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

Seventy-Seventh Session
February 25, 2013

The Committee on Health and Human Services was called to order by Chair Marilyn Dondero Loop at 1:34 p.m. on Monday, February 25, 2013, in Room 3138 of the Legislative Building, 401 South Carson Street, Carson City, Nevada. The meeting was videoconferenced to Room 4401 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 nelis.leg.state.nv.us/77th2013. In addition, copies of the audio record may be purchased through the Legislative Counsel Bureau's Publications Office (email: publications@lcb.state.nv.us; telephone: 775-684-6835).

COMMITTEE MEMBERS PRESENT:

Assemblywoman Marilyn Dondero Loop, Chair
Assemblywoman Ellen B. Spiegel, Vice Chair
Assemblywoman Teresa Benitez-Thompson
Assemblyman Wesley Duncan
Assemblyman Andy Eisen
Assemblywoman Michele Fiore
Assemblyman John Hambrick
Assemblyman Pat Hickey
Assemblyman Joseph M. Hogan
Assemblyman Andrew Martin
Assemblyman James Oscarson
Assemblywoman Peggy Pierce
Assemblyman Michael Sprinkle

COMMITTEE MEMBERS ABSENT:

Assemblyman Steven Brooks (excused)

GUEST LEGISLATORS PRESENT:

None

STAFF MEMBERS PRESENT:

Kirsten Bugenig, Committee Policy Analyst
Risa Lang, Committee Counsel
Terry Horgan, Committee Secretary
Macy Young, Committee Assistant

OTHERS PRESENT:

Angie Pratt, Regional Director, Northern Nevada Alzheimer's Association
Ruth Gay, Director, Public Policy and Advocacy, Northern Nevada Alzheimer's Association
Valerie Wiener, Chair, Legislative Committee on Health Care's Task Force to Develop a State Plan to Address Alzheimer's Disease
Wendy Simons, Private Citizen, Reno
Bruce Arkell, representing Nevada Senior Advocates and the Personal Care Association of Nevada
Jane Gruner, Administrator, Aging and Disability Services Division, Department of Health and Human Services
Albert Chavez, Regional Director, Desert Southwest Chapter, Alzheimer's Association in Southern Nevada Region

Chair Dondero Loop:
[Roll was called. Committee rules and protocol were explained.] Our presentation today will give us a background about how Alzheimer's disease and other dementias have affected Nevada's population and what steps we are taking to handle this devastating disease.

Angie Pratt, Regional Director, Northern Nevada Alzheimer's Association:
We sent a PowerPoint presentation (Exhibit C) which I hope you all have. The Alzheimer's Association in Nevada is divided into two different chapters. The northern chapter is the Northern California and Northern Nevada Chapter, the one I work with. The southern Nevada Alzheimer's Association is the Desert Southwest Chapter with an office in Las Vegas. We are speaking for both chapters today, and we work very closely together.

We begin with asking the question, "What is dementia?" We ask this question because Alzheimer's disease is the most common form of dementia. About 70 percent of cases of dementia are Alzheimer's disease. Dementia is a set of symptoms a person displays when he or she develops the disease. Listed on the slides (Exhibit C) are the common types of dementia. The most common is Alzheimer's disease. The second most common type is vascular dementia which is caused by reduced blood flow to the brain, often as a result of a stroke. The third type of dementia we deal with is called dementia with Lewy bodies. That dementia manifests with a lot of visual hallucinations as well as muscle rigidity and tremors—very similar to what one would see with Parkinson's disease. The fourth type of dementia that is well-known in Nevada is frontotemporal dementia. Although there are not a lot of these cases, this dementia affects the frontal lobes of the brain where our social mores are centered. People with frontotemporal dementia have very little impulse control. For instance, if food is placed in front of them, they eat the whole plateful. Many people are diagnosed with mixed dementia, meaning that they have more than one type of dementia. For instance, an individual might have Alzheimer's disease and vascular dementia or frontotemporal dementia and Alzheimer's disease. Often late in Parkinson's disease a person might develop a type of dementia. All of these dementias are irreversible; however, there is a reversible dementia that can occur when someone has an infection. Once the infection is cleared up, the dementia can reverse. In hospitals, for instance, you might see a person who displays signs of dementia but that does not mean it is permanent dementia.

What is Alzheimer's disease? It is an irreversible type of dementia that causes problems with memory, thinking, and behavior. There are a lot of jokes about people's memories, but this disease actually affects the entire person. It manifests early with short-term memory problems, but eventually the disease overtakes every part of the person. The symptoms are slow and insidious, but become more severe over time. People with Alzheimer's disease not only have memory loss, but they have problems thinking, problems with numbers, and eventually they have problems performing simple tasks. They are unable to do what we call "activities of daily living," which means that eventually they will not be able to drive or shop any more, eat, prepare meals, and things like that. Sixty percent of persons with Alzheimer's disease wander, which can be a safety issue.

As Alzheimer's disease progresses, the individual may have a personality change, become agitated, have delusions or hallucinations. These things occur as the disease progresses, but every case of Alzheimer's is unique so I am giving you general symptoms. That does not mean that every person with this disease is going to have them all.

After diagnosis a person lives with this disease for 8 to 12 years on average, although we have had clients who lived as long as 20 years. There are those with the genetic form of Alzheimer's who live with the disease for as short a time as five years.

What are the risk factors for Alzheimer's disease? Age is the number one risk factor, so if you are 65 and older, your rate of risk for getting the disease is about 13 percent. If you are 85 and older, your risk rate rises to 47 percent. Family history and heredity are also factors. If you have a parent or sibling with Alzheimer's disease, you have a risk factor of developing this disease twice that of someone who does not have a parent or sibling with the disease. If you have both a sibling and a parent with the disease, your risk factor for developing the disease is much higher.

There is a genetic form of this disease that is quite rare, but we do have some cases of it. These people generally have numerous cases of Alzheimer's in their families. We know families with as many as 12 persons with the disease, and these families are really struggling. This type of Alzheimer's develops quite young in a person—as young as the 30s, although it is more common in the 40s and 50s. Right now there is a 45-year-old woman who developed the disease at age 40. Her children are still in grade school.

Over five million Americans have Alzheimer's disease. It is one of the top ten causes of death and the only cause for which we have no early detection, prevention, or effective treatment. There are medications that can be prescribed for people with Alzheimer's, but there is nothing to stop it. No one survives this disease.

Alzheimer's disease has become an epidemic. Because of all the research that has been conducted for diseases like AIDS/HIV, strokes, heart disease, prostate and breast cancers, deaths due to those diseases have been declining. The deaths from Alzheimer's disease increased by 66 percent from 2000 and 2008. In Nevada, there are 29,000 cases of Alzheimer's disease at the present time; however, we know that there are many people not getting diagnosed. It is an old wives' tale that this disease is a mental illness. It is not. There is also the belief that the condition is just normal aging, but it is not normal aging.

Ruth Gay, Director, Public Policy and Advocacy, Northern Nevada Alzheimer's Association:
We know that across the country fewer than 50 percent of the people ever receive a diagnosis. These are families who are caring for someone, but they do not know whether the condition is just normal aging.

Chair Dondero Loop:
How do you know the difference?

Ruth Gay:
A diagnosis of Alzheimer's disease should include a comprehensive exam. They should rule out any of the reversible changes. As Angie said, sometimes an infection in an older person will look like confusion or disorientation dementia. Is it depression? Have we ruled out other psychotropic kinds of medications that might be causing the symptoms? Has a magnetic resonance imaging (MRI) or computed tomography (CT) scan of the brain been done so that we know there is not a tumor or stroke going on? What is happening that is causing the change? For instance at the Cleveland Clinic, doctors now can do a really comprehensive workup and make a diagnosis with an approximately 98-percent degree of certainty.

Nevada is one of the six states in the country currently experiencing the greatest increase in Alzheimer's disease. The prevalence is projected to increase 100 percent between 2000 and 2025. The baby boomers are hitting that time of most risk right now. Nevada's population grew 35 percent between 2000 and 2010, while the nation's population grew less than 10 percent. Twelve percent of Nevadans are 65 and older, and we estimate the number of people in Nevada with Alzheimer's disease or dementia, diagnosed or not, to be about 29,000 individuals. By 2025 we expect that number to be around 42,000, which translates into about 126,000 caregivers—the people who are dealing with this disease in a number of ways.

I had the honor of serving on the Task Force, and one item of information that emerged is a realization of what a public health crisis this is becoming. There is a need for early recognition and identification of people with Alzheimer's, so families know what they are dealing with. We also need to educate families about management of the components of the disease. We know that rural communities are especially hard hit. When families have to travel 100 miles or more for medical care and treatment, it is not feasible if they have somebody who is confused, disorientated, agitated, and anxious in the car for that period of time.

We need to expand services and we need to know that we are serving people without age restrictions. Sometimes we have people under the age of 65 with the disease and the issues for those families are immense. When you lose a breadwinner to something like Alzheimer's disease, almost certainly you are losing the health insurer for that family, so these families have unique and difficult challenges.

Assemblywoman Spiegel:
How many of the 29,000 Nevadans who currently have Alzheimer's moved here from somewhere else? They may not necessarily have caregivers in Nevada

who can help take care of them and help deal with their disease. I know we have attracted a number of senior citizens, especially in southern Nevada, but many of the people who moved here do not have their support networks in Nevada.

Ruth Gay:
You are right, and add to that the fact that the baby boomer population is one with a much higher divorce rate than many others. I do not have good data to allow me to answer your question. I know that in some metropolitan areas we have looked at, as many as 40 percent of the population in that age group are single and without help. Some people are almost what we would call the "un-befriended." They really do not have anyone in the community. They do not have a church or social network, and they do not seem to have any family network either.

Assemblyman Hambrick:
The horrific aspect of someone in his or her forties with school-age children bothers me, but as with any bell curve, is there a point in someone's life where the person may statistically be beyond worrying about this?

Ruth Gay:
I did ask one of our statisticians about that. Logic would dictate that if one in eight over age 65, and almost one in two over age 85, are at risk for developing this disease, then would you say that at age 100 everyone has it? The answer I received was that was not the case. In fact, many people continue to age without losing their cognitive function. Those people who live beyond 90 and into their 100s, if they have not developed the disease, tend to be a very hardy group. They may or may not be at any more risk than they were at age 85. Does that mean they are not going to get the disease? No, but it means that their risk does not keep increasing up to 100 percent.

Chair Dondero Loop:
I happen to have a 93-year-old mother who can run circles around all of us, but she does forget things. What is really the difference between her at age 93 forgetting things and any of us forgetting things? How do we know when something is not right?

Ruth Gay:
That is one of the most common questions we get: What is normal, what is not, and when should you worry? Short-term memory loss is one of the key beginning features we see, and it is in people who can talk about what happened 20 or 30 years ago and in detail. What we also see are things such as personality changes and difficulty performing tasks the individual used to be

able to do. Just because people are older, if they balanced their checkbooks to the penny when they were in their 40s and 50s, they usually can still do it when they are in their 80s and 90s. What you look for is whether they are no longer able to do things they should be able to do such as set the table. Are they having trouble dressing appropriately? Is their judgment and reasoning impaired? Those are the kinds of things, that array of things, we begin to look at that changes cognitive function and safety in the home.

Angie mentioned safety as she discussed wandering, but one of the first things that often changes for folks is their ability to safely discern who is safe and who is not. These people are often at risk for financial abuse. They are often at risk for being taken "to the cleaners" when it comes to things such as needing a new roof on the house. Sometimes a kind, reasonable stranger seems more appealing to them than the family who is trying to manage their finances because the finances are in disarray, they are forgetting to pay bills, or they have lost the ability to recognize when bills are due.

Angie Pratt:
What we see with many clients we work with is a decrease in good judgment. I actually had a client who went to the grocery store for herself and her husband. She came home with 12 gallons of ice cream. That was one of the first signs. We advise people to ask the individual what he or she had for breakfast that day. That is a short-term-memory question. There has to be more than just forgetfulness or one inappropriate purchase. You must explore this, but if it begins to be a pattern, then I would take my loved one to a doctor.

Ruth Gay:
What we see, and what we saw as part of our Task Force work in Nevada, is the immense toll it takes on families. What we often find with someone who is caring for somebody with cognitive loss is they feel as though they are being driven crazy. They will tell us that they cannot take it anymore. They are exhausted, frustrated, and their loved one is not safe alone even if that person is physically robust.

We also know that Alzheimer's disease and dementia drive up the cost of Medicare. A person without Alzheimer's disease costs Medicare three times less than a person who is cognitively impaired because they forget how to manage their medications. They forget whether they took their medications, and they do not know when to take their medications or do their physical therapy. They do not remember why people are coming to the house to help them.

Assemblyman Oscarson:
One of the things we see in some of the smaller rural hospitals are families feeling trapped. A lot of times these patients come into the emergency rooms with kidney infections, urinary tract infections, and those kinds of things, but there is no one to discharge those patients to. The families just cannot take it anymore and do not want to bring the patient home. That creates a significant problem for discharge planners for hospitals and other facilities that do not have the ability to take care of those folks. It becomes a discharge nightmare to try to find a safe, appropriate discharge for those patients. I know the costs that are incurred, and not only for Medicare, but also for some of the private/public facilities that are taking care of these patients until they can find an appropriate discharge plan.

Ruth Gay:
We talk about the immense pressure on hospitals and the need to not have readmissions occur, yet these are the folks who are at highest risk. Part of it is because there is no safety net in place for a person who is cognitively impaired to go back home. The flip side of that is the family member who is so exhausted, so frustrated, and so desperate that he or she is willing to take his loved one to the emergency room hoping that the person will get care. This is simply to give the caregiver a break when he or she has hit a point where they just do not know what else to do. Both sides of this coin are painful to think about, and there are no easy answers to the problem. This is not just a Nevada challenge. It is a very real, growing phenomenon. Assuming we will get better with diagnosis and that we will be diagnosing people earlier, we are more likely to see a growth in the younger-onset population just by virtue of getting better at diagnosing it.

Who is providing long-term care? There has been a myth that Americans just throw their loved ones away; that they put them in nursing homes, but that has not been our experience. Seventy percent of the people with Alzheimer's disease and dementia are living at home or in some kind of home setting. We know that they are often cared for by an array of family members and friends who are combining their resources to make it work. Sixty percent of these family or unpaid caregivers are women; 56 percent are aged 55 or older. Over 50 percent are primary decision makers and household breadwinners and 26 percent have children of their own under the age of 18 at home. The most common thing we see are adult children who are helping an elder parent care for a spouse with dementia, or they are caring for an elder loved one so that person can stay at home in a setting of their choice.

We know that the cost of caring for people with Alzheimer's disease is almost predominantly out of pocket. The costs we see that drive up the expense of

Medicaid nationwide and state-by-state are skilled nursing facilities, and that is where Medicaid will pay for care. People are looking at an immense financial drain. Many caregivers must reduce their work hours or quit their jobs. As was mentioned earlier, if the victim is under 65, we might be dealing with a loss of health insurance. Sometimes we are driving an entire family onto a state-provided health insurance plan. We know that caregivers of people with dementia suffer immensely from stress and the physical burden of care.

Assemblywoman Fiore:
You said you estimated that there were 29,000 Nevadans suffering from Alzheimer's disease.

Angie Pratt:
The reported number for this year is 29,000.

Ruth Gay:
There are diseases that have shaped the character of an entire nation. When we think about polio in the 1950s and 1960s, there was a prediction at that time that we would need half a million iron lungs to serve the population of people who were going to develop polio. You know what happened with polio. We did not cure polio; we kept people from getting it. As we look at the direction we are going with this disease, we are starting to talk about whether there might be a vaccine. Are there things we can do that would prevent people from developing the disease or at least reduce the risk? These are some of the directions being taken in the research arena. We know we have to change the way this disease goes in the coming century.

Assemblyman Hambrick:
We have heard a lot of statistics, but can you mention a few that might give us some hope? Is there any way to relate environment to this disease, or rural versus urban living, or Scandinavians versus people living in the Pacific Rim? I realize that ten years of research is probably just the beginning of the process, but what research is being pursued? In our research is there an indication that there might be a vaccine or are there other factors that could give us some hope?

Ruth Gay:
I think you are talking about risk factors or directions we could take that might help us change the way we look at this disease in the future. The way research is going right now, we are starting to look at a number of things we think might make a difference for people. Something we are looking at is whether your cholesterol and blood pressure were under control in your middle years. If not, does that increase your risk for Alzheimer's disease in your

later years? That is a really important area of investigation. We know that heart health is brain health; the things you do and the way you eat for your heart are almost certainly going to be good for your brain as well. One direction they are going is looking at whether the medications and treatments being used to reduce blood pressure and manage cholesterol in a person's middle years could be factors in reducing the risk for Alzheimer's disease later in life. Those are big research questions. The challenge right now is that Alzheimer's is very underfunded, and that is an area of national concern.

We are also looking at other indications for Alzheimer's. We know diabetes is a huge risk factor for Alzheimer's disease. You asked about populations. We know the Latino population has a high prevalence of diabetes, so there is also a higher risk for Alzheimer's disease in that culture because of the diabetes risk. We are also looking at the role of insulin in the brain and whether we can alter those factors long before an individual has the symptoms that take you to the doctor. We know that in order to change the way we treat this disease we have to find ways to manage it much earlier—long before people are well into the disease process. The suggestion has been made that some of the drugs that failed to reduce the plaques and tangles in the brain may have been introduced to people too late in the disease. If we can get better at diagnosis and get earlier diagnosis, can we also develop drugs and treatments that might prevent the plaques and tangles?

Assemblyman Sprinkle:
Is early detection and diagnosis part of what led to the 66-percent increase you referred to early on or are there other factors that led to such an increase?

Angie Pratt:
As I stated earlier, we are an aging population. I think the number one reason for the increase is that we are living a lot longer. The question becomes whether we can live longer and have a good quality of life. As Ruth mentioned, there is a lot of research focused on this disease right now. Some of it is very hopeful research both within and outside the United States. There is a really interesting study right now in Colombia. There are 300 cases of Alzheimer's disease in one extended family in a town in Colombia. The family is being extensively researched and experimental drugs are being given to family members who are in their 20s and early 30s to try to stop the plaques from forming in their brains. When I explain plaques to our caregivers I tell them it is as though you had duct tape, it all started to stick together, and you could not get it apart. That is what plaque in the brain of a person with Alzheimer's disease is like. I believe Harvard University is working with the Colombian government on the research being done. There is another fabulous piece of research going on at the University of Washington. It is around sniffing insulin

to try to stop the movement of Alzheimer's in the brain. That is another hopeful piece of research.

Ruth Gay:
You are asking about the 66-percent increase in deaths. When we invest in research and treatments for diseases, it has resulted in a reduction in deaths because of better treatments, earlier diagnosis, and earlier treatments. You know what we have done with cancer. People know now that if you have a lump under your arm you need to get to the doctor earlier and not wait.

With Alzheimer's disease, those death rates are rising mainly because we do not have a way to prevent, treat, or change the course of the disease at this point in time. There are no survivors; there is no one in therapy with Alzheimer's disease. Last year we passed a national plan to defeat Alzheimer's disease. The plan has predicted that we will have a viable treatment in the next 15 years, but we have to do better at diagnosis and treatment.

Assemblyman Hickey:
You are certainly providing a good education to all of us. Earlier someone asked a question about studies in different places in the world. When I hear things like plaque and references to high blood pressure and some of the other related diseases, I start thinking about environment and diet. Have there been any studies in societies that, for instance, eat fewer processed foods?

Angie Pratt:
There have been extensive studies done on diet as it relates to the development of Alzheimer's disease. They do know that diet does play a factor, but of course diet plays a factor in getting diabetes. We have 14 support groups in the Northern Nevada Alzheimer's Association. We ask how many people in those support groups are caring for someone who has Alzheimer's and diabetes. Fifty percent raise their hands. That shows a correlation, so yes, there are plenty of studies saying that what we eat does affect this. On the other hand, you could have the most wonderful Mediterranean diet in the world and you could still develop Alzheimer's disease.

Chair Dondero Loop:
Thank you so much for this information. I know it will transition very nicely into the next bill we will hear. I will now open the hearing on Assembly Bill 80. This bill creates the Task Force on Alzheimer's Disease within the Health Division of the Department of Health and Human Services.

Assembly Bill 80: Creates the Task Force on Alzheimer's Disease within the Health Division of the Department of Health and Human Services. (BDR 40-546)

Valerie Wiener, Chair, Legislative Committee on Health Care's Task Force to Develop a State Plan to Address Alzheimer's Disease:
It was my joy and privilege to serve as Chair of the Legislative Committee on Health Care's Task Force to Develop a State Plan to Address Alzheimer's disease in Nevada. The bill before you is a byproduct of the work we did as a result of Assembly Concurrent Resolution No. 10 of the 76th Session. We were charged with developing a state plan to address Alzheimer's disease. In addition, a report was required detailing the plan and making recommendations for legislation. This report was the dream of many people representing this community who work with Alzheimer's every day. You just heard from two extraordinary advocates who are the voices for people who are not always able to speak. Several organizations have been working together and wanted to do more to make something happen. They wanted to provide opportunities for legislators to learn more about what this disease does, the needs these various populations have, and the lack of services that are available. This disease affects not only the people who have it, but also the families who support them and the communities in which they live.

The Legislative Committee on Health Care appointed the members of the Task Force. We had five full-day meetings, and the people who participated in the Task Force were passionate about this subject. The people who came before us providing testimony were extraordinary as well. They were experts in medicine, nursing, psychology, public policy, social work, and other related disciplines, as well as those who are personally affected by what Alzheimer's can do—not only to the people who have this disease, but also those who support them, especially the families. We had very compelling testimony from families that shifted us as we sat there listening.

The plan evolved to tell the story of Alzheimer's disease in Nevada. You will often hear the reference to "Alzheimer's and related disorders," because there are other cognitive disorders that will benefit from the work we did, but as I recall, about 70 percent of the time a cognitive disorder is Alzheimer's. Though we had the charge to develop a state plan, what we realized was that this was, or should be, a living document. This is not something we finish, send out to legislators for policy, and say we are done. This is something that needs constant attention and nurturance because it affects so many people. Our awareness that the work of the Task Force should continue is why this measure, A.B. 80, is before you.

This bill gives details such as the components of membership and the tasks it should be charged with. You will also see that there will be a member from the Assembly and one from the Senate appointed, because part of the mission is to keep awareness at the Legislature fresh as policy continues to evolve to address this problem. Those two voices will be very important.

The language in the bill indicates that this Task Force will be housed in the Health Division. It is my intent to offer an amendment at this time to house it in the Department of Health and Human Services. We have talked with the Director, Mr. Willden, and he has agreed to that change. During drafting of this bill, we realized the subject is so big and so important to all of us that, even though several divisions within the Department can work on certain pieces, the umbrella provided by the Department of Health and Human Services would be able to address all aspects. My suggestion would be to amend section 5, subsection 1, where the Health Division is referenced to say, "the Task Force on Alzheimer's Disease would be created within the Department of Health and Human Services."

On a personal note, after one of our meetings there was a voicemail waiting for me. One of the many people listening to our meetings online is someone I have known since the 1980s. He listens regularly to legislative processes and his voicemail went something like this, "I just listened to the hearing and it was one of the most depressing things I ever heard." My voicemail going back the other way said, "We have a different perspective."

We know that this disease is here. What we also know is people are reluctant to talk about it and are embarrassed to have conversations about it. I am thrilled that we had an opportunity for five meetings to talk openly and publicly about Alzheimer's disease and other dementias. It is about time we had these open conversations because we have a responsibility to do something about it. We talked about services, or the lack thereof. We talked about support systems; we talked about what needs to be done, and we are talking about how we can do it.

What was so important to me throughout, and we had examples of it brought to us, was the fear factor. That is why we have not talked about it. When a patient and family go into a doctor's office, the doctor does not necessarily know what to do. The diagnosis is very expensive. The doctor's diagnostic experience may say that a patient has Alzheimer's, but now what is the doctor's responsibility? The patient often does not want to know because that information is a life change. Often the family does not want to know because that information changes their lives too.

Many diseases we often speak of in health committees, the chronic diseases such as heart disease, diabetes, and others, are horrible things to happen to a person. However, very few diseases are diseases of family as Alzheimer's is. Assuming there is a family to help, if one member of a family gets it, it becomes a part of the rest of the family.

I am thrilled that we are able to come here today and talk about continuing the conversation with this Task Force and keeping this message in front of the people of Nevada.

Chair Dondero Loop:
Are there any questions from the Committee at this time?

Assemblyman Sprinkle:
Section 7 says that the very first thing the Task Force shall do is, "Develop a state plan to address Alzheimer's disease." Exactly what does that mean?

Valerie Wiener:
The language following that statement mentions monitoring and adjusting. There was nowhere in statute that creation of the plan was required. We are codifying it. Is that correct?

Risa Lang, Committee Counsel:
Yes, that is correct, and it is referred to in section 9.

Assemblyman Hickey:
Section 5, subsection 3, contains language referring to appointment of Task Force members from this body. I see you are having the appointments made by the Legislative Commission. Would you explain your thinking, and how that would be best done?

Valerie Wiener:
In my experience, that is generally what happens when the Legislative Commission makes all those appointments at the end of session.

Assemblywoman Spiegel:
Is this plan only covering people once they present with symptoms and actually get a diagnosis, or will it go back further to cover people who are genetically predisposed, but have not necessarily presented with any symptoms yet?

Valerie Wiener:
The plan is based on the working groups that were interested in various issues. It works around access to services, the quality of care, quality of life,

public awareness, and the regulatory process. The primary focus would be on those who have it, because our diagnostic practices are not as substantial as we would like them to be. We came away with a substantial number of recommendations. *The Nevada State Plan to Address Alzheimer's Disease* (Exhibit D) has been provided to Committee members electronically. It contains 20 recommendations, but we probably had an exponential number that were offered.

We learned from the medical community and one of our Task Force members, Dr. Bernick, that at this point in time the reimbursement for even attempting to diagnose the disease is very, very low. That low reimbursement rate is not an incentive to screen all patients just to see if Alzheimer's is coming. Maybe in 15 years we will have a treatment and a way to know earlier, and once that happens, reimbursement will come very quickly because the earlier we diagnose, the more quickly we will deal with it. We have a lot of things to accomplish and address. This is for those who are working with the circumstances as they are now. That is why it is a living document and that is why we are before you.

Chair Dondero Loop:
Are there any additional questions from the Committee? [There were none.] Thank you for your testimony. Before we begin hearing testimony in support of A.B. 80, I would like to mention that Dr. Charles Bernick of the Cleveland Clinic Lou Ruvo Center for Brain Health has submitted written testimony in support of this bill and that is available to all of us on the Nevada Electronic Legislative Information System (NELIS) (Exhibit E). Now, I will call those who would like to make comments in support of this bill to come forward.

Wendy Simons, Private Citizen, Reno:
I am speaking in support of the bill today, not as a state employee who was on the Task Force, but from a personal standpoint representing only myself and my opinions. [Ms. Simons presented a letter in support of A.B. 80 (Exhibit F).]

Sitting here today, I have been impressed: Mrs. Benitez-Thompson, we have had conversations and you are in the field; Mr. Oscarson, your awareness of the rural issues and the impact that can occur; Mr. Sprinkle, having been a paramedic and emergency medical technician, you have probably responded numerous times to people suffering from this disease. Assemblyman Hickey, I believe you have a father-in-law who is in his late 90s, and the Chair has a mother in her 90s. You both get that gut-level feeling of concern. I watched everyone's faces as the testimony unfolded, and it is impressive and gratifying to me.

Previously I was in the health care industry. In fact my parents started the first senior care facility in Nevada in 1948. I have had the great privilege of living with senior populations for four decades. The individuals I lived with had varying stages of what was Alzheimer's disease, although 40 years ago it was not acknowledged. It has become more recognized, discussed, and revealed as each decade has passed.

Angie Pratt and Ruth Gay gave you the history, but I lived with it in many varying stages for over 40 years. I provided supportive care to individuals afflicted with Alzheimer's disease and other related dementias. I shared the lives of physicians, nurses, lawyers, housewives, developers, race car drivers, a Pentagon contract negotiator, and even legislators. The experience of living with so many people, and then the gift of being invited to participate in this Task Force last session, broadened my understanding even more. As a result of the work of this Task Force, we really are on the cusp of being able to move things forward in much better fashion.

A lot of research was presented to us, and so many individuals are committed to providing for initiatives, but because the State of Nevada is small there is no link. There is not really great communication. There are tremendous gaps in putting systems and potential solutions together. The Task Force clearly identified that. It recognized a need to have a multi-agency and industry collaborative. The camaraderie in that group and the way people pulled together who presented to us was the most impressive effort I have ever been involved in.

You all saw the product—the result of only five meetings. There is great value in sustaining the effort of the Task Force and in moving forward. The groundwork has been laid. In the spirit of good business planning and good government planning, I would encourage the continuation of the Task Force.

Bruce Arkell, representing Nevada Senior Advocates and the Personal Care Association of Nevada:
We worked on the initial resolution that came through the 76th Session. This is the first time I have seen a plan that was really directed by the Legislature. Usually the plan will be turned over to a state agency, so I hoped you would take more ownership of it. I think that is extremely important because this is a disease that is not going to be dealt with today, or in the next two weeks, and there is not an instant solution anywhere. You have an excellent start on it; I think the continuation of the Task Force is important and that its work is just beginning. I have been following Alzheimer's disease, and it is amazing to me the increase in research and studies taking place, all of which are leading down

some very positive roads. I would encourage your support of A.B. 80, as amended.

Jane Gruner, Administrator, Aging and Disability Services Division, Department of Health and Human Services:
I am here to speak in favor of this Task Force. The Aging and Disability Services Division will work diligently with the Task Force and its work.

Ruth Gay, Director, Public Policy and Advocacy, Northern Nevada Alzheimer's Association:
I was a member of the Task Force, and I want to demonstrate the changing landscape of this disease. I was speaking to a support group about six months ago, talking about behaviors and what happens with people who have dementia. There was a woman sitting next to me who had been providing care for her mom for about a year. Her mother lived with her and she was expressing her frustration with the stress involved. I asked her whether her mother had a diagnosis. Do you know what you are dealing with? Do you know if it is Alzheimer's, or is it something else like a stroke? The woman replied that they had not taken her mother to the doctor. "Why bother? There is nothing you can do anyway?"

One of the challenges we see is that there is this myth that there is nothing we can do. We have made great strides with this disease in the last ten years. There are currently three drugs out that can help with symptoms of the disease. There are drugs that can help with the behaviors and functional changes that occur. Can we cure this disease? We cannot. Can we change the course of this disease? We cannot; but we can help families cope. We know that education of caregivers helps them understand what is happening, helps them plan better for their families, and helps them be part of the process.

In our country right now there is an early-stage group of people who are diagnosed and aware that they have the disease. They are looking for solutions now and they are a part of their families' planning. That phenomenon will be growing over the next five to ten years. These are the people who are pushing for change, and we will see changes. One of the biggest challenges is getting the information out there and creating public awareness. This is a disease that you may live with for a very long time. You may have many good years ahead of you. Many times our vision of a person with Alzheimer's is that of a person in a nursing home who is no longer aware, and yet what we are seeing are these folks who are aware, functioning, living in the community, and trying to make their lives as good as they can be while suffering with the disease. The fact that the government embraced this plan and got it started is really what drove that process. I want to thank you for that, and I hope you will vote favorably for this bill.

Albert Chavez, Regional Director, Desert Southwest Chapter, Alzheimer's Association in Southern Nevada Region:
Over the course of the last couple of years I have had the privilege to be part of a couple of different groups in creating a state plan. I have worked with my colleagues in the Northern Nevada Alzheimer's Association in preparation of the plan. I have also had the opportunity to work with the Clark County Alzheimer's Action Network in southern Nevada. It has been a privilege and an honor to be a part of the Task Force. Over the course of the last two years we have heard a lot of testimony and facts. We have heard that there are four major areas in which the State of Nevada is lacking. The first is awareness; the next is diagnosis and assessment; followed by navigation and placement. When we speak about awareness, we are talking about the three types of people we have come to know over the last several years: people who know about Alzheimer's disease; people who know about Alzheimer's disease but do not want to know about it; and people who do not know about Alzheimer's disease.

The people who know about Alzheimer's disease are typically those people who have had experience, whether they are family caregivers, professionals, or people who have worked in the industry. People who know about Alzheimer's but do not want to know about it are those people we see at health fairs who pass our table with their faces averted. Then there are people who just do not know about Alzheimer's disease.

Diagnosis and assessment is the next category. Misdiagnoses are an issue we face within the State. Then there is navigation from A to Z covering someone from reception of the diagnosis of Alzheimer's disease all the way through to the end. That is quite an issue in our state. Placement is also an issue. You have heard about placement in some of the testimony today, and out-of-state placement in particular.

Our Task Force built three work groups that worked tirelessly over many hours to put together the state plan. In southern Nevada, the Desert Southwest Chapter would like to ask you to please consider A.B. 80, and we are in support of it.

Chair Dondero Loop:
Are there any additional supporters? [There were none.] All right, we will go to opposition to Assembly Bill 80. I do not see anyone down south. Is there anyone who wishes to testify as neutral? [There was no one.] Thank you,

I will close the hearing on A. B. 80. Thank you for the amendment. Please be certain it gets to the right place.

Are there any additional comments from the Committee? [There were none.] Does anyone wish to make public comment? [There was no response.] Thank you very much, this meeting is adjourned [at 2:48 p.m.].

[A proposed amendment (Exhibit G) was provided after the meeting.]

RESPECTFULLY SUBMITTED:

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Terry Horgan
Committee Secretary

APPROVED BY:

____
Assemblywoman Marilyn Dondero Loop, Chair

DATE: ____________________________

EXHIBITS

Committee on Health and Human Services

Date: February 25, 2013 Time of Meeting: 1:34 p.m.

Bill	Exhibit	Witness / Agency	Description
	A		Agenda
	B		Attendance Roster
	C	Angie Pratt, Regional Dir., No. Nev. Alzheimer's Assn.	"Alzheimer's Disease in Nevada"
A.B. 80	D	Kirsten Bugenig, Committee Policy Analyst	*The Nevada State Plan to Address Alzheimer's Disease*
A.B. 80	E	Dr. Charles Bernick	Letter in support
A.B. 80	F	Wendy Simons, Private Citizen	Letter in support
A.B. 80	G	Jane Gruner, Administrator, Aging and Disability Services Division, DHHS	Proposed amendment