NEVADA LEGISLATURE
LEGISLATIVE COMMITTEE ON HEALTH CARE'S TASK FORCE TO DEVELOP A STATE PLAN TO ADDRESS ALZHEIMER'S DISEASE

(Assembly Concurrent Resolution No. 10 [File No. 42, *Statutes of Nevada 2011*])

SUMMARY MINUTES AND ACTION REPORT

The first meeting of the Nevada Legislature's Legislative Committee on Health Care's Task Force to Develop a State Plan to Address Alzheimer's Disease was held on Wednesday, June 13, 2012, at 9 a.m. in Room 4401 of the Grant Sawyer State Office Building, 555 East Washington Avenue, Las Vegas, Nevada. The meeting was videoconferenced to Room 3138 of the Legislative Building, 401 South Carson Street, Carson City, Nevada. A copy of this set of "Summary Minutes and Action Report," including the "Meeting Notice and Agenda" (Exhibit A) and other substantive exhibits, is available on the Nevada Legislature's website at http://www.leg.state.nv.us/interim/76th2011/committee/. In addition, copies of the audio record may be purchased through the Legislative Counsel Bureau's Publications Office (e-mail: publications@lcb.state.nv.us; telephone: 775/684-6835).

COMMITTEE MEMBERS PRESENT IN CARSON CITY:

Virginia "Gini" Cunningham
Wendy Simons

COMMITTEE MEMBERS PRESENT IN LAS VEGAS:

Senator Valerie Wiener, Chair
Charles Bernick, M.D.
Albert Chavez
Ruth Gay
Sandra Owens, Ph.D.

LEGISLATIVE COUNSEL BUREAU STAFF PRESENT:

Roger McClellan, Health Care Policy Specialist
Marsheilah D. Lyons, Supervising Principal Research Analyst
Casey Catlin, Doctoral Student, University of Nevada, Reno
Anne Vorderbruggen, Senior Research Secretary

OPENING REMARKS AND TASK FORCE SCHEDULE

- Senator Valerie Wiener, Chair, welcomed members, presenters, and the public to the first meeting of the Legislative Committee on Health Care's Task Force to Develop a State Plan to Address Alzheimer's Disease, and explained the procedures for conducting the business of the Task Force and providing testimony. Chair Wiener introduced the Task Force members and staff.

  Chair Wiener reported that at the June 12, 2012, meeting of the Legislative Committee on Health Care, the Committee approved her request that each Task Force member be authorized to name two people who could serve as an alternate if the member was not able to attend a meeting. She requested that the Task Force members submit their proposed names to Task Force staff: either Marsheilah D. Lyons, Supervising Principal Research Analyst, Research Division, LCB; or Roger McClellan, Health Care Policy Specialist, Research Division, LCB.

  Chair Wiener stated that the Task Force has four working groups: (1) Impact of the Disease on the State; (2) Access to Services; (3) Independence and Safety; and (4) Quality of Care and Regulation. She requested that Task Force members volunteer to coordinate the activities of the working groups. She also requested that the Task Force members who are willing to be coordinators provide their names and the particular group that each member prefers to coordinate to Ms. Lyons or Mr. McClellan within a week.

OVERVIEW OF THE STRUCTURE, CHARGE, AND DUTIES OF THE LEGISLATIVE COMMITTEE ON HEALTH CARE'S TASK FORCE TO DEVELOP A STATE PLAN TO ADDRESS ALZHEIMER'S DISEASE (A.C.R. 10)

(As directed by Chair Wiener, this agenda item was taken out of order.)

- Roger McClellan, Health Care Policy Specialist, Research Division, LCB, stated that Assembly Concurrent Resolution No. 10 (File No. 42, *Statutes of Nevada 2011*) is the culmination of the efforts of a group of Alzheimer's connected organizations coordinated by Angie Pratt, Northern Nevada Regional Director for the Alzheimer's Association, to bring the issues and needs of sufferers of Alzheimer's Disease and their families to the attention of the Legislature. He noted that A.C.R. 10 directs the Legislative Committee on Health Care (*Nevada Revised Statutes* 439.200) to create a task force to develop a State plan to address Alzheimer's Disease and submit a report of the findings and plan developed by the Task Force and any recommendations for legislation to the 77th Session of the Legislature.

  Mr. McClellan said the Task Force is a public body and he described the requirements of Nevada's Open Meeting Law, which governs meetings of public bodies in Nevada.

  In conclusion, Mr. McClellan described the Task Force's four working groups and the areas suggested for review by each group. (Please see Exhibit B.)

- Marsheilah D. Lyons, Supervising Principal Research Analyst, Research Division, LCB, stated that the working groups are informal groups that would allow a member of the Task Force to work with interested parties in between the Task Force meetings in preparing to put together a strategic plan. She noted the Chair is looking for an individual Task Force member to coordinate each working group, and that LCB staff would be available to assist with locating meeting rooms, or providing access to video or telephone conferencing. Ms. Lyons stated that the proposed working groups originated from what was presented during the discussion of A.C.R. 10 during the 2011 Legislative Session.

PRESENTATION ON THE NATIONAL PLAN TO ADDRESS ALZHEIMER'S DISEASE

(As directed by Chair Wiener, this agenda item was taken out of order.)

- Donald B. Moulds, Principal Deputy Assistant Secretary for Planning and Evaluation, United States Department of Health and Human Services (HHS), testified by telephone from Washington, D.C. He noted that as the HHS started to work on the national plan, they learned that in a little over one-half of the states there currently are Alzheimer's Disease or related dementia strategies, and there are also countries that are doing important and innovative things around Alzheimer's Disease and related dementias. Mr. Moulds provided a written overview of the national plan to address Alzheimer's Disease (Exhibit C).

  Mr. Moulds described the National Alzheimer's Project Act (NAPA), which was passed by the United States Congress in December 2010, and required the creation of a national strategic plan to address Alzheimer's Disease. The strategic plan is to be updated annually through 2025. Mr. Moulds stated the three primary categories of issues related to Alzheimer's Disease and related dementias to be covered in the strategic plan are research, clinical care, and long-term services and support.

  Mr. Moulds described the Advisory Council on Alzheimer's Research, Care, and Services and the Interagency Group on Alzheimer's Disease and Related Dementias. Mr. Moulds stated that all materials and information regarding the Advisory Council are available on the HHS website at: http://aspe.hhs.gov/daltcp/napa/.

  Continuing, Mr. Moulds reported that in March 2012, President Barack Obama announced a two-year $156 million investment in Alzheimer's Disease as part of his "We Can't Wait" initiative. He also stated that when HHS Secretary Kathleen Sebelius introduced the strategic plan at the National Institutes of Health, she previewed the first television ad that will be aired this summer that directs people to a new governmental website, http://alzheimers.gov/, which is a resource for caregivers and for people with a positive diagnosis. Mr. Moulds said that Ms. Sebelius also announced two new clinical trials that will be funded in 2012, one of which is looking at an amyloid plaque reducing drug. This is the first large-scale clinical trial looking at plaque reduction, which is the leading theory of why people get Alzheimer's Disease. Mr. Moulds further stated that an insulin nasal spray is available that has shown some promise for stemming some of the symptoms of dementia.

Mr. Moulds announced that the next meeting of the Advisory Council will be July 23, 2012, in Washington, D.C., and it will be webcast through the meeting information at: http://aspe.hhs.gov/daltcp/napa/.

In response to Dr. Owens' question if he had a recommendation regarding plans of other states that are particularly well aligned and well coordinated with the national plan, Mr. Moulds stated that the current state plans preceded the national plan, but it is hoped that going forward the plans will be well coordinated with the national plan. He noted that David P. Hoffman, M.Ed., is the state representative on the Advisory Council and is extremely knowledgeable about state plans and would be a helpful resource.

- Ms. Gay asked if the plan is going to look at staging, because, as diagnosis is improved and better treatments are developed, people will be identified younger and earlier in the process and they will be kept in the community longer. She is looking specifically at where there might be cost savings by serving people and supporting families much earlier to avoid the extended costs and the long-term care later in life.

- Mr. Moulds responded that the Advisory Council has looked at the disproportionate impact the disease has on racial and ethnic minorities and particularly on people with developmental disabilities. He stated they have also been focusing on early onset and the populations that have a higher likelihood of contracting the disease at an earlier age. Mr. Moulds noted there is a tremendous amount of interest in how the disease affects government programs and the economy. He stated a project is being funded at the University of California, Los Angeles, that is looking at innovative dementia care, and promises to provide much better care at a dramatically reduced cost, and various models of care are being researched.

PUBLIC COMMENT

- Becky Calhoun, R.N., M.S.N., C.C.R.N., Reno, stated she is a nursing professor at Truckee Meadows Community College, is affiliated with the Alzheimer's Association, and is the daughter and sister of people who suffer from Alzheimer's Disease. She addressed education in the acute care hospital setting and stated that incentives and funding to support acute care education are an essential element for the current and future care of Alzheimer's patients and those with related dementia. (Please see Exhibit D.)

In response to Ms. Simons' question if there is capacity within the community colleges and the university system to provide the expanded acute care education, Ms. Calhoun stated that the programs could be revamped for an extended education, especially in psychological approaches and medications. She stated there should also be some continuing education for nurses in the field of the acute care setting.

Discussion ensued between Ms. Simons and Ms. Calhoun regarding what would be needed to expand the outreach to the hospitals. Chair Wiener noted that the agenda for the next meeting of the Task Force will include a witness panel on the topic of training.

- Ms. Gay stated that, in addition to treatments and medications while people are in the acute care settings, one of her concerns is about discharge planning and what happens when people leave who may need more care coordination than other patients.

PRESENTATION ON MEDICAL MODEL OF ALZHEIMER'S DISEASE AND THE DIFFERENCE BETWEEN YOUNGER AND OLDER ONSET

(As directed by Chair Wiener, this agenda item was taken out of order.)

- Charles Bernick, M.D., Associate Medical Director, Cleveland Clinic Lou Ruvo Center for Brain Health, reviewed the information provided in his Microsoft PowerPoint handout titled "Medical Model of Alzheimer's Disease and the difference between young and old disease onset" (Exhibit E).

  Dr. Bernick stated that Alzheimer's Disease begins in the brain years or decades before there are symptoms. Those symptoms evolve very slowly and by the time a person develops dementia, the person is at the end of the disease, yet that is where most of the attention is focused and where all the resources are used. Therefore, if people can be delayed from getting to that point, it is a major success.

  Dr. Bernick discussed the following items covered in his presentation handout:

  - Alzheimer's dementia and reasons why it is underdiagnosed;
  - Potential benefits of early recognition and treatment;
  - Diagnostic evaluation;
  - Which older adults should be evaluated for Alzehimer's Disease;
  - Young onset Alzheimer's Disease; and
  - Targets of treatment.

  Dr. Bernick noted that the State of Nevada, particularly through the Aging and Disability Services Division, has been very proactive about Alzheimer's Disease, beginning as long as 17 years ago.

  In summary, Dr. Bernick stated that Alzheimer's Disease extends over a long period of time; early detection requires a high index of suspicion; and treatments may help maintain function and reduce costs of care.

- Ms. Simons thanked Dr. Bernick for his presentation and stated that he has been a tremendously impressive and instrumental individual in any progress that has been made in family care, early diagnosis, and education throughout the last 17 years.

In response to Dr. Owens' inquiry if he has any suggestions about how to overcome the social stigma associated with the diagnosis of Alzheimer's Disease, Dr. Bernick stated that the image of what the disease is has to change so there can be early detection and more aggressive treatment. It is also important to get the message out that earlier intervention and early diagnosis provide the best option for leading a more productive and valuable life.

- Chair Wiener asked Dr. Bernick to address the issue of compensation as an incentive for doctors to participate more vigorously in earlier detection.

- Dr. Bernick stated that a doctor gets very little compensation for a diagnosis that does not involve procedures. He noted that the way the medical system is currently set up for Medicare, because most older people have Medicare, it is a disincentive to spend the time necessary to make a diagnosis; however, the labs and radiologists are well reimbursed for the tests ordered by the doctor. He noted this is one of the gaps in the medical system in the United States and there is nothing the State can do about it, but it needs to be addressed.

Ms. Gay asked if there are ways that would be effective in helping bring primary care doctors up to speed to recognize when they see warning signs or hear about them from the patient, family, or caregiver, so they would know to refer a patient to a specialist. Dr. Bernick responded that the drug companies have thought about this for many years. He said it is difficult and there are many educational programs, but the people who participate are already interested and there are some people who think the drugs will not make a difference, so why bother. He noted the field will definitely change once there is a disease modifying therapy. He noted there are many trials of disease modifying therapy, some of which are being done in Las Vegas.

PRESENTATION ON ALZHEIMER'S RESEARCH AND CLINICAL TRIALS

(As directed by Chair Wiener, this agenda item was taken out of order.)

- Charles Bernick, M.D., previously identified, referred to his Microsoft PowerPoint handout titled "Alzheimer's Research and Clinical Trials." (Please see Exhibit F.) Dr. Bernick stated that to prevent Alzheimer's Disease three things are needed: (1) to understand the disease process; (2) to detect it early; and (3) to have disease modifying treatments.

  Dr. Bernick stated that the current theory regarding how Alzheimer's Disease develops is that Beta-amyloid builds up in the brain and causes cells to malfunction and degenerate. He noted that most of the treatments being looked at for disease modification to prevent or slow progression of the disease involve how to interfere with the Beta-amyloid.

  Dr. Bernick said there are many different research initiatives being undertaken, one of which is early detection. He noted that Las Vegas is involved in one of the national studies of brain imaging and a blood test for Alzheimer's Disease. Dr. Bernick described the early detection tests, including:

- Spinal fluid measuring of amyloid;
- Imaging amyloid in the brain through a scan; and
- Testing to measure the volumes of the brain, because when certain areas of the brain start shrinking, it is an indicator of Alzheimer's Disease.

Continuing, Dr. Bernick described the treatment strategies and prevention trials that are being undertaken. He noted that the limiting factor in research trials is recruitment. Dr. Bernick commented that there is limited research in basic science in Nevada, and there are not any biotech companies focused on this disorder in Nevada.

Chair Wiener asked how people are recruited to participate in trials. Dr. Bernick responded that most come from the Cleveland Clinic's patient population and the Clinic's research network throughout southern Nevada, which also identifies people from various medical practices that refer patients for the clinical trials.

Discussion ensued between Chair Wiener and Dr. Bernick regarding the possibility of geographical or environmental factors that influence the progression of the disease and may affect the research.

- Ms. Gay asked if there are any barriers for people with dementia to enroll in studies that should be addressed legislatively. She noted this may not be an issue since the studies being conducted are early studies.

- Dr. Bernick responded that he understands there had been some clarification in the State laws of what was required to participate in the trials.

- Chair Wiener requested that legal counsel clarify what the statutory provisions are for consent to enroll in studies to ensure there is not a need to clarify the provision.

In response to Mr. Chavez's question regarding how to raise awareness that there is hope for people with Alzheimer's Disease, Dr. Bernick stated that ads on television or radio may not be as effective as needed. He suggested there could be a campaign or promotion within the health care system that research is being conducted and prevention trials are going on that can delay progression.

Discussion ensued between Dr. Owens and Dr. Bernick regarding whether the Patient Protection and Affordable Care Act could be used for marketing and getting the message out to achieve more participation and knowledge about the disease.

- Ms. Cunningham referred to a recent article in the *Las Vegas Review-Journal* about a test for early detection that would soon be available, and asked Dr. Bernick about the test.

- Dr. Bernick responded that the test referred to in the article is for amyloid imaging. He stated it has been approved by the U.S. Food and Drug Administration, and it will be commercially available in the next few weeks. However, it will not yet be covered by insurance. Dr. Bernick also noted that the spinal fluid measurement test, which is just as accurate and readily available, also is not covered by Medicare. He noted that there will be a change when there is a disease modifying therapy that can delay progression, in which case these early detection tests will become very important.

Responding to Dr. Owens' question regarding a timeline for the State Plan to Address Alzheimer's Disease, Chair Wiener stated that the goals and benchmarks will unfold as the Task Force receives information and works together. She noted Nevada often undertakes these types of projects that are innovative and set the stage for the rest of the country and she looks forward to the Task Force doing just that.

- Julie Lesko, Reno, stated she is a family nurse practitioner and is representing herself and the Nevada Advanced Practice Nurses Association. She commented that early detection is what is important, but nobody is paying for it. She suggested that, although money would be lost by doing the early assessment, resources would be saved at the later stages of the disease.

  Ms. Lesko pointed out that, with the Patient Protection and Affordable Care Act, there is now being implemented in communities an incentive for health care organizations to conduct in-depth comprehensive health care screenings, that can provide early detection for some of the most serious but hard-to-detect diseases like Alzheimer's.

PRESENTATION ON THE COLLECTION AND ANALYSIS OF ALZHEIMER'S- AND DEMENTIA-RELATED DATA THROUGH THE CENTERS FOR DISEASE CONTROL AND PREVENTION BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM SURVEY FOR THE STATE

(As directed by Chair Wiener, this agenda item was taken out of order.)

- Jay Kvam, State Biostatistician, Health Division, DHHS, reported that the Behavioral Risk Factor Surveillance System (BRFSS) was established in 1984 by the Centers for Disease Control and Prevention (CDC) and is conducted annually. He stated it has been a key factor in developing surveillance reports to understand what is going on with communities and investigating correlations between behaviors and health outcomes. Mr. Kvam noted the BRFSS provides a wealth of information related to diseases and disabilities, the prevalence of those diseases, and their burden on communities and societies. It also collects demographic information, as well as behaviors.

  Mr. Kvam stated the survey has three main categories: the core questions, optional questions, and state-added questions. The core questions and optional questions are defined by the CDC, and the states may select the optional questions at their discretion. Mr. Kvam noted that, in the current grant cycle, Nevada has selected an optional CDC component with a variety of questions that deal with Alzheimer's Disease and other cognitive impairments and their burden on the community, titled "Impact of Cognitive Impairment Module." (Please see Exhibit G.)

  Mr. Kvam noted the BRFSS is conducted by telephone land lines and is a sampling of individuals statistically designed to be representative of the community. He stated the

University of Nevada conducts the telephone interviews with the respondents, in conjunction with the Health Division. Mr. Kvam noted the "Impact of Cognitive Impairment Module" specifically addresses whether an individual has ever been formally diagnosed by a professional for Alzheimer's Disease, measures the burden of these diseases, evaluates health care seeking behaviors, and asks about treatments received for Alzheimer's Disease. He stated that in some cases, the survey allows them to analyze demographic characteristics of those who might be impacted by such disorders or even their geographic location; however, that is not always possible because of the sampling and the number of respondents per a particular demographic.

In response to Chair Wiener's inquiry regarding the status and timeline of the survey, Mr. Kvam stated the survey is currently being conducted and, at a minimum, the information could be provided to the Task Force by 2013.

Responding to Ms. Simon's question regarding the total estimated participation in the survey, Mr. Kvam stated the number is in the thousands, and the parameters are established by the CDC.

- Ms. Cunningham noted that many people hang up when they get a call, especially because this is an election year. She asked if she could have the caller identification number for the survey so she could inform her community that the call from that number is a vital survey.

- Mr. Kvam stated he would provide the telephone number for the Task Force. He noted that people who do not respond are called back a number of times before it is finally determined that they are a nonrespondent.

- Ms. Simons suggested that consideration be given to partnering with health spas, health clubs, health programs, and fitness centers, since those people are committed to health and well being and would be the first ones to recognize they were experiencing changes.

- Mr. Kvam responded that these kinds of creative thoughts of how different segments of the community can be engaged are valuable; however, in terms of the survey, it is quite structured so it is unlikely that responses will be preferentially chosen from any demographic.

In response to an inquiry from Ms. Gay regarding whether there is any attempt to look at cultural or geographical diversity in the survey, Mr. Kvam said that various races, ethnicities, and age groups are always represented in the survey. However, because so many questions are asked and they are not designed based on whether a state is going to add its own questions or select an optional module, although a number can be generated, cultural and geographical diversity are not statistically reliable.

OVERVIEW OF THE STATE OF ALZHEIMER'S DISEASE IN NEVADA: COST AND FUNDING RESOURCES INCLUDING MEDICAID, MEDICARE, VETERANS' ASSISTANCE, PRIVATE INSURANCE, AND FAMILY RESOURCES

- Chair Wiener thanked Mary Liveratti, Administrator, Aging and Disability Services Division, Nevada's Department of Health and Human Services (DHHS), for the extraordinary leadership she has provided through the years to the issue that is before this Task Force.

- Ms. Liveratti provided a Microsoft PowerPoint handout describing the Aging and Disability Services Division's programs, projects, and partnerships related to Alzheimer's Disease, including: (Please see Exhibit H, Exhibit H-1, and Exhibit H-2.)
  - Alzheimer's Disease Supportive Services Programs, a federally funded program;
  - Partnerships with the Alzheimer's Association–Northern Nevada Northern California, the Alzheimer's Association–Desert Southwest Chapter, the University of Nevada Reno Caregiver Support Center, and the Cleveland Clinic Lou Ruvo Center for Brain Health;
  - CarePRO-ADSSP (Care Partners Reaching Out, Alzheimer's Disease Supportive Services Program);
  - Nevada Lifespan Respite Care Program;
  - Supportive services grants;
  - National Family Caregiver Support Program;
  - State Volunteer Programs;
  - Home and Community Based Service Programs;
  - Long-Term Care Ombudsmen Program; and
  - Out-of-State Task Force on Long-Term Care.

Chair Wiener inquired if the federal funding requires State match money, and Ms. Liveratti responded that it does. She stated that the tobacco settlement funds are used to match some of the grants.

- Ms. Liveratti stated that the Division now has two Medicaid waivers instead of three, as the Community Home Based Initiatives Program and the work waiver for residential care have been combined so there is not a waiting list for one service while there are slots in another service.

In response to Chair Wiener's inquiry regarding what the stay at home extension before having to go into institutional care would be now that the two programs have been combined, Ms. Liveratti stated that she has not looked at those numbers. She noted many people do not ever go into institutional care, as they can stay at home. She said she would be happy to provide that number for the Task Force members.

- Continuing, Ms. Liveratti stated the Division also has an assisted living waiver and only 30 people are currently in that program. She noted that there are only two residences in Nevada where people can be eligible for the affordable assisted living waiver and they are both in Las Vegas: Deer Springs Assisted Living and Silver Sky Assisted Living.

  Ms. Liveratti reported that the Division has about $6.9 million in its budget that comes through the Medicaid funding to support its approximately 1,680 clients. She further reported that the State is spending about $194 million annually for institutional care and about $84 million for home and community-based care. She noted that those numbers are estimates at this time, since the providers have a lag time in submitting their bills. Ms. Liveratti said her concern has always been that at some point other states will stop accepting Nevada's residents with behavioral problems and the State does not have the capacity to take care of those residents. She stated that there are currently 35 individuals with Alzheimer's or dementia-related conditions in out-of-state nursing facilities at an annual cost of $2.3 million, and with the other Medicaid costs it comes to about $2.45 million that is being spent in other states.

  Ms. Liveratti referred to two publications by the Alzheimer's Association. A Fact Sheet titled "2012 Alzheimer's Disease Facts and Figures," and a report titled "Money Matters, Helping a Person with Dementia Make Financial Plans." She stated that the information from "2012 Alzheimer's Disease Facts and Figures" indicates that Medicare is paying for about 51 percent of the costs of Alzheimer's Disease, 20 percent is paid by Medicaid, out-of-pocket is about 17 percent and other sources account for about 12 percent. Ms. Liveratti noted that "Money Matters" includes information about payment sources for people who need assistance and have Alzheimer's Disease or other related dementia-related conditions. She reviewed the payment sources, which include health insurance, COBRA, disability insurance, long-term care insurance, life insurance, Social Security disability income for workers under 65, Medicaid, and veterans' benefits.

  Ms. Liveratti reported that, nationally, Medicare is paying three times more for people who have Alzheimer's Disease or dementia-related conditions, as opposed to those who are receiving care at the same age and do not have dementia-related conditions. She also noted that 29 percent of Medicare beneficiaries with Alzheimer's Disease also have Medicaid, compared to 11 percent of the population who do not have dementia-related conditions, and Medicaid payments are 19 times higher for those with Alzheimer's care. She noted that this information is available on the material she has provided to the Task Force (Exhibit H-1 and Exhibit H-2).

  Ms. Liveratti further noted that Medicaid is the only public program that covers long-term (custodial) care stays, and Medicare beneficiaries with Alzheimer's Disease are more likely to have other chronic diseases or conditions and are more likely to be hospitalized than those who have the same conditions but do not also have dementia-related conditions.

Discussion ensued between Chair Wiener and Ms. Liveratti regarding the value of the contributions by unpaid volunteers and family members who care for those with Alzheimer's Disease, and the impact the baby boomers will have on the health care system.

Responding to Dr. Bernick's question regarding whether other states have given breaks to businesses to provide benefits for children caregivers of people with Alzheimer's Disease, Ms. Liveratti said she was not aware of any but would provide that information to the Task Force.

In response to an inquiry by Ms. Gay if the Alzheimer's Out-of-State Placement Task Force is still active, Ms. Liveratti stated they do still meet but she did not know if they meet regularly and would look into it.

Ms. Simons asked if there is a new acronym for the two waivers that have been combined, and Ms. Liveratti said she was not aware of a name that has been communicated to the public, but she would find out.

- Ms. Simons commented that, in projecting for long-term goals, the Task Force should also consider any culture shift, as the baby boomers are somewhat committed to providing cost-effective care at home for their family members with dementia-related conditions, and the next generation may not have that same commitment.

- Ms. Catlin noted that other states have proposed having different levels of residents in nursing homes that would provide different levels of compensation to more accurately reflect the level of care and amount of staff time required. She asked if that might be a consideration for Nevada.

- Ms. Liveratti responded that Medicaid does pay more if somebody requires more heavy duty care. She noted that Nevada has in the past discussed an enhanced behavioral rate to encourage and incentivize businesses to come to Nevada and provide behavioral health care and it might be time to re-examine that.

In response to Mr. Chavez's question regarding whether there are any data or reports of incidents where individuals were kept in jail because long-term care could not be found for them, Ms. Liveratti stated that those cases are complex and difficult to resolve and it usually encompasses several different agencies coming together, but she would provide the Task Force with the number of incidents her Division is aware of.

PRESENTATION ON CULTURAL ISSUES, NEEDS, AND CONSIDERATIONS IN THE TREATMENT OF ALZHEIMER'S PATIENTS

- Cyndy Soto, Doctoral Candidate, University of Nevada, Reno, stated that she is a doctoral student in the clinical psychology program, works at the Nevada Caregiver Support Center, and is present to talk about Hispanic or Latino persons with dementia-related conditions and their family caregivers.

  Ms. Soto reported that in 2050, one in five persons will be over the age of 65, and dementia-related conditions afflict one in two people over the age of 85. Ms. Soto provided information on the following: (Please see Exhibit I.)

- The Latino population in the United States;
- The heterogeneity of the Latino population in the U.S.;
- The high risk of Latinos developing Alzheimer's Disease and other dementias;
- The most frequently perceived barriers to health care and early diagnosis and treatment;
- The burden and stress of caregiving for someone who is severely impaired;
- Information regarding Latino caregivers; and
- Statistics from *Evercare® Study of Hispanic Family Caregiving in the U.S.* *(Exhibit I-1).*

In response to Chair Wiener, Ms. Soto stated that Evercare is a research foundation and the study focused on Latino caregivers in the U.S. through telephone interviews. She noted that one of the limitations of the study was that only 6 percent of the caregivers in the study cited dementia-related conditions as the primary reason for caring for the individual. Ms. Soto also referenced a report by the Alzheimer's Association titled "Hispanics/Latinos and Alzheimer's Disease" (Exhibit I-2).

Mr. Chavez observed that Ms. Soto had said that the Latinos in her research often exhibited three years of symptoms before they attempted to access services, and he asked how they could be engaged earlier. Ms. Soto responded that part of her research is a needs assessment to ascertain what people are looking for and she suspects that the specific services that are needed are not being provided.

Responding to Chair Wiener's inquiry about how to address some of the cultural issues, Ms. Soto stated that research found that, even when individuals are fluent in English, if Spanish was their first language, they have a preference for services in Spanish. She suggested that increasing providers' proficiency in Spanish would be helpful.

In response to Ms. Gay's question regarding when some of the outcomes of her research would be available, Ms. Soto stated there would not be anything definitive for about a year but she would be happy to share anything she finds with the Task Force.

Discussion ensued between Ms. Simons and Ms. Soto regarding communication materials targeted to the variety of subgroups in the Latino community, and educating the community that they should not go to unlicensed practitioners.

- Ms. Cunningham noted that, quite often, people are stopped from seeking services or going to licensed practitioners because of the suspicion that someone illegal within the family would be deported.

REPORT ON THE CLARK COUNTY ALZHEIMER'S ACTION NETWORK

- LeeAnn Mandarino, Program Manager, Cleveland Clinic Lou Ruvo Center for Brain Health, stated that in September 2011 a diverse group of stakeholders from the government, the private sector, nonprofit, academia, and advocacy organizations assembled at the Cleveland Clinic Lou Ruvo Center for Brain Health to address Alzheimer's Disease in southern Nevada and explore ways to improve the quality of care and of life for patients and their caregivers. Ms. Mandarino said the mission of the Clark County Alzheimer's Action Network (CCAAN) is to make Alzheimer's Disease and other dementia-related conditions a community priority.

Ms. Mandarino reported that after ten months of meetings, CCAAN developed action steps around two primary challenges:

1. Public awareness—Alzheimer's Disease is under-diagnosed; people are unclear about the warning signs; and the early diagnosis of dementia-related conditions offers many benefits.

2. Navigating the system once a diagnosis has been made—Primary care physicians might be more comfortable diagnosing Alzheimer's if they knew there was a comprehensive network of resources to support their patients. Members of CCAAN discussed the possibility of a dedicated Alzheimer's Disease patient navigator who would work along with physicians to support the family and individuals with Alzheimer's Disease, and they created an Alzheimer's Disease compass, a chart of resources printed on a card listing the available community resources and important considerations for the Alzheimer's patient.

A copy of Ms. Mandarino's testimony is included as Exhibit J.

- Michael Schumacher, Ph.D., Chief Executive Officer, Solaris Consulting, provided information regarding his background and his private and public sector experience and education. Dr. Schumacher stated that in developing and delivering services for the patients with Alzheimer's Disease and dementia-related conditions, it is important to act globally (the State of Nevada), but always deliver locally. He described the "spider plant" model network he has used to ensure that nothing gets too centralized but there is one place where everybody can go. (Please see Exhibit K.)

  Dr. Schumacher stated that five components must be clearly identified for everyone involved, and he described the following:

  1. A clear vision for each item that comes up;
  2. The existing resources;
  3. The existing skills—education, training, knowledge, research, know-how, and applied action;
  4. Incentives; and
  5. A clear action plan.

In response to an inquiry by Chair Wiener if he had found successes in addressing the fear component, Dr. Schumacher stated that dialogue is the most effective way to take fear out of the equation.

- Dr. Owens stated her area of research expertise is female caregivers of the elderly women that she surveys, and one thing that is prominent is the depression rate. She noted that one thing that tempers the depression is that they have someone with whom they can talk and who understands what they are going through. Dr. Owens requested that the Task Force receive a copy of CCAAN's report.

- Dr. Schumacher stressed the importance of peer groups and educational outlets for caregivers, noting that togetherness around the Alzheiemer's world is critical, politically, organizationally, and on the human level.

- Ms. Gay stated it is critical for the work that is coming out of CCAAN to continue in some cohesive way, and she hopes it will continue to provide insight into work that is done and implemented later.

PRESENTATION ON COST, AVAILABILITY, AND CAPACITY FOR LONG-TERM CARE FOR ALZHEIMER'S PATIENTS

- Wendy Simons, Chief, Bureau of Health Care Quality and Compliance, Health Division, DHHS, stated that her parents started the first care facility in Nevada in 1948, and she also operated facilities in the State for more than 35 years before going into the public service arena. Ms. Simons provided an overview of the Bureau of Health Care Quality and Compliance, which licenses, inspects, regulates, and holds accountable all medical and other related facilities in the State. (Please see Exhibit L.)

  Continuing, Ms. Simons discussed the options for care and services under BHCQC, including personal care agencies, residential care facilities for groups, and skilled nursing facilities (Exhibit L-1). She noted there are nine skilled nursing facilities that accommodate individuals in a secured setting in Nevada, three of which are in northern Nevada and six are in southern Nevada. Ms. Simons stated that an additional resource in Nevada is Adult Day Care Centers. Ms. Simons noted there currently are 25 facilities with 11 residents or more that target the Alzheimer's population—eight in the north and 17 in the south—and 76 facilities with 10 residents or fewer, all currently in the south. Ms. Simons reported that the rates charged by facilities with an Alzheimer's endorsement range from $1,000 per month for low income, up to $5,700 per month. She noted that some larger facilities have the option of shared accommodations and the rate ranges from $2,995 to $3,850 per month.

  Ms. Simons stated that she has provided to the Task Force the regulations pertaining to training for individuals who provide care for persons with Alzheimer's Disease (Exhibit L-2). Ms. Simons reported that the BHCQC does not review and/or approve training programs, so while there is specific criteria of how many hours and some subject areas, it is up to the individual facility to find their own training program to meet the subject area of the requirements.

- Chair Wiener suggested that the Behavioral Risk Factor Surveillance System module presented by Jay Kvam, previously identified, could be adapted to be used to help discern the needs of persons who are being cared for, and Ms. Simons responded that is a brilliant idea and she would take the suggestion back to the personal care advisory council and offer it as a strong recommendation.

In response to Ms. Gay's question regarding licensing requirements for in-home care providers, Ms. Simons stated that agencies that send in-home caregivers into the home are required to be licensed. The individuals who work for those agencies are required to be trained in 15 subject areas under the BHCQC's regulations. Also required are criminal history and background checks, along with first aid and CPR training.

Ms. Gay asked about the requirements for a facility if they suspect someone has a dementia-related condition but there is no diagnosis involved. Ms. Simons responded that when surveyors or inspectors look at a facility, they do not negate or prohibit an individual from being in the facility as long as the care needs are being managed and the individual is not at risk.

- Marsheilah D. Lyons, previously identified, noted there have been concerns from the family court about bad outcomes when someone's need for care has increased and they have not been appropriately referred to a different facility, either because there was no slot for them, no payment ability for them, or because the family wanted them to stay in a different type of facility. She noted many of the judges she has talked with have concerns about educating the family on knowing when their loved one may need to transfer to a different type of care facility, and an agenda item related to that is being developed for the next meeting of the Task Force.

- Ms. Simons stated she has been meeting with hospitals and skilled nursing facilities and has discovered there seems to be a disconnect in the understanding of what is inappropriate discharge. She noted that the BHCQC does have the ability to fine for inappropriate discharges.

PRESENTATION REGARDING FAMILY CAREGIVERS

- Mary Lee Fulkerson, caregiver, related her experiences and the difficulties she has encountered in caring for her husband, who has Alzheimer's Disease. She noted that she recently was given the name of Nevada CareGivers and, through them, found the Alzheimer's Association in Reno. She also participated in a program called CarePRO and, through that program, developed coping skills and learned about resources in the community. Mrs. Fulkerson stated she wished she had learned about these agencies earlier. She suggested that educating the medical community, and having a barrage of public service announcements would bring some hope to people and their caregivers. Mrs. Fulkerson stated that she realizes the caregivers need specific Alzheimer's training.

PUBLIC COMMENT

- Mary Liveratti, previously identified, stated that her Division would be happy to work with the Task Force in any way they can. She noted she did not have a chance to provide information on the Medicaid money in the State and would be willing to provide that information to the Task Force.

- Angie Pratt, Director, Northern Nevada Alzheimer’s Association, Reno, thanked the Task Force, and Roger McClellan for all the work he has done. Ms. Pratt stated she explains the State plan as a navigation tool for people to be able to access the many services available in the State.

- Chair Wiener announced that the next meeting of the Task Force will be July 11, 2012, and requested that the members provide to Ms. Lyons or Mr. McClellan the names of the two alternates they have selected if they are unable to attend a meeting.

ADJOURNMENT

There being no further business to come before the Committee, the meeting was adjourned at 2:47 p.m.

Respectfully submitted,

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Anne Vorderbruggen
Senior Research Secretary

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Roger McClellan
Health Care Policy Specialist

APPROVED BY:

____
Senator Valerie Wiener, Chair

Date: ________________________________

LIST OF EXHIBITS

Exhibit A is the "Meeting Notice and Agenda" provided by Roger McClellan, Health Care Policy Specialist, Research Division, Legislative Counsel Bureau (LCB).

Exhibit B is a document titled "Legislative Committee on Health Care's Task Force to Develop a State Plan to Address Alzheimer's Disease (A.C.R. 10)," provided by Roger McClellan, Health Care Policy Specialist, Research Division, LCB.

Exhibit C is a document dated June 2012, titled "Overview of National Plan to Address Alzheimer's Disease," presented by Donald B. Moulds, Principal Deputy Assistant Secretary for Planning and Evaluation, United States Department of Health and Human Services.

Exhibit D is the written testimony of Becky Calhoun, R.N., M.S.N., C.C.R.N., Reno.

Exhibit E is a Microsoft PowerPoint handout titled "Medical Model of Alzheimer's Disease and the difference between young and old disease onset," provided by Charles Bernick, M.D., Associate Medical Director, Cleveland Clinic Lou Ruvo Center for Brain Health.

Exhibit F is a Microsoft PowerPoint handout titled "Alzheimer's Research and Clinical Trials," submitted by Charles Bernick, M.D., Associate Medical Director, Cleveland Clinic Lou Ruvo Center for Brain Health.

Exhibit G is a document titled "Behavioral Risk Factor Surveillance System, Optional Impact of Cognitive Impairment Module," provided by Jay Kvam, State Biostatistician, Health Division, Department of Health and Human Services.

Exhibit H is a Microsoft PowerPoint handout titled "Nevada Aging and Disability Services Division Presentation to Task Force to Develop a State Plan to Address Alzheimer's Disease," submitted by Mary Liveratti, Administrator, Aging and Disability Services Division, Nevada's Department of Health and Human Services (DHHS).

Exhibit H-1 is an Alzheimer's Association Fact Sheet dated March 2012, titled "Costs of Alzheimer's to Medicare and Medicaid," provided by Mary Liveratti, Administrator, Aging and Disability Services Division, DHHS.

Exhibit H-2 is a SCAN Foundation Data Brief dated May 2012, titled "Prevalence of Alzheimer's Disease and Other Dementias," provided by Mary Liveratti, Administrator, Aging and Disability Services Division, DHHS.

Exhibit I is the written testimony of Cyndy Soto, Doctoral Candidate, University of Nevada, Reno.

Exhibit I-1 is a report dated November 2008, titled "Evercare® Study of Hispanic Family Caregiving in the U.S." provided by Cyndy Soto, Doctoral Candidate, University of Nevada, Reno.

Exhibit I-2 is an Alzheimer's Association report titled "Hispanics/Latinos and Alzheimer's Disease," provided by Cyndy Soto, Doctoral Candidate, University of Nevada, Reno.

Exhibit J is the written testimony of LeeAnn Mandarino, Cleveland Clinic Lou Ruvo Center for Brain Health, representing the Clark County Alzheimer's Action Network.

Exhibit K is the testimony of Michael Schumacher, Ph.D., Chief Executive Officer, Solaris Consulting.

Exhibit L is an Overview of the State's Licensing and Certification Program provided by Wendy Simons, Chief, Bureau of Health Care Quality and Compliance, Health Division, DHHS.

Exhibit L-1 is the written testimony of Wendy Simons, Chief, Bureau of Health Care Quality and Compliance, Health Division, DHHS.

Exhibit L-2 is a document titled "Memory Care Regulations," provided by Wendy Simons, Chief, Bureau of Health Care Quality and Compliance, Health Division, DHHS.