bill to go forward.

Georgene' Glass, Founder/President, Dreamsickle Kids Foundation:

[Georgene' Glass spoke from prepared text (Exhibit O).] I am the mother of this 3-year-old who has sickle cell disease, and also the founder of the first sickle cell foundation in Nevada—Dreamsickle Kids Foundation. I am here in support of A.B. 254. This bill is important for people with sickle cell disease. I came here three years ago from California and immediately noticed the difference in care for people with sickle cell. This bill would help cover medications like hydroxyurea and penicillin for children from ages 0 to 5. In California, I could get a 3-month supply of the penicillin prophylactic. Here, I can get it every 14 days, so a 28-day supply.

Hydroxyurea is proven to be something that helps enhance the quality of life for children or people with sickle cell. Unfortunately, the compounding of the medication costs too much for me to afford, so I have decided not to put her on that medication because I do not feel comfortable trying to guess the dosage at home. So she is not taking medication that could help her quality of life right now.

This sickle cell bill would be a first for Nevada and it would set an example for the other 50 states that probably need to do a sickle cell bill as well, because this concerns a population of people who historically are overlooked and underserved. This bill would help enhance tracking. I do not want my daughter to grow up and be ashamed of her disease or have to go to the hospital and attempt to educate the doctors and nurses and be looked at as a drug seeker because she knows her body, her illness, and what would help her manage her pain. Because of the lack of knowledge, my daughter spent ten days in the hospital in January. When we left, the doctor prescribed 15 milligrams of morphine in a pill form. She has never taken morphine. The next day she experienced a pain crisis, but I could not give her that medication because I knew it was not the right dosage to give her.

If people knew more about the population here that has sickle cell, they would be better able to treat people. My employer, an African-American man with four African-American children, had never heard of sickle cell. There is a lack of knowledge and a lack of awareness and education when it comes to sickle cell. I was terminated from that job because of my absences when my daughter got sick, but I watched this same company afford accommodations to another woman who had a small child with a heart condition. I know it was because my daughter does not look sick, but she was hospitalized, so I know that is probably the reason why there was not as much compassion for me who missed work because of my sick child.

This is something very much needed. Ever since I moved here, I have been advocating for sickle cell. When Assemblywoman Neal said that she was drafting a sickle cell bill, it was the highlight of my life. I did not think it would happen so fast, but I am happy that it did, and I think you should support this bill.

Don Gallimore, Private Citizen, Reno, Nevada:

I am a third vice president of the Reno-Sparks NAACP. I thank Assemblywoman Neal for bringing the bill. I have been fortunate in my family because we have never been affected by this disease. I had a friend years ago who expressed to me his remorse that he would have to leave the program when he turned 18, so I have a lot of sympathy for the continuation of case management care in this bill. I hope you consider passing this bill.

Pamela White, Private Citizen, Las Vegas, Nevada:

I am in the process of forming a sickle cell foundation that focuses on assisting the adult sickle cell community along with their families. This is dear to my heart because of my 40- and 19-year-old adult children who are battling with this disease.

After 40 years of dealing with this, there have been very minimal changes as far as how they are treated when they go to the hospitals and when they are going to get their prescriptions. I support this bill because it requires the Chief Medical Officer to establish a system to report information on sickle cell disease and its variants. We do not know the numbers; we do not know exactly how many people in Nevada have sickle cell or its variants. I am supportive of the fact that it will require a health insurer to include coverage for prescription drugs that are needed to manage the pain that occurs with this disease. I also support the fact that hospitals and MCOs that provide services for patients living with sickle cell disease will treat all patients—children and adults alike—without prejudice, without looking at them and thinking they are drug seekers. Due to the severity of this debilitating disease, we ask you to support this bill.

Ingrid Williams, Private Citizen, Las Vegas, Nevada:

I am a 58-year-old sickle cell patient and my 59-year-old brother also has the disease. The specific points I would like to speak about include lack of medical care for sickle cell disease and other chronic hereditary pain sufferers in Nevada—specifically adults 19 and older and especially people 40 and older with sickle cell disease.

I am in support of this bill. When I was in my teens, my father and others established a sickle cell foundation, but over time it went away. As you grow older, there are fewer opportunities to manage the disease and especially, manage the pain. People have had to give up their jobs because they did not have employers who were sensitive to the disease and the complexities of it. I was fortunate that I was able to work for 30 years, but over that time, I had to learn how to hide. I had to learn how to hide my pain in front of everyone; I had to hide my pain in front of my family. As a child, a teen, as a young adult, an adult, and now as a senior citizen, you learn how to hide what you have in order that your family does not feel badly that you feel bad. I want sickle cell patients to come out of the shadows and have unlimited lives.

I have not met another woman with sickle cell who is my age. I was always given a sunset date during my life. At first, I was told I would not see the age of 14. Then I was told that I would not live to be 21; then I would not live to be 30-something; then I would not live to be 42; but here I am, 58 and still kicking it. There must be something left for me to do on this earth.

Sondra Williams, Private Citizen, Las Vegas, Nevada:

I am 40 years old and the daughter of Pam White who just spoke. I am a wife and the mother of three children who was told my children were not supposed to be here, but they are here and they are healthy. I support A.B. 254 because I am an advocate for sickle cell due to the fact that I have sickle cell hemoglobin S-C disease. For all my adult years I have dealt with undeserved treatment such as being called a drug seeker by doctors in ERs and by pharmacists. Doctors who are not familiar with me, or sickle cell, look at vital signs to determine the need for hospitalization. They look for signs of a fever or infection to determine the severity of the pain crisis, not realizing that if those signs are there, the crisis has gone to a detrimental level. I have had problems getting medications that my primary physician prescribed filled at local pharmacies because the pharmacist did not understand the medication that is needed to subdue the pain that occurs with the disease—often on a daily basis. Education and awareness are truly needed. Recently, I was escorted out of a hospital by security who said that I was seeking drugs and they would not even listen to me explain what was needed to help me out. I support this bill.

Zavier White, Private Citizen, Las Vegas, Nevada:

I am Pam White's son, and my sister just spoke. I am 19 years old and I have sickle cell anemia. I have been battling with this since I was 9 years old. I had my first crisis at age 9, and ever since then, it has continued to happen. I am in full support of this bill because every single day, sickle cell patients feel the lack of policies in anything we do, such as going to the doctor or getting prescriptions. Like they say, the doctors and the pharmacists do not know too much about the disease, so they try to label us as people who just want the medication and are not in any pain. I have been hospitalized a bunch of times, and most of those times I have been let out early in excruciating pain because they just thought I wanted pain medication. When I was a child, I even had doctors tell me that the pain was in my head because I wanted medication. It is very heartbreaking, especially when so many of us have it and we battle every day. I am hesitant to leave my pediatrician because when I go to an adult doctor, I may not get the help I need at all. I have been on many pain medications, but some of them are so hard to get. We were talking about doing hydroxyurea, but it is hard to find a pharmacy that carries it; and when we do, it is too expensive to buy it. This bill will help fill all the gaps.

Tina Dortch, Program Manager, Office of Minority Health and Equity, Department of Health and Human Services:

It is a good day to be a public servant here in the state of Nevada. I am so very proud of the advocacy that sits in this room and the productive work that has been done. The system has been working as it should.

I would like to talk about how this bill, if passed, will leverage the ability to bind federal-level support. The public health adviser with the U.S. Department of Health and Human Services visited the state last year. One of their six major priority areas is sickle cell disease. The work that is happening with this bill, the work that will happen with the state action plan—those things will result in our ability to identify additional dollars at the federal level. As recently as today, working with my team at the Department of Health and Human Services, we were able to identify and notice a funding opportunity that AstraCrux Clinical Trial and Consulting will establish a clinical site consisting of a research team and an advisory group that looks at 300 individuals between the ages of 18 and 45—so it addresses that critical transition period.

There is opportunity for the Office of Minority Health and Equity to help elevate this issue. I have heard so many people talk about the ability of education and that there is a large swath of the community that is not aware of the disease. I am very excited that my office can help elevate awareness and we will be supporting next month's Warrior Drive during National Minority Health Month. We will also, as it relates to my office's role with the work on clinical trial diversification, be holding listening sessions. I am looking forward to having members from this community be a part of that so we can talk about clinical trials and how we break down those barriers and get more people doing donor lists and all that good stuff. On behalf of the Office of Minority Health and Equity, I am in support of A.B. 254.

Chike M. Nzerue, M.D., Chief Medical Officer, Dignity Health-St. Rose Dominican Hospitals:

I am here to testify in support of <u>A.B. 254</u> which will help sickle cell disease patients and their families start to get some peace of mind and the appropriate care they deserve. We have submitted a letter to the Committee (<u>Exhibit P</u>), so I will try to summarize the support we presented in that letter.

I am here not just as a physician or medical administrator, but I am also the father of a child with sickle cell, so I have been on both sides of that stethoscope. My kids were born in Georgia where I was training at Emory University. At Emory, we have a comprehensive sickle cell center that pretty much does a lot of what we hope A.B. 254 will do. This center furnishes information and raises awareness. With sickle cell, basically, ignorance and lack of information is the enemy. Sickle cell was described as a molecular disease as early as 1949. You would think that after all this time more people would know about it. Unfortunately, there is such a lack of knowledge, and this bill will help address that. It will shine a light so that most people will know about the disease and what it is about. They will not approach the patient thinking only about drugs. There are so many complications. You have a patient—and if you assume the patient is just there to seek medication, then you are going to miss the more severe issues that patient might have—it is a chronic condition. I think this bill will help us with the hands-on approach that we need to provide information and support that the families and patients need. I wholeheartedly support this bill.

Erica Edden, Private Citizen, North Las Vegas, Nevada:

I have an 11-year-old son who has sickle cell. Awareness, as everyone has said, is a big thing, but so is education because I am still learning. I just got information from the school letting me know that my son is fatigued, and now they are trying to offer counseling and tutoring for him. He is very smart, but every day there is something different when dealing with a child with sickle cell. A lot of people out here do not know about it. I have family members doing research, finding information, sharing it with me, and giving me that support. I learned a lot from some of the people testifying today, and these are things I will have to teach my son to watch out for as he gets older. Dr. Rashid and the center have been great as have the hospitals and the family center we have gone to. We definitely need improvement as far as awareness goes; our kids have a hard time mentally because of the association with the disease and the socialization with children. I am in support 1,000 percent.

Barron D. Hall, Private Citizen, Las Vegas:

I am 59 years old. Currently, I am the oldest person with sickle cell I know. There are a lot of misconceptions as far as pain management goes. The pain management programs concentrate on drug management and not on pain management. When we need brain surgery we go to a neurosurgeon; we go to a cardiologist for heart problems. But when we go to a pain management program, they throw a blanket over it and everyone's pain is dealt with in one way—drug treatment. The drug treatment they provide for sickle cell patients many times causes a lot of problems, and you get the stigma of being a drug addict.

Now they test infants before they leave the hospital for the sickle cell trait, and then that is it—out of sight, out of mind. Twenty years later, you are having children, and a lot of people do not remember that they were tested when they were infants. They need to close that gap in between being tested when they are born and then not again until they are having children of their own. Thank you for your time, and I am here to support this bill.

Esperanza Brooks, Private Citizen, Las Vegas, Nevada:

I have a loved one who was diagnosed with sickle cell at birth. It is not just when our loved ones are in pain, it is also the care after they leave the hospital. It is the care to try to prevent them from going into the hospital. One day my loved one may be okay; then he can have a fever of 102 degrees; and the next day he is better again. I strongly support this bill and I ask you to support it as well. I also want to thank everyone at Cure 4 The Kids, because they are truly making a difference for us. Not only are African Americans affected by this disease, but so are Latinos and Caucasians and others.

Chairwoman Cohen:

Is there anyone else in support in Las Vegas? [There was no reply.] Is there anyone in Las Vegas or Carson City in opposition? [There was no reply.] Is there anyone neutral? [There was no reply.] We do have another question for Assemblywoman Neal.

Assemblywoman Gorelow:

Working with the pediatric population in my other life, I know how difficult it is to get treatment for people who have these types of illnesses. I was concerned hearing some of the

supporters mentioning that they could only get a 30-day supply of a certain drug and having to miss a day of medication during a 31-day month. Is there any way the bill could be changed so as to reflect the actual days of the month when they are getting prescriptions?

Assemblywoman Neal:

I think that is a question for Dr. Rashid. What they have been getting is a 14-day supply and they are trying to get that to be a 30-day supply.

Dr. Rashid:

With regard to some medication, penicillin was mentioned and it comes in a compounded version. But compounded penicillin only lasts for 14 days, so most of the time a pharmacy will only give a 14-day supply. We get around that by requesting the powdered version and saline so the parents can mix it at home. A lot of our computer systems have 30 days as the default, so sometimes doctors just click that option. That can be overcome if the insurance company or Medicaid would allow us to prescribe more than 30 days at one time—say a 90-day supply for the medication. That way they would have extra time to make appointments, see their doctors, and get refills.

Assemblyman Assefa:

Would you mind walking us through sections 15 through 45? I was just kidding. I just wanted to put a smile on your face after such a long day. This is a very serious issue. Thank you for spending the time and investing so much energy making sure this is happening in our state. I can relate to this. I lost my older brother to sickle cell anemia when I was a little boy. I remember the pain and suffering he went through and the burden on the family as we saw him fade away. If you do not mind, I would like to add my name to the bill.

Assemblywoman Neal:

I have no problem with that. Thank you for your indulgence this afternoon and for hearing A.B. 254. I hope you can see the value of this legislation and moving it out of the Committee and having this be effective in the state of Nevada. It will be a positive direction for the families you heard from down south, and we will be able to move the needle in regard to access to care and actually creating a case management pathway for those families.

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

Chairwoman Cohen:

We will close out the hearing on A.B. 254.

I will now open the floor for public comment. Is there anyone who wishes to make public comment in either Las Vegas or in Carson City? [There was no reply.] Seeing no one, does anyone on the Committee have any comments? [There was no reply.] Our next hearing will be Monday at 12:30 p.m. With that, we are adjourned [at 3:45 p.m.].

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

EXHIBITS

Exhibit A is the Agenda.

Exhibit B is the Attendance Roster.

Exhibit C is the Work Session Document for Assembly Bill 169, dated March 29, 2019, presented by Marsheilah Lyons, Committee Policy Analyst, Research Division, Legislative Counsel Bureau.

Exhibit D is a copy of a PowerPoint presentation titled "Crisis Stabilization Services, A.B. 66 Overview," presented by Charles Duarte, Chair, Washoe Regional Behavioral Health Policy Board.

<u>Exhibit E</u> is written testimony presented by Jamie Sellar, Chief Strategy Officer, RI International, in support of <u>Assembly Bill 66</u>.

Exhibit F is a proposed conceptual amendment to Assembly Bill 66, dated March 29, 2019, presented by Charles Duarte, CEO, Community Health Alliance; and Chair, Washoe Regional Behavioral Health Policy Board.

Exhibit G is a letter dated February 25, 2019, to former Chairman Sprinkle and members of the Assembly Committee on Health and Human Services, authored by Heidi Howe, Private Citizen, Reno, Nevada, presented by Laura Hale, Private Citizen, Reno, Nevada, in support of Assembly Bill 66.

Exhibit H is correspondence dated March 29, 2019, to the Assembly Health and Human Services Committee, submitted by Alyce Branigan, Private Citizen, in support of <u>Assembly Bill 66</u>.

Exhibit I is a letter dated March 29, 2019, to the Assembly Health and Human Services Committee written and submitted by Terry Smith, Private Citizen, Reno, Nevada, in support of Assembly Bill 66.

Exhibit J is a letter to Chairwoman Lesley E. Cohen and members of the Assembly Committee on Health and Human Services, submitted by Rick Porzig, President, NAMI Nevada, in support of Assembly Bill 66.

Exhibit K is a letter dated March 27, 2019, submitted by Amy Roukie, Director, Community Triage Center Services; and Government Liaison, The Well Care Foundation, Inc., Reno, Nevada, in support of <u>Assembly Bill 66</u>.

Exhibit L is a proposed amendment to Assembly Bill 254 dated March 13, 2019, presented by Assemblywoman Dina Neal, Assembly District No. 7.

Exhibit M is a document titled "Sickle Cell Disease Summary, Nevada Residents, by Race/Ethnicity, 2015-2017," prepared by the Office of Analytics, Department of Health and Human Services, presented by Assemblywoman Dina Neal, Assembly District No. 7, in support of <u>Assembly Bill 254</u>.

Exhibit N is a letter with fact sheet enclosure, dated March 29, 2019, to Assemblywoman Lesley E. Cohen, Chair, and members of the Assembly Committee on Health and Human Services, presented by Linetta Barnes, President, Sickled Not Broken Foundation of NV, Las Vegas, Nevada, in support of <u>Assembly Bill 254</u>.

<u>Exhibit O</u> is a letter dated March 29, 2019, to the Assembly Health and Human Services Committee presented by Georgene' Glass, Founder/President, Dreamsickle Kids Foundation, Las Vegas, Nevada, in support of <u>Assembly Bill 254</u>.

Exhibit P is written testimony dated March 29, 2019, presented by Chike M. Nzerue, M.D., Chief Medical Officer, Dignity Health-St. Rose Dominican Hospitals, in support of Assembly Bill 254.

Exhibit Q is data prepared by the Office of Analytics, Department of Health and Human Services, titled "Medical Conditions Among Unique Patients Diagnosed with Sickle-Cell Disorder, Emergency Department Visits and Inpatient Admissions, Percent of Total Sickle Cell Patients, Nevada Residents, 2016 and 2017," supplied by Assemblywoman Dina Neal, Assembly District No. 7, in support of Assembly Bill 254.

Exhibit R is a professional paper dated Spring 2014, titled "A Statewide Needs Assessment: On the Path to Developing Tailored Sickle Cell Trait Education in the State of Nevada," authored by Yasmine A. Mohamednur, MPH Candidate, University of Nevada, Reno, supplied by Assemblywoman Dina Neal, Assembly District No. 7, in support of <u>Assembly</u> Bill 254.