# MINUTES OF THE MEETING OF THE COMMITTEE TO STUDY THE NEEDS RELATED TO THE BEHAVIORAL AND COGNITIVE CARE OF OLDER PERSONS
## (Senate Bill 121 [Chapter 522] Statutes of Nevada 2017)
## January 29, 2018

The meeting of the Committee to Study the Needs Related to the Behavioral and Cognitive Care of Older Persons (created by Senate Bill 121, 2017) was held at 9:30 a.m. on Monday, January 29, 2018, in Room 3137 of the Legislative Building, 401 South Carson Street, Carson City, Nevada, with videoconference to Room 4401 of the Grant Sawyer State Office Building, 555 East Washington Avenue, Las Vegas, Nevada.

**COMMITTEE MEMBERS PRESENT IN CARSON CITY:**
Senator Woodhouse, Chair
Senator Ratti
Senator Goicoechea
Assemblywoman Benitez-Thompson, Vice Chair
Assemblyman Wheeler

**COMMITTEE MEMBERS PRESENT IN LAS VEGAS:**
None

**COMMITTEE MEMBERS ABSENT:**
Assemblyman Daly (Absent Excused)

**STAFF:**
Mandi Davis, Program Analyst, Fiscal Analysis Division
Sarah Coffman, Principal Deputy Fiscal Analyst, Fiscal Analysis Division
Mark Krmpotic, Senate Fiscal Analyst, Fiscal Analysis Division
Judy Lyons, Committee Secretary, Fiscal Analysis Division
Kristin Roberts, Senior Principal Deputy Legislative Counsel, Legal Division

**EXHIBITS:**

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| (Exhibit A) | Meeting Packet and Agenda |
| (Exhibit B) | Work Plan and Meeting Schedule |
| (Exhibit C) | The Age Wave: Implications for States, Health Management Associates |
| (Exhibit D) | Presentation by Michael Splaine, Splaine Consulting |
| (Exhibit E) | Alzheimer's Disease, The Public Health Crisis of Our Time, Alzheimer's Association |
| (Exhibit F) | Mental and Behavioral Health of Older Adults, HealthInsight |
| (Exhibit G) | Community Health Workers, HealthInsight |

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| (Exhibit H) | Programs and Services for Care of Older Persons with Behavioral and Cognitive Care Needs in Nevada, Aging and Disability Services Division, Department of Health and Human Services |
| (Exhibit I) | Direct Services and Supports for Older Adults, Division of Health Care Financing and Policy, Department of Health and Human Services |
| (Exhibit J) | Overview of Task Force on Alzheimer's Disease, Senator Valerie Wiener |

## I. ROLL CALL.

Chair Woodhouse called the meeting of the Committee to Study the Needs Related to the Behavioral and Cognitive Care of Older Persons (Committee) to order at 9:34 a.m. and the secretary called roll. The members were present at the Carson City meeting location with the exception of Assemblyman Daly (absent excused).

Chair Woodhouse thanked everyone for attending the meeting and announced meeting room protocol to all in attendance. She asked the presenters and committee members to define the acronyms used in their presentations and discussions. Chair Woodhouse relayed that all meeting materials were posted to the Committee's webpage on the Nevada Legislature's website.

## II. PUBLIC COMMENT.

Chair Woodhouse asked for public comment from attendees in Las Vegas and Carson City. There was no public comment at either location.

## III. OPENING REMARKS AND COMMITTEE INTRODUCTIONS.

At the request of Chair Woodhouse, members of the Committee gave brief introductions.

Assemblywoman Benitez-Thompson (Assembly District 27) stated the topic of conversation relative to the Committee was timely, and that the Committee would provide opportunity for good policy solutions to grow from and better serve the community.

Assemblyman Wheeler (Assembly District 39) conveyed that he served on the Legislative Committee on Senior Citizens, Veterans and Adults with Special Needs during the 2013-2014 Interim, and was pleased to be appointed to this Committee, focusing on the lives of Nevada's elderly.

Senator Goicoechea (Senate District 19) described his district as large and rural, thus subjected to major issues unique to those regions. He recognized the loss of his mother to Alzheimer's disease, and emphasized how the disease affects people differently. He stated Alzheimer's was clearly a subject that needed attention.

Senator Ratti (District 13) identified her district as the urban core of Reno and Sparks, and stated there was a lot of room for progress relative to the behavioral and cognitive care of Nevada's elderly.

Senator Woodhouse (District 5) said her district was comprised of Henderson and unincorporated areas in Clark County. She recalled her membership on the Health and Human Services Committee during the 2013 and 2015 Legislative Sessions, and stated Alzheimer's disease was discussed frequently. She reported that after an unsuccessful attempt in the 2015 Legislative Session, Senate Bill (S.B.) 121 (2017) approved the appointment of this Committee to conduct a study with a much broader scope that included the needs of caregivers. She noted both short- and long-term goals would be addressed.

At the request of Chair Woodhouse, staff to the Committee gave brief introductions, including Mandi Davis, Program Analyst; Mark Krmpotic, Senate Fiscal Analyst; Sarah Coffman, Principal Deputy Fiscal Analyst; Judy Lyons, Secretary; and Kristin Roberts, Senior Principal Deputy Legislative Counsel.

## IV. DISCUSSION REGARDING THE COMMITTEE WORK PLAN AND MEETING SCHEDULE.

**Senator Joyce Woodhouse, Chair**
**Mandi Davis, Program Analyst, Fiscal Analysis Division, Legislative Counsel Bureau**

Ms. Davis referred the members to a handout titled Work Plan and Meeting Schedule (Exhibit B) that outlines the following issues examined by the Committee pursuant to S.B. 121.

a) Potential sources of state funding available to support evidence-based, statewide community programs to aid caregivers who are caring for older persons with behavioral and cognitive health issues, including, without limitation:

   1. Information about programs and services designed to aid caregivers who are caring for older persons with behavioral and cognitive health issues;

   2. The provision of training in select evidence-based community programs for caregivers, social service providers, health care workers and family members;

   3. The creation of a sliding fee scale to address the affordability of mental health services;

   4. Providing a substitute caregiver to ensure the safety and well-being of an older person who has behavioral or cognitive health issues while the family attends training; and

   5. The creation of a sliding fee scale to address the affordability of respite services.

b) Potential sources of state funding to assist Nevada Care Connection and Nevada 2-1-1 in the creation of a "No Wrong Door" program to assist caregivers of older persons with behavioral and cognitive health issues.

c) The potential for establishing a higher rate of reimbursement by Medicaid for nursing facilities prepared and trained to support older persons with behavioral and cognitive health issues; thereby allowing such older persons to remain in their own communities rather than being placed in out-of-state facilities.

d) The provision of education and training for health care professionals in the screening, diagnosis and treatment of behavioral and cognitive diseases prevalent in older persons.

Ms. Davis provided an overview of discussion points for this meeting and future meetings to be held by the Committee.

| **Date and Time** | **Emphasis** |
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| 1/29/18 at 9:30 a.m. | Overviews on the issues facing older persons with behavioral and cognitive care needs; national and local trends of the aging population and prevalence of behavioral and cognitive diseases; and overviews of the state's programs. |
| Second Meeting | Supports and Training for Providers and Caregivers – screening, diagnosis and treatment of behavioral and cognitive diseases prevalent in older persons; assistance, respite, and training for caregivers; and suicide awareness, education and prevention. |
| Third Meeting | Funding – state and federal funding for institutional and home- and community-based care for older persons. Potential funding sources for provider and caregiver supports and training. |
| Final Meeting | Consideration of recommendations and work session. |

Ms. Davis proposed the following dates for the final three meetings of the Committee: March 5, 7 or 8; April 10 or 12; and June 11, 12 or 14. Ms. Davis informed the committee members that staff would reach out to confirm their availability.

## V. PRESENTATIONS REGARDING NATIONAL AND STATE OVERVIEWS AND TRENDS FOR BEHAVIORAL AND COGNITIVE CARE NEEDS OF OLDER PERSONS.

### A. Samantha Scotti, Policy Associate, National Conference of State Legislatures (via teleconference)
### Barbara Coulter Edwards, Principal, Health Management Associates (via teleconference)

Samantha Scotti, Policy Associate, National Conference of State Legislatures (NCSL) explained that the NCSL is a bipartisan membership organization that provides policy makers with the opportunity to exchange ideas and promote policy innovations, and serves Legislators and staff from 50 states and territories. She introduced colleague Barbara Edwards, Principal, Health Management Associates, a nationally recognized expert in Medicaid policy, including managed care, long-term care, behavioral health, and state and federal health reform. Ms. Edwards served as the Director of the Disabled and Elderly Health Programs Group at the Centers for Medicare and Medicaid Services (CMS), and served as the Director of Ohio's Medicaid program and its Children's Health Insurance Program (CHIP).

Ms. Edwards directed the Committee to page 2 of her handout (Exhibit C), The Baby Boomers are Here! She said the baby boomers significantly impact public and private systems, including education and healthcare as well as how we face retirement. She reported the leading-edge baby boomers turn 72-years-old in 2018 and age 80 in 2026. She indicated that, nationally, the number of people who are age 65 and older is projected to double by 2030, to over 71 million, since 2010.

Ms. Edwards reported that Nevada's population age 65 and older grew by 49 percent over a 10-year period, and its population age 85 and older grew by 78 percent. Nevada's elderly population is expected to grow to over 1.0 million individuals by 2030. She said, in 2016, 5.4 million Americans had Alzheimer's disease, the leading cause of dementia, of which 5.2 million were over the age of 65. Furthermore, it is estimated that Alzheimer's affects one in nine individuals age 65 and older, and one in three of those age 85 and older. Ms. Edwards identified dementia as a major neurocognitive disorder that not only interferes with everyday activities, such as preparing meals, paying bills, and shopping, but also hampers memory, speech, judgement, and planning. She said it is estimated that 20 to 25 percent of Nevada's population age 65 and older has a mental health disorder, including chronic psychiatric illness, onset of dementia, stroke, etc., which adds an additional challenge as that population ages.

Ms. Edwards implied that the growing numbers of individuals with cognitive needs will subsequently increase health care spending (page 5, Exhibit C). She clarified that Medicare is typically the payer for primary care, acute care and pharmacy needs for the elderly population, and Medicaid is the primary payer for long-term services and supports (LTSS), and represents 62 percent of all spending, including out-of-pocket expenses. Frequently, the need for long-term care triggers the application for Medicaid, either initially or after an individual has spent down private resources. The U.S. Senate Commission on Long-Term Care projected the number of Americans needing long-term care between 2010 and 2050 to double to nearly 27 million people.

Ms. Edwards referred the members to the chart on page 8 (Exhibit C) that illustrates the share of older adults with private long-term care insurance by age and year between 2002 and 2014. She testified that the sale of long-term care insurance policies fell by 83 percent with only 129,000 policies sold in 2014 despite an aging population. She attributed the decline in private long-term care insurance to its high cost and life-long payment schedule, or payments until that person receives care. She noted a 55-year-old couple could expect to pay between $2,000 and $5,000 per year for long-term insurance. As of 2012, the average income of a person over age 65 was $32,000 per year, and the median income was approximately $20,000 per year. Ms. Edwards denoted that a relatively small percentage of the population can afford long-term care insurance, and how quickly an individual can spend down into Medicaid eligibility once long-term care costs are incurred.

Nationally, Medicaid and states have been working the last ten years to rebalance the long-term care system in Medicaid to prepare for growth and demand, and to respond to consumer preferences. Ms. Edwards said states are working to move the dependence away from institutional care and into home and community-based services where individuals are more likely to pay their own cost of housing and rely on family and friends to provide care. She noted over 50 percent of Medicaid spending for LTSS, nationally, was for home- and community-based services.

Ms. Edwards said community-based LTSS is cost effective for Medicaid. She turned to the chart on page 10 (Exhibit C) of her handout (data provided by Money Follows the Person [MFP]), and explained that states have helped individuals move out of long-term placement in a nursing home and back into community-based living, which amounted to a significant savings when comparing the pre- and post-transition monthly costs for Medicare and Medicaid. Ms. Edwards apologized for an error on the chart, and explained that the bars representing Medicare and Medicaid were correct in terms of color and size; however, the numbers were flipped. The dollar numbers for Medicaid were actually the dollar numbers for Medicare and vice versa. Continuing, Ms. Edwards said, in 2015, states reported the cost for care in a nursing home for Medicaid (pre-transition) dropped to approximately one-third of the cost once those individuals were placed into a community supports center.

In FY 2015, Truven Health Analytics identified Nevada as one of ten states that experienced a significant increase in Medicaid spending for home- and community-based services, reporting approximately 5 percent growth from FY 2013 to FY 2015. Ms. Edwards reported that only 36 percent of LTSS spending for elders and adults with disabilities was community-based compared to the national average of almost 44 percent. In terms of individuals with intellectual and developmental disabilities, Nevada led the nation in long-term care spending in home- and community-based spending. She said Nevada's heavy dependency on nursing facilities for the elderly population suggests there is room for cost efficiency if those numbers continue to move toward community-based care.

Ms. Edwards stressed that states need to pay attention to the federal Medicaid financing policy as it deals with growth and needs in their older population, especially relating to cognitive care. She noted the following troubled areas relative to federal Medicaid reform debate (see page 13, Exhibit C):

- Recent reform proposals included per capita caps on growth in federal financing for Medicaid, including for elderly and disabled populations.

- Per capita cap proposals did not put states at risk of growth in the numbers of elderly Medicaid eligible, but ***did*** put states at risk of growth in per member costs, which raised the following concerns: 1) average per person costs will increase as baby boomers age. For example, a person age 85, on average, costs more than a 65-year-old. As the baby boomer population ages, a natural growth in the per member per month cost will occur that was not accounted for by Congress when considering per capita caps; and 2) as breakthroughs in treatment for dementia come to market, such as pharmaceuticals, they will likely be expensive, whereas populations today are mostly incurring costs for care over the long term. The per capita caps calculated in recent proposals do not leave room for federal participation in any kind of increase in cost of treatment in the short term.

- Recent proposals did not provide states with options to solve rising health care costs for high-need populations.
  - Did not change mandatory benefits; did not provide pharmacy reforms.
  - More flexible block grant option was not available for elderly or disabled groups.

- Federal Medicaid caps are likely to be proposed again, as well as limits on state financing options.

Ms. Edwards gave an overview on state strategies going forward relative to cognitive care.

- Medicaid remains the backbone of financing LTSS for an aging population, including the increased number of individuals with cognitive and behavioral challenges.

- Accelerating system "rebalancing" to move away from institutional dependence. Many states are adopting managed LTSS delivery models as a tool to encourage use of community-based options.

- Collaboration across agencies and systems of care, as well as shared financing strategies (public and private).

Ms. Edwards voiced an important strategy for states is to find ways to provide better support for family caregivers, to increase the longevity of unpaid supports in communities as well as extend the ability for family to provide care. She highlighted the following programs (page 15, Exhibit C):

- A recent report, *Emerging Innovations in MLTSS for Family Caregivers*, co-written by the AARP Public Policy Institute and Health Management Associates, looks at emerging innovations in managed long-term services and supports (MLTSS) for family caregivers, implemented by managed care plans. These innovations include dedicated caregiver assessment tools that help identify the needs of caregivers, such as increased respite options and/or links and referrals to community supports, which can be accommodated through the health plan. The goal is to pay attention to the caregiver and address their medical needs.

- “No Wrong Door” linkage and referral strategies for individuals and families to find help faster, to get linked to funding sources.

- Expand access to respite. Ms. Edwards stated Wisconsin uses state funds to expand access to respite, and Minnesota and Washington leverage Medicaid through Section 1115 waivers.

- Adopt evidence-based options to improve the services that are available for individuals, such as the Resources for Enhancing Alzheimer’s Caregiver Health (REACH), a National Institutes of Health program that tests and evaluates the effectiveness of different interventions with regard to support for caregivers. Private strategies, such as Respite, Education and Support Tools (REST), also referred to as “Train the Trainer,” which provides the skills and tools needed to provide quality respite. Additionally, the Older Americans Act (OAA) funds the National Family Caregivers Support Program that is able to provide community-based services for caregivers. Ms. Edwards noted that Hawaii adopted a state-level program called Kapuna Caregivers that provides up to $70 per day to support qualified working caregivers for qualified recipients.

Ms. Edwards indicated the direct-care workforce is not keeping pace with the growing elderly population due to its low pay and the physical and emotional demands. She highlighted the following strategies that are being used by states:

- Tennessee allows workers to stack credentials and credits over time that are on a career path to becoming a direct-care worker. Eleven states in 2017 targeted wage increases for home care workers through their Medicaid program to boost the availability of this workforce.

- Many states are promoting consumer-directed care to expand the direct-care workforce for long-term care by allowing eligible individuals to hire and manage their own caregivers, including friends, neighbors and family members, who in return are paid for their service in an effort to keep individuals in their homes.

- Nevada expanded access to direct care via Telehealth, including remote monitoring.

- Nevada has a Community Paramedicine agreement, which allows paramedics and emergency medical technicians to operate in expanded roles to provide routine health care services to underserved populations.

Relative to expanding access to in-home supports (pre-Medicaid), Ms. Edwards stated that Minnesota uses Medicaid’s Section 1115 to provide services to those who are not Medicaid eligible. The state’s goal is to slow down the individual’s decline and their need for full Medicaid benefits by providing some targeted benefits earlier, like respite. She said Ohio uses local county levy programs to offer Medicaid’s 1915(c) waivers to allow home- and community-based services, such as personal care and homemaker services, to assist individuals who are not yet eligible for Medicaid in an effort to keep individuals in their homes longer, delaying high-cost services in institutions. In Maine, a statewide ballot initiative passed that proposed universal home care services to the elderly and disabled by increasing taxes on high-wage earners. Similar movements are projected to occur as people research how to broaden access to in-home supports (page 17, Exhibit C).

Ms. Edwards reported that states are re-examining their geropsychiatric systems to expand care for individuals with serious or chronic mental illness or substance use disorders and who are experiencing the challenges of aging or dementia. States are finding that community mental health facilities are not adequately prepared to handle the increased needs that come with people who have cognitive challenges or struggle with managing their daily lives. She said Wisconsin has mobile crisis units that are trained to serve people who are in a dementia crisis. Wisconsin also has a pilot program that provides a more appropriate setting for crisis intervention compared to the setting in a mental health system. Ms. Edwards recognized strategic rebalancing plans set forth in Connecticut, and their efforts to increase the LTSS capacity for hard-to-place individuals, such as persons with a history of psychiatric illness or a person exiting prison; and in Virginia, who's public system of care for older adults is challenged due to the growing segment of the aging population, as well as the dementia and Alzheimer subpopulations.

Ms. Edwards mentioned that Wisconsin has an Alzheimer's group that is working on a tool kit that provides the ability for communities to plan and develop around supports at the community level. She said addressing needs for affordable and accessible housing is progressively becoming an important challenge relative to building dementia-friendly communities.

Lastly, Ms. Edwards introduced additional resources to the Committee and staff, including contact information for Samantha Scotti and information from the AARP Public Policy Institute and the Scan Foundation.

Senator Goicoechea asked for an assessment of community-based LTSS in the rural areas of Nevada. He commented that, of the 240-mile drive from Eureka to Carson City, there was no LTSS facility within the first 180 miles.

Ms. Edwards said rural and frontier areas are challenged with obtaining person-centered services in the home, such as personal care, homemaker services and bill paying assistance, and with finding direct-care home workers and senior day care centers. However, Ms. Edwards mentioned that more creative resources were being offered, such as remote monitoring for patient/doctor interaction.

Senator Goicoechea stated that rural communities try to keep individuals with dementia-related disorders at home for as long as they can, but if that individual ends up in a facility, the transition back to the community is very difficult, because that patient becomes very familiar with the facility's setting. He said many rural communities with population under 10,000 do not have a long-term care facility available, and the high-mileage commutes between home and the facility becomes a burden. Senator Goicoechea noted that it becomes impossible to maintain individuals with dementia or Alzheimer’s when they are experiencing a decline in physical and mental health combined.

Ms. Edwards recalled her days as a caregiver for her father, stating his last days were spent in a nursing facility due to his expanded need for physical care and the lack of accommodations in the private home. She said states are directing serious thoughts toward immediate solutions, and how to better prepare for environmental impacts in advance in an effort to keep individuals living at home. She added some states are rethinking the services they provide and contemplating potential changes to better serve individuals who are community based.

Senator Goicoechea said the rural areas are struggling with the ability to place institutions, whether county, state or federally funded, that could keep people closer to home and be considered home-based or community-based.

### *B. Michael Splaine, Owner and Principal, Splaine Consulting, Managing Partner, Recruitment Partners LLC*

Mr. Splaine said he has consistently worked with the State of Nevada over his six-year career as a consultant, which has included supporting Nevada Senior Services with the implementation of a federal Alzheimer Disease Initiative Grant; experiments in community organizing related to Alzheimer’s disease in Clark County, and working with the Sanford Center for Aging on the development of their geriatrics program.

Mr. Splaine stated dementia is increasingly understood and planned for from a policy perspective as a life course disease. He said public perception has changed to recognize that Alzheimer’s disease progresses in stages, which are identifiable, and is not limited to elderly, disabled persons in need of care. Public health has enhanced the perception of cognitive health as a lifelong process, not inconsistent with heart disease and diabetes that progress over time. Mr. Splaine informed the Committee that brain imaging is available in Reno and Las Vegas, which can reveal signs of Alzheimer’s disease prior to its symptoms occurring.

Mr. Splaine drew attention to the pictorial in his handout (Exhibit D) that identifies the stages and policy interventions related to Alzheimer’s. He reported mobilized public health tools can aid in reducing the risk of Alzheimer’s disease, and recognized the Alzheimer’s Association, in collaboration with the Centers for Disease Control and Prevention, for their development of the Healthy Brain Initiative. He said public health tools include flu shots, clean water, and sewage, as well as broadcast messaging aimed to reduce the risk and impact of dementia and to promote awareness of the early stages of Alzheimer’s disease.

Mr. Splaine recognized that detection and diagnosis of Alzheimer’s are stubborn problems nationwide. United States figures suggest that 50 percent of people living with Alzheimer’s disease or related disorder get a formal diagnosis, and of that 50 percent, one-third are not told their diagnosis. He indicated that without a diagnosis, there cannot be treatment, care, organized or mobilized support, or the opportunity to volunteer for clinical research. Mr. Splaine stated that people with impaired thinking and other chronic diseases are expensive, have difficult lives navigating complex health decisions and treatment, and are likely to first receive care in later stages of the disease. He encouraged the Committee to take a special interest in the diagnostic and detection gap, along with the disclosure gap.

Mr. Splaine said that, around the world, a broader community has become socially cognizant and has expressed interest in dementia and support for caregivers. He attributed that interest to the promotion of brain health, society's experience with Alzheimer's disease over generations, and the attention directed toward the care needed for people of age and fragility in the aftermath of natural disasters.

Mr. Splaine requested special policy and programmatic consideration, under the umbrella of the Committee's mandate, be directed toward persons with dementia or other related disorder to individuals living in rural and frontier communities, people with intellectual disability who are now experiencing early signs of dementia, persons who exhibit behavioral symptoms of an underlying brain disease, people with dementia who live alone, and persons with lifelong mental illness who now have some form of dementia. He suggested the Committee review the following programs that are operated by other states and municipalities:

- North Dakota provides care management and support to rural and frontier residents through a program well-evaluated by the Center for Rural Aging.
- Wisconsin is researching small-scale, community-based residential facilities (CBRF) in rural areas.
- Native American and Tribal Health Authorities are experimenting with mobile day care and home-based services, as well as small-scale residential support for people who live in rural areas.

Mr. Splaine made reference to a report titled, "My Thinker's Not Working," issued by the National Task Group on Intellectual Disabilities and Dementia Practices. The report indicates that individuals with an intellectual disability and dementia are entering the age of high risk, posing a significant challenge to families, friends and caregivers concerned with supports and services. Furthermore, 90 to 95 percent of people with Down syndrome, over the age of 45, will develop the characteristic plaques and tangles of Alzheimer's disease. He also referenced the Summit on Intellectual Disability and Dementia, which has published nine peer-reviewed journal articles about different aspects of dementia from diagnosis, to treatment, to care for this special group. Mr. Splaine stated that many people with intellectual disabilities and dementia are not reported to any state or local health or social care system due to lack of exposure to these systems by their parents. He said outrages occurred in the 1960's and early 1970's relative to the care for that population that influenced families' decisions to not seek assistance from governmental entities.

Mr. Splaine communicated that difficult behavior exhibited by people with Alzheimer's disease and related disorders can be triggered by root causes, such as hunger, thirst, pain, and boredom, which can be identified through training. Included in this population are people who exhibit unexplained outbursts unrelated to a root cause and a very small group of people who suffer with a severe behavioral disorder due to changes in the brain. He explained that the plaques and tangles related to Alzheimer's disease progresses through the brain and leads to cerebral atrophy, which subsequently contributes to a behavioral problem and can require specialized care. Mr. Splaine mentioned the State of New Jersey developed three super specialized units, funded by a specialized Medicaid rate, that are specific to the temporary care of extreme behaviorally disordered persons.

Mr. Splaine reported 35,000 households are led by a single person over the age of 65 in Clark County, and nationally, one in nine people over 65 have Alzheimer's or a closely related disorder. He said this population may consist of individuals who are socially disconnected from their neighbors and family and are frequently found in crisis situations.

Mr. Splaine turned his focus to the mandate of the Committee, and cautioned using the term "evidence-based" programs. He said if evidence-based is defined as a program proven by a random clinical trial, such as with a pharmaceutical or medical device, then very few programs exist that meet that standard. However, many "evidence-informed" approaches exist and should be considered in addition to evidence-based caregiver supports.

As a former Director of State Government Affairs in 2007 for the Alzheimer's Association, Mr. Splaine recalled his effort to encourage every state in the country to develop an Alzheimer's plan. He mentioned there were three goals associated with the campaign: 1) recognize Alzheimer's disease as a public health problem; 2) develop a policy home for Alzheimer's disease in states' public health division versus their aging and disability division; and 3) keep state plans evergreen as they continue to research and understand dementia and its health care and policy implications.

Lastly, Mr. Splaine said housing is essential for individuals with Alzheimer's; however, he was unaware of any programs that incorporated housing into their Alzheimer planning. He thought housing might be included in the next wave of serious Alzheimer planning by government at the state, local and national levels.

Senator Ratti asked for more details relative to Wisconsin's research on small-scale, community-based residential facilities in rural and frontier areas.

In response, Mr. Splaine explained the CBRFs were targeted for rural communities that was made available for public financing with Medicaid waiver funds. The facilities can occupy five or more people and can specialize in persons with an intellectual disability who are aging, or people with dementia who need a new form of residential support. He said the funding formulas are as such that it takes between 10 and 20 people to make them work financially. The challenge is making facilities that accommodate 3 to 4 individuals work financially within a rate structure that is Medicaid based.

Senator Ratti questioned the waiver, and in response, Mr. Splaine stated that Wisconsin uses the Medicaid long-term care 1915 waiver to fund the program.

Assemblywoman Benitez-Thompson asked how it was determined that 30 percent of persons with an Alzheimer's diagnosis had not been informed of their diagnosis.

Mr. Splaine referred to a state-based public health survey called Behavioral Risk Factors Surveillance Survey (BRFSS) that collects state data related to rates of diagnosis and diagnostic disclosure. In that survey, adults over the age of 45 are asked a series of questions about their behavior when they think they have a cognitive health problem. He said in terms of the 30 percent statistic on nondisclosure of an Alzheimer diagnosis, there were a half dozen journal articles that he could forward to the staff upon request. He also mentioned that the Alzheimer's Association, the National Institute on Aging, and the Centers for Medicare/Medicaid Services cite that 30 percent statistic quite frequently. Mr. Splaine implied that medical professionals hesitate to disclose the diagnosis because they do not like to deliver bad news related to a terminal illness that cannot be medically treated, stating it could possibly trigger suicide.

Assemblywoman Benitez-Thompson found it interesting that medical professionals could not pinpoint a specific diagnosis yet the characteristics of the disease were apparent. She wondered if the medical history described dementia-like behaviors instead of a confident diagnosis of dementia.

Mr. Splaine expressed there are warning signs that lead to Alzheimer's disease, which should lead to a confident diagnosis. He said most steps to a diagnosis can be performed by a nurse practitioner or primary care physician, because the goal is to rule out other causes for the memory loss, confusion, and disorientation, such as drug interactions, overall physical health, infection, or trauma. He encouraged the Committee to look at California's science-based practice guidelines for primary care physicians. Because a simple medical answer to fixing dementia does not exist, Mr. Splaine thought medical personnel would prefer not to disclose a diagnosis or record their impression of dementia in a medical record.

Senator Goicoechea acknowledged the use of swing beds in rural hospitals to treat individuals with dementia. He expressed the level of care might not be sufficient for individuals with dementia and Alzheimer's; however, they are satisfying a need for service to those individuals. He expressed concern with the possibility of building dementia centers in small communities with a population of over 10,000, and how that would impact the rural hospitals. He suggested the Committee do a cost comparison.

Mr. Splaine alluded to a program in the State of Iowa that uses swing beds to treat individuals with dementia. He offered to provide staff with additional informational regarding that swing bed program.

## C. *Nevada Senior Services*

Mr. Jeffrey Klein, President, Nevada Senior Services, and Chair of the Legislative Commission on Aging, complemented the Committee for launching this initiative related to the behavioral and cognitive care of older persons, and to Senator Woodhouse for her ongoing commitment to these issues.

Mr. Klein acknowledged Nevada Senior Services as the aging and disability resource center for Esmerelda, Lincoln, Nye and Clark counties that is challenged with caregiver support, training issues, and workforce matters on a daily basis. When President of the American College of Healthcare Executives Nevada Chapter, and former hospital administrator, Mr. Klein indicated he had a history of identifying dementia cases that were not previously identified by other health care professionals He said Nevada currently has 435,000 individuals over the age of 65, and is aging at a rate much faster than most other states. Additionally, many people have relocated to the state over the last 20 years, which has resulted in a lack of infrastructure to support this population. Based on conservative estimates, Mr. Klein reported approximately 25 percent of seniors are impacted by mental health or cognitive disorders, and because seniors are not good utilizers of healthcare resources, particularly for cognitive issues, that number is expected to be underreported. He indicated that many people are hesitant to discuss certain issues with their primary care physician, such as depression, anxiety or other behavioral or cognitive issue; therefore, he believes the 25 percent number is underestimated.

Nevada is reported to have one of the highest senior suicide rates in the U.S. Mr. Klein said Nevada Senior Services tries to head off suicide with their health care providers and LTSS agencies. He said there are over 500,000 caregivers in the state, and although they are significantly contributing to providing for seniors in Nevada, they are very likely to be the victims of self-neglect. Caregivers tend not to seek care for themselves, which can result in behavioral issues, cognitive issues, depression, anxiety or general medical issues, and it is not unusual for a caregiver to become hospitalized, leaving no one to take care of the person they are caregiving for.

Mr. Klein emphasized the need for a well thought out approach to the state's plan that includes policies for aging, not for the aged.

Mr. Klein suggested the following measures be taken to support Nevada's aging (page 9, Exhibit A):

- Address the stigma associated with behavioral and cognitive issues by implementing and promoting education and training for mental health related issues.
- Identify gaps in the community to offer continued services throughout the state which integrate with the ability to keep people in their homes successfully.
- Look at ways to support the "No Wrong Door" issue more effectively.
- Integrate the evidence-based protocols presented by Michael Splaine, including evidence-informed protocols, into our daily life in terms of resourcing for our community.

- Create affordable care options for our community.
- Focus on shifting people from institutions to home- and community-based services as a cost effective way to keep individuals in their homes and with their family.

Mr. Klein described the effects of Alzheimer's and related disorders as wide-ranged and complex. Instead of trying to dissect the cognitive issues, it would be more appropriate to accept these individuals as they are and figure out how to support them.

Mr. Klein stated depression in older adults is highly treatable, yet is often undiagnosed and untreated. Depression and anxiety are the two most common mood disorders in older people and should not be regarded as a normal part of the aging process. He reported 5 percent of seniors are affected by major depression and 15 percent meet the criteria for minor depression, which he deemed staggering numbers considering Nevada's population. The presence of one or more medical illnesses increases the occurrence of depression significantly, including chronic pain, side effects of medications, drug interactions, alcohol or drug misuse, bereavement, social isolation, loneliness, and decline in the ability to function independently. Mr. Klein named symptoms of sadness, loss of interest in activities, weight changes, poor sleep, feelings of worthlessness, low energy, impaired cognitive function, and thoughts of suicide or death as key identifiers of depression. Depression can interfere with the effectiveness of medical treatments and increase the need for medical and emergency services. Mr. Klein emphasized suicides committed by seniors, and stated 20 percent of suicides are committed by people who were seen by their physician within a month of taking their life.

It is estimated that 3 to 4 percent of older adults have symptoms consistent with an anxiety disorder that interferes with daily activities, causing excessive worry, nervousness, fear, and apprehension. Mr. Klein recognized other factors, such as medical illness, memory loss and major life adjustments due to the loss of a spouse or a new living arrangement that can increase the percentage of those affected. He said it is not uncommon for a senior who is forced into an institution to pass away within six months of admittance. Other risk factors in anxiety disorders include poor sleep, medication side effects, alcohol or drug misuse, poor coping skills, lack of social support system, and high levels of stress. He noted depression and anxiety can occur jointly and exacerbate the symptoms. Screening tools exist, but oftentimes are not directed toward those who need them the most. Those who suffer from mood disorders experience increased physical pain, which can lead to suicide. Mr. Klein conveyed that emergency service costs related to behavioral issues is high in Nevada, partially due to emergency visits that sometimes mistakenly lead to psychiatric care due to lack of premorbid history.

Mr. Klein stressed the fragmented practice of delivering services to those with behavioral and cognitive care has contributed to the high suicide rate in seniors. He said the diagnosis process is difficult and unwelcoming for providers. For example, once the disease is identified, the course of action becomes very problematic in long-term services. As previously stated, physicians and other health care providers felt sometimes it is better for the patient to not know their diagnosis.

According to the Alzheimer's Association, individuals in Nevada with Alzheimer's disease is projected to increase from 37,000 in 2014 to 64,000 in 2025. Mr. Klein said, given the pervasive impact of cognitive and psychiatric symptoms, individuals with dementia require a significant level of care and support over the course of the their disease, and unfortunately, the current practice of delivering services to this population is inadequate.

In closing, Mr. Klein suggested the following legislation (page 14, Exhibit A):

- Expand Nevada's Medicaid Complex Care Program to include community-based, long-term care services that include the following: 1) parity in reimbursement between institutional and community care providers serving behavioral complex services; 2) expand community-based care options for older adults who want to remain in their home; and 3) shift the state's financial obligation to less costly types of care.

- Fund evidence-based demonstration projects targeted toward better care and interventions for individuals with behavioral and cognitive needs.

## D. Alzheimer's Association

Ms. Anakaren Lamas, Nevada State Affairs Lead for the Alzheimer's Association, introduced her colleagues Ruth Gay, Chief Public Policy Officer, Alzheimer's Association–Northern Nevada; and Niki Rubarth, Regional Director, Alzheimer's Association–Northern Nevada. She said the Alzheimer's Association has an office in both Southern and Northern Nevada where they offer a robust network of supportive services for providers, caregivers and individuals who are living with the disease. She highlighted the following services provided by the Alzheimer's Association:

- Around-the-clock helpline that is available at no cost to families, offered in multiple languages.
- Peer and professionally led support groups for early-stage individuals as well as families and friends who are involved in the care of persons with Alzheimer's disease and other related forms of dementia.
- Comprehensive educational programs ranging from an overview of Alzheimer's disease and normative related changes as well as communication techniques and behaviors that often accompany the diseases' progression. The programs equip professionals and families with the knowledge and skills needed to provide person-centered care for individuals with dementia.
- Respite care services at no cost to families that provides a 24 hour break from their daily caregiving.
- MedicAlert safety service resource to provide around-the-clock emergency response.
- Online resources and caregiving forms are available on the Alzheimer's Association national website at www.alz.org.

Ms. Lamas stated the Alzheimer's Association is the world's largest nonprofit funder of dementia research. The organization's mission is to eliminate Alzheimer's disease through the advancement of research, and enhance care and support for all those affected, as well as reduce the risk of dementia through the promotion of brain health. She reported 43,000 Nevadans are living with Alzheimer's disease or other related forms of dementia, with growth projected to reach 64,000 people by 2025. Additionally, one in six Nevadans over age 45 are experiencing cognitive decline that is severe enough to interfere with their daily tasks (Exhibit E). Of those experiencing cognitive declines, only half have confided in their doctor. Ms. Lamas indicated that less than half of people living with dementia have been told their diagnosis, and because dementia is underdiagnosed and underreported, those numbers may be much higher than reflected.

Nationally, one in nine people over the age of 65 and one in three people over the age of 85 have Alzheimer's disease. There were 606 reported deaths in Nevadan in 2014 due to Alzheimer's disease. Ms. Lamas relayed that the manifestation of Alzheimer's disease has become a growing concern, as well as the demand of care and the high cost of care. In 2015, Nevada had the highest Medicare cost of any state in the nation of nearly $30,000 per person for those living with Alzheimer's disease (Exhibit E). According to the 2017 Alzheimer's Association Facts and Figures report, Nevada is projected to have the second-highest increase in Medicaid costs relative to dementia care by 2025. To compare, Nevada's cost to Medicaid today is estimated at $158 million, which is expected to rise to $270 million by 2025. Ms. Lamas informed the Committee that Nevada currently has 143,000 people who serve as caregivers and who have provided 162 million hours of unpaid care.

Ms. Lamas explained that individuals with Alzheimer's typically develop behavioral symptoms as part of the disease progression, and they are very difficult to manage without being properly educated and trained. The behavioral symptoms are often a determining factor for hospitalization and long-term care placement, and sometimes forces individuals to be hospitalized out of state. She said admission into these facilities can be cost prohibitive for families; therefore, the quality of life of the individual might be compromised. Ms. Lamas noted that symptoms of Alzheimer's vary tremendously between individuals, as some experience depression, anxiety or irritability, which should be managed as part of a disease process prior to entering a crisis situation and requiring hospitalization, and others develop severe agitation, sleep disturbances, hallucinations, verbal and physical outbursts, and emotional distress. She noted these behavioral symptoms can be exacerbated by medical conditions, pain, infections, and environmental influences, as well as the way in which others communicate with a person with dementia. With proper intervention, patient symptoms can often be reduced and managed more effectively.

### *Ruth Gay, Chief Public Policy Officer, Alzheimer's Association, Northern Nevada Chapter*

Ms. Gay said, when assessing and identifying dementia as a potential cause of behavioral disorders, it helps if families understand what they are dealing with and address the symptoms as opposed to react to their behaviors as something that is inappropriate or socially unacceptable. Ms. Gay noted that behavior is a form of communication when somebody loses the ability to verbally communicate their needs.

The role of the Alzheimer's Association is to train, educate and provide resources for families and professionals who are trying to serve this population. Education and training relative to modifying environment, simplifying requests, establishing a routine, redirecting rather than confronting, and monitoring comfort factors, such as background noise, glare, room temperature, or activity, can help families and professionals in settings to intervene without causing more severe interactions. Ms. Gay reported that a large number of Nevadans live alone and have no social supports in place. She said when someone lives alone, without ways to monitor and or protect their behaviors, they are more likely to end up in hospitals or skilled nursing facilities as a result of an interaction with the police, and sometimes end up in jail. People with dementia often lose the ability to understand that they need care, need help to manage their finances and medications, and often lose the ability to identify crucial resources to keep them safe at home.

Ms. Gay noted that medical evaluation is critical relative to dementia, and managing behaviors and enhancing care can be part of the guidelines for managing the disease. Communicating best practices regarding how to access, manage and treat behavioral systems in people with dementia can often reduce the need for hospitalizations and crisis-driven episodes.

Ms. Gay referred to a trend mentioned earlier by Mr. Splaine called small house nursing homes, also known as "Green House," because they are very home-like rather than institutional looking. These homes are a good alternative in rural areas, as they are a licensed nursing home that can receive Medicaid dollars, accommodate six to eight beds, and are staffed by trained workers who live onsite. Ms. Gay said these homes exist in Texas and New York.

In closing, Ms. Gay proposed the following policy recommendations on behalf of the Alzheimer's Association:

1. In partnership with other state agencies, such as the Division of Aging and Disability Services and the Department of Public Health, host a town hall event to gather statewide partners that are working in dementia-friendly and rural and frontier communities to hear about their challenges and gaps, along with potential solutions.

2. Through a commitment from the Department of Public and Behavioral Health, survey professionals throughout the state to gather potential solutions.

3. Present to the Committee, at a future meeting, a summary of recommendations received from items 1 and 2 above.

Ms. Gay recommended the following areas for potential consideration that may be consistent with the Committee's goals:

1. Increase respite care services for caregivers. A caregiver is more likely to keep a parent or family member at home if they receive a break in the around-the-clock demands associated with caring for someone with dementia.

2. Examine the Legal 2000 process in NRS 433(a) and determine if an application exists for people with dementia in emergency situations. Currently, individuals with dementia are specifically excluded from placement on a legal hold; however, there are times when patients exhibit severe behaviors, have no support system in place, or they are a danger to themselves or others, that it may be appropriate to do a short-term hold at a skilled nursing or hospital setting to evaluate their needs, medications and other circumstances that might be driving those behaviors.

3. Consider providing the Elder Protective Services (EPS) staff with dementia competency training and the legal ability to manage a situation and perform an assessment. Staff should be provided the ability to respond appropriately and provide intervention when the safety of an individual is compromised.

Assemblywoman Benitez-Thompson restated dementia is exempt from Legal 2000 holds. She said when a caregiver is in place, someone is legally responsible for watching out for the person with cognitive deficits. However, there are increasing numbers of people who do not have support who are estranged from family and friends and get stymied in the system. She said positive changes were made in terms of guardianship, specifically targeting private guardianships and related abuse. Anecdotally, she heard changes to policy requires the EPS to file a petition versus issuing a referral to the public guardians, which could potentially create some new problems. What happens is we are stuck with people in the community who are given a mental examination, fail, and do not have a physician that is willing to deem them incompetent. In order to take away a person's legal rights and designate someone to assist them in decision-making processes, a diagnosis is needed. She said the end goal is to keep people safe. Assemblywoman Benitez-Thompson stated she had yet to work with a family that had a loved one with dementia or cognitive issues who did not have difficulties determining when to start making decisions on the individual's behalf.

Ms. Gay agreed and voiced concern for the "baby boomers" who are likely to be divorced, widowed, living alone, or do not have children to offer care. She said people living alone without a caregiver pose the most liability. Ms. Gay said she was uncertain if there was a legal avenue that allowed an individual to assist with decision making, such as a durable Power of Attorney (POA) or other course of action. States are researching the ability to provide individuals with legal-assisted decision making; however, the complexity of the individual's situation is not always understood. Individuals that live alone may need to be linked with remote family. She declared a need for discussion relating to implementing a course of action for individuals who have no other supports to keep them safe and protect them from financial abuse and exploitation.

Senator Goicoechea extended his concern for keeping individuals with Alzheimer's and dementia in their home. He realized many individuals hit a threshold when their living arrangements no longer work. He expressed his determination to make sure that option becomes available, whether it be in a community-based or long-term facility.

Chair Woodhouse asked Ms. Gray to repeat her policy recommendations, and Ms. Gay obliged.

## E. HealthInsight

Ms. Fantasi Pridgon, HealthInsight, stated HealthInsight is a private, nonprofit community-based organization that works on quality health improvement initiatives with locations in Nevada, Utah, New Mexico and Oregon. HealthInsight receives federal funding from the Centers for Medicare and Medicaid Services, and works with local organizations to improve behavioral health care.

Ms. Pridgon clarified that mental health is a person's condition with regard to their psychological and emotional wellbeing that include illnesses such as depression, anxiety, bipolar disorder, schizophrenia and post-traumatic stress disorder. Behavioral health is the connection between behaviors and the health and wellbeing of the body and mind, and include behaviors such as drinking or illicit drug use that impact physical and/or mental health (page 3, Exhibit F).

Ms. Pridgon reported primary care providers have been advised to screen patients for depression and alcohol use due to the rise in suicide rates, especially among older adults, and because of its impact on the health of patients who suffer from other chronic conditions. She directed the Committee to page 5 (Exhibit F) of her handout, the Patient Health Questionaire-2 (PHQ-2) that is used for screening depression. If a patient shows positive for a depression diagnosis, then the Patient Health Questionaire-9 (PHQ-9) is introduced to acquire information relative to the severity of their symptoms. She also identified the alcohol tool that is used to determine alcohol misuse (page 7, Exhibit F).

Ms. Pridgon turned her focus to inpatient psychiatric facilities (IPFs). She said IPFs oftentimes encounter patients who are "frequent fliers," meaning people who repeatedly show up in facilities for medical care. Typically these patients have limited funds, are homeless or affected by unstable housing, and do not have reliable transportation; therefore, are less likely to follow up with outpatient providers and manage prescription medications and end up back in facilities (page 8).

Ms. Pridgon provided the following information related to mental and behavioral health:

**<u>Statistics: Mental and Behavioral Health Care</u>**

- 20.4 percent of adults aged 65 and older met criteria for a mental disorder. Ms. Pridgon added, older adults are more likely to seek and accept services in primary care versus specialty mental health care settings, thus her strategy to target physician offices to identify these disorders and develop early intervention plans.

- Approximately 11 percent of older adults have anxiety disorders.
- Many suicides may be prevented, as older adults who commit suicide reach out for help; 20 percent see a doctor the day they die, 40 percent see a doctor the week they die, and 70 percent see a doctor the month they die.
- Depression is frequently missed by physicians, because older adults tend not to seek treatment for depression.
- In 2010, at least 5.6 to 8.0 million older adults had one or more mental health/substance use conditions. Illicit drug use nearly doubled among people between the ages of 50 to 59 from 2002 and 2007, increasing from 5.1 percent in 2002 to 9.4 percent in 2007.
- The number of older adults in need of substance abuse treatment is estimated to increase from 1.7 million in 2001 to 4.4 million in 2020.
- Approximately 80 percent of older adults have at least one chronic health condition and approximately 60 to 65 percent have two or more conditions which can impact a person's ability to manage their mental health disorder. Mental health disorders can impact recovery from a chronic condition.
- Negative, modifiable behaviors that contribute to the onset of or exacerbate chronic diseases include poor nutrition, inactivity, smoking and alcohol misuse.

### Factors Impacting Mental and Behavioral Health Care

- Among the Medicare, Medicaid population in Nevada, research shows high rates of homelessness/unstable housing, lack of transportation, substance abuse and financial strain.
- Health care challenges in Nevada include limited outpatient services/in-residence substance abuse treatment programs, provider shortages, and a lack of non-clinical professionals. (Ms. Pridgon acknowledged, but did not discuss, a separate handout (Exhibit G) relative to community health workers.)

### Potential for Improvement of Mental and Behavioral Health Care

- Expansion and development of housing programs. Ms. Pridgon learned from administrators that many patients have unstable housing, resulting in missed appointments. Healthcare organizations and homeless shelters have minimal communication and coordination.
- Development/streamlining of transportation services/programs would aid in transferring patients to follow-up appointments after a hospital stay and stimulate overall stability.
- Development of free prescription drug programs.
- Suggested improvements specific to Nevada health care organizations include the following:
    - Collaboration between health care organizations and homeless shelters.
    - Development/streamlining of incentive programs to attract quality health care providers to the state. Ms. Pridgon expressed waiting periods between hospital discharges and follow-up appointments are too long and result in return hospital visits due to lack of medication and/or refills.

- Creation of Community Health Worker, Discharge Planner, Social Worker, etc. positions.
- Development of more in-residence substance abuse treatment programs. Ms. Pridgon stated people are interested in substance abuse treatment programs, but the waitlists are too long and people lose interest.
- Development of pharmacies within hospitals/inpatient psychiatric facilities.

Assemblyman Wheeler observed a pattern of people seeking care from a primary care physician versus a specialist and not receiving a proper diagnosis. He asked how these solutions could be introduced to those who are undiagnosed.

In response, Ms. Pridgon disclosed that many physicians communicated they are not comfortable asking intrusive questions related to mental health disorders; therefore, the University of Nevada, Las Vegas (UNLV) Lincy Institute developed a program to aid providers in screening patients and developing treatment plans. She testified that her job focuses on promoting training programs and mental health awareness amongst medical professionals.

Assemblyman Wheeler questioned whether there were any training programs available to primary care physicians that specifically correlated to older Americans and the onset of dementia or Alzheimer's.

Ms. Pridgon said she was not aware of any programs other than the funding received at the UNLV Lincy Institute for their Screening, Brief Intervention, and Referral to Treatment (SBIRT) program. However, resources are available through the National Institute of Alcohol Abuse for substance abuse and alcohol misuse.

## VI. PRESENTATIONS REGARDING PROGRAMS AND SERVICES FOR CARE OF OLDER PERSONS WITH BEHAVIORAL AND COGNITIVE CARE NEEDS IN NEVADA.

### A. Aging and Disability Services Division, Department of Health and Human Services (DHHS)

Ms. Dena Schmidt, Administrator, Aging and Disability Services Division, Department of Health and Human Services (DHHS), thanked the members for inviting her to present. She introduced Homa Woodrum, Chief Advocate, Aging and Disability Services Division, as an additional presenter.

Ms. Schmidt identified the following funding provided within the Aging and Disability Services Division (ADSD): 1) Older Americans Act funding, 2) Direct Services, and 3) Policy and Advocacy. She said case management is provided as a direct service to recipients affiliated with programs such as the ADSD's waiver programs and EPS. The division provides policy decisions about services and supports and finds ways to advocate for necessary changes. She said the ADSD acts as a safety net provider to offer support in the least restrictive environment possible while honoring individuals' choices and self-determination, allowing people to have a part of that decision-making process for the care they receive.

Ms. Schmidt explained that the ADSD receives the OAA funding from the federal government and grants those funds to community organizations that provide services to seniors throughout the state. Out of the approximately $14.2 million received from the OAA funding, approximately $5.5 million was allocated to the Home-Delivered Meals and the Congregate Meals programs, which are the meals served at the senior centers, and approximately $8.7 million was granted to organizations that provide services such as respite care, the Homemaker Program, medication management, and caregiver training.

Ms. Schmidt communicated that the ADSD funds several organizations to provide services to older adults with cognitive needs. She noted these organizations also supplement their programs with private funding, donations and fundraising efforts. Specific services include Case Management; Senior Companion Program; Voucher (Respite); Adult Daycare; Personal Emergency Response System (PERS); Representative Payee, Aging and Disability Resource Center (ADRC); Evidence Based Care/CarePRO, which is a series of skill-building workshops for caregivers; Early-stage Partners In Care (EPIC) program, which assists people with early-stage memory loss via education and workshops; and the Alzheimer's Diagnostic program, which allows access to diagnostic services in rural areas and follow-up treatment using videoconferencing to the Lou Ruvo Center for Brain Health in Las Vegas.

Ms. Schmidt reported many of the grants for direct services were applied for through the Administration on Community Living, including the 2016 Dementia Capable Expansion grant; the Lifespan Respite grant; and the 2016 Alzheimer's Disease Initiative. Other direct services include home-based services for frail and elderly as well as physical disabilities; Elder Protective Services; Prescription Assistance program through Senior Rx/Disability Rx, which provides wrap-around services to Part D plans through Medicare and offers prescription drug assistance to those who do not have prescription coverage; services through an Elder Rights Specialist; and the Office of Consumer Health Assistance (OCHA). The OCHA has a group of Ombudsman who help individuals navigate the health care system, and the long-term care Ombudsman program advocate for individuals in long-term care facilities and residential facilities. Lastly, she mentioned the "No Wrong Door" philosophy that connects with other divisions within Health and Human Services to make sure individuals get the services they need regardless of who they contact first.

Ms. Schmidt indicated that Assembly Bill (A.B.) 31 (2017) expanded the role of the Elder Rights Attorney Advocate to provide services to older persons across their lifespan, as well as expand the role to groups that advocate for older persons to serve these individuals. This has provided an opportunity to identify the gaps and the barriers throughout the ADSD's services system.

Referring to the ADSD's FY 2018 budget, Ms. Schmidt said funding was received for additional waiver slots through an improved maintenance unit agreement, as well as an enhancement in the budget. Under the Frail Elderly Waiver, the division is currently operating at 96 percent capacity in terms of slots filled, with 198 individuals waiting for services. The Physical Disability waiver is operating at 97 percent capacity with 166 people on the waitlist for services. She informed the Committee that the ADSD performs outreach through billboards, health fairs and community events, as well as through aging and disability resource centers and their programs, to make sure people have access to what they need, when they need it.

Ms. Schmidt revealed that the EPS averages 535 new cases per month, averaging 67 cases per caseworker due to staffing vacancies (21 percent vacancy rate). The desired caseload is 40 per caseworker. She explained that EPS has a robust training module and brings in outside training as often as possible; however, 77 percent of that workforce stays in that job for less than two years due to high turnover to other agencies. The EPS also faces the inability to serve individuals with intellectual disabilities or Down syndrome populations that have a 50 percent higher rate of developing dementia, and often at an earlier age. The EPS must report cases of abuse or neglect in that population to law enforcement. Nevada is one of several states that has not moved from Elder Protective Services to Adult Protective Services. As such, there are no protective services for individuals between ages of 18 to 59.

### *Ms. Homa Woodrum, Chief Advocate, Aging and Disability Services*

Ms. Homa Woodrum directed the Committee to page 9, (Exhibit H), and summarized the following behavioral and cognitive needs of older persons:

Declining Resources: Nevadans who have experienced discrimination in the past may have had a difficult time maintaining a job, and as such, may not have contributed significantly to social security, which impacts the amount of funds they receive when they are eligible to draw these benefits.

Uncertain Familial Supports: Many Nevadans are transplants who left family members behind. As the Advocacy Attorney, Ms. Woodrum stated many out-of-state family members want to help, but have kids and other responsibilities; therefore, those resources should not be taxed to the point where they no longer exist. Those supports can be uncertain.

Planning Needs: Advanced Directive and Power of Attorney documents are important to convey one's wishes. Ms. Woodrum said there is a need to support individuals who are aging versus intervene in their lives, because intervening can potentially cause great harm. For example, caregivers in the rural and frontier communities adapt their way of life to accommodate the individual they are caring for instead of uprooting the individual and relocating them too urban areas. Ms. Woodrum said she is undertaking a project that protects people from purchasing unneeded, high-cost legal services in lieu of seeking simple, free legal services. She noted there is a sample Power of Attorney and advance directive form in the *Nevada Revised Statutes* (NRS).

Susceptibility to Exploitation: The needs of individuals with dementia are going to exacerbate over time, especially when they face declining cognitive health. This population is vulnerable to those who prey on them. The people who have regular contact with these individuals, such as those who deliver home meals or staff the senior center, may be in a good position to observe any behavioral or mood changes.

Ms. Woodrum reported that Alzheimer's disease is the most common form of dementia and accounts for 60 to 80 percent of cases. Vascular dementia, which occurs after a stroke, is second most common. Dementia is not a specific disease, but is a range of symptoms. She said when providing supports it is possible to identify and intercept causes of dementia-like symptoms, but are not dementia related, such as medication interactions, urinary tract infections or thyroid issues. Another common misconception is that dementia is limited to senior populations. Early-onset of Alzheimer's disease refers to those under the age of 65; however, the EPS statute sets the limitation to persons 60 years old and older. Genetics can be a factor as well (page 12, Exhibit H).

Ms. Woodrum said she searched the NRS going back to the 2015 Session, and dementia appeared in four Chapters and Alzheimer's appeared in three. It is mentioned generally by exclusion, meaning when dementia is not being considered.

She highlighted the timeliness of this Committee's study, and reported that in 2015, Nevada led the country in per capita Medicare spending on beneficiaries with a dementia diagnosis. She noted the disproportionate amount of aging individuals in the state.

Ms. Woodrum brought attention to an illustration on page 16 (Exhibit H) that depicted the approach of connecting individuals to supports and navigating them through services to determine their unmet needs. She said this approach captures people at their first entry into the system and directs them to their unmet needs.

Ms. Woodrum highlighted the experiences she had witnessed with misuse of Legal 2000 holds. She called out NRS 433A, Admission to Mental Health Facilities or Programs with Community-Based or Outpatient Services, and explained it as a very narrow mechanism by which somebody who needs mental health assistance can be held for 72 hours. She explained that a portion of the form gets completed, usually by law enforcement, to initiate a "mercy hold." The intent is to place an individual who is in eminent danger on a 72-hour hold for evaluation by an independent physician for further diagnosis. By statute, the hold cannot continue if dementia is diagnosed. If it is only dementia, meaning no presence of comorbidity with other mental health issues, they cannot be held. Ms. Woodrum said it is her understanding that, in consolidation with the Department of Public and Behavioral Health (DPBH) and other entities that serve this population, this is a very intentional exemption and one that should remain. The exemption is in place because any intervention that a mental hospital is capable of delivering is usually medicinal and is not something that will help an individual with dementia. She said she had several cases where individuals with dementia were held at a mental health hospital for over three months without an attorney, without contact with family, and without anyone to assist them. In one instance, an individual was not released because they were being abused by a person in their home and the police declined to actively remove that individual. Through observation, Ms. Woodrum stated the court in some cases will continue a hearing, so the person being held is in limbo without appropriate assistance. She recognized that if the 72-hour hold does not continue, many times the individual does not get connected to the resources needed to provide wraparound supports. She suggested, from a legislative standpoint there needs to be a policy in place for those who are on a legal hold, but cannot continue to be held by statute. She suggested that ADSD or EPS be notified when a person with dementia is being held.

Ms. Woodrum noted the passage of legislation in the 2017 Session regarding guardianship. She believed guardianship should only be used when other supports have failed.

Ms. Woodrum defined guardianship, stating it is a court-driven mechanism to assist someone declared legally incapacitated, such as when there is insufficient coverage of an existing advance directive or plan. Ms. Woodrum added that guardianship is often used by attorneys mistakenly as a tool to remove a bad POA. She noted some states approach fiduciary mismanagement in small claims court; however, she expressed the need for an inexpensive mechanism to remove a fiduciary. She implied that many POAs are abusing their authority.

Ms. Woodrum informed the Committee that Judge Frances Doherty, Second Judicial District, spearheaded the Supportive Decision-Making State Grant Program that increases awareness of, and access to, supportive decision-making for those with intellectual and developmental disabilities. There are national best practices being looked at to examine interdisciplinary networks regarding guardianship. Ms. Woodrum stated the ultimate goal is to avoid guardianship.

Assemblywoman Benitez-Thompson interjected, and recalled legislation that was passed to modify the health care POA for people with intellectual disabilities. Relative to supportive decision making, she questioned how to empower people to make the best decisions for as long as they can. She stated that when discussing persons with intellectual disabilities, it is assumed there is a stability in their intellectual disability, meaning their disability is not progressing. However, dementia has constant erosion of that capacity and physical and cognitive ability. She questioned at what point does a person begin receiving intensive interventions.

Ms. Woodrum acknowledged a POA form that was created in the 2015 Legislative Session, specifically targeting health care decisions for individuals with intellectual disabilities. She clarified the disabilities were specific to those presented during the developmental stage, the disability had to be present at birth, and the individual had a set situation showing improved abilities. She indicated the form in statute has a lot of plain language that should be adopted by the form utilized by individuals without intellectual disabilities, because of the clarity relative to what the POA can and cannot do. She was encouraged that the POA had to sign off on the form, acknowledging care decisions, because of issues like forced sterilization, which is a common issue in guardianship. Ms. Woodrum indicated supportive decision making for individuals with intellectual disabilities could also work for individuals with dementia, because for each marker point in the cognitive decline, that person would have the ability to select the person to assist them. She said as soon as someone is diagnosed with dementia, at that time, should be encouraged to make their wishes known, which would eliminate the need for guardianship if their estate planning covered all their needs. Ms. Woodrum implied that with supportive decision making, individuals with intellectual disabilities can confer with their network supporters and trust their decisions are respected. There are other individuals who live in a long-term care facility, have no guardian, have a dementia diagnosis, and progress through the remainder of their lifespan without any intervention. She said a doctor can make a medical decision that determines intervention is not in the individual's best interest. A popular example that occurs with individuals with intellectual disabilities is when sedative dental work is required, and the individual is denied because of a lack of guardianship. She said in those cases, helpless individuals go to court, get the guardianship, and leave themselves open to exploitation down the road. She emphasized the goal behind supportive decision making is to create a mechanism, through the legislative process, for physicians and financial authorities to recognize forms, such as the POA, rather than ignore them, because they assume there could be a potential legal ramification for relying on it.

Ms. Woodrum voiced the idea is to empower individuals with evidence-based approaches, and reiterated the following solutions:

- In regard to Legal 2000 holds.
    - Courts need tools to transition people that are perhaps wrongfully held.
    - Communication is required between agencies to provide awareness of supports.

- Vulnerable individuals need good planning, prevention, care navigation and supports, and <u>not</u> interventions. Under the Older Americans Act, Nevada receives funding for free legal services for older Americans over 60 with no income requirement. These services should include free wills, free POA, free advance directives, etc.

- Look at alternatives to guardianship, such as service coordination and the Representative Payee Program. Ms. Woodrum reminded the committee members that the Clark County Public Guardian adjusted its policy, and refuses to take referrals. She explained that the EPS, upon identifying an individual with severely diminished capacity, would request an evaluation by a physician and then refer that individual to the Clark County Public Guardian. She explained that as of the summer of 2017, the Clark County Public Guardian no longer accepted referrals and required a judge's order to take the case. She noted that other counties are interpreting the statutes differently than the Clark County Public Guardian and are still accepting referrals.

Assemblywoman Benitez-Thompson questioned what legal opinion the Clark County Public Guardian was operating from to implement that change. She stated she wanted to make sure that we have not stymied the people who are most in need of care.

Ms. Woodrum said Public Guardianship is governed under NRS 253, and it is Clark County's District Attorney's Counsel's interpretation that the Public Guardian cannot receive medical or financial data about anybody until they are granted guardianship.

## B. Division of Health Care Financing and Policy, DHHS

Kirsten Coulombe, Chief, Long Term Services and Supports, Division of Health Care Financing and Policy (Medicaid), defined long-term services and supports as essential, cost-effective services that enable individuals to remain independent, allowing them to achieve their highest level of self-sufficiency while they age in place, ideally among family members and friends, until they advance to a level of care that would require a facility setting.

Ms. Coulombe turned to page 3 (Exhibit I) of her handout that illustrated the direct services and supports offered by Medicaid. She explained the color-coded services ranging from a community-based level to the facility-based services that require a higher level of needs. Medicaid offers non-emergency transportation; in-home personal care services; self-directed care for those individuals that do not want an agency-assigned caregiver; adult day health care for people who need medical attention while at day care; home health services for individuals living at home that might have a chronic illness or are recovering from a hospital stay, private-duty nursing; nursing facility; and hospice services for end-of-life care.

Ms. Coulombe described the following three waivers administered by Medicaid:

- Frail Elderly Waiver: This waiver is age specific to individuals 65 and older who meet a nursing facility level of care, but want to stay in their home. The services include case management, homemaker services, chore services, respite, personal emergency response system (PERS), adult day care, adult companionship, adult residential care, and augmented personal care.

- Physical Disability Waiver: This waiver is offered to individuals who have a physical disability. There is no age restriction, but individuals are required to meet a nursing facility level of care. The services included are identical to the Frail Elderly waiver, with the addition of environmental accessibility adaptations, special medical equipment, home delivered meals, assisted living services, and attendant care services.

- Intellectual Disability Waiver: This waiver serves recipients of all ages who have a need for an intense care facility level of care. The services include jobs and day training, residential support services, residential support management, behavioral consultation, counseling, non-medical transportation, nursing services, and nutrition counseling.

Ms. Coulombe directed her focus to Medicaid's Behaviorally Complex Care Program (BCCP) on page 7 (Exhibit I), a program specific to nursing facilities. To be eligible, an individual must be a fee-for-service recipient over 18 years of age who has a severe, medically-based behavioral disorder that would cause diminished capacity. They must meet the nursing facility level of care and have a history of persistent, disruptive behavior that is not easily altered or requires an increase in resources. She said Medicaid offered an add on to the daily rate for the nursing facilities to assist with providing additional resources from staff to address those individuals that potentially disrupt others or harm themselves.

Ms. Coulombe recapped the following results pertaining to BCCP determinations:

- Currently there are 313 recipients
- 480 recipients were reviewed for the BCCP program in 2017
    - 423 initial reviews
    - 150 reviews completed and denied
    - 57 were redeterminations for tier level
        - 16 Tier 1 reviews were approved for a different tier
        - 10 Tier 2 reviews were approved for a different tier
        - 31 Tier 3 reviews were approved for another tier
    - 17 recipients were discharged or are now deceased

Senator Ratti asked if the Medicaid system offered other supports to caregivers besides respite.

Ms. Schmidt said, depending on the caregiver's eligibility for those same services, other Medicaid services, or their private insurance coverage, case managers and care managers have an obligation to that recipient to make sure their caregiver is also taken care of. Examples of support given were enrollment in a respite program, linkage to health insurance, as well as some of the same supports that are available to the recipient, depending on the caregiver's financial eligibility. She said the ADSD tries to take a holistic approach by finding natural supports that might be available in the community, such as recruiting help from neighbors.

Senator Ratti wondered if health challenges of the partner are not recognized until it becomes a crisis.

Ms. Schmidt stated she imagined that situation may occur.

## C. Nevada Task Force on Alzheimer's Disease

Senator Valerie Wiener, Nevada Task Force on Alzheimer's disease, provided the following written testimony below (Exhibit J). She summarized the work done throughout the history of the task force, legislative successes, and their services provided to Nevadans.

# Overview of Task Force

# on Alzheimer's Disease January 29, 2018

*Senator Valerie Wiener (Retired),*
*Chair, TFAD*

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# Committee to Study the Needs Related to the Behavioral and Cognitive Care of Older Persons

# (SB 121-2017)

Let me start by providing some perspective. Alzheimer's disease and other forms of dementia dramatically and uniquely impact individuals who have been diagnosed with the disease and all those who support them. This includes family, friends, caregivers, health care providers, first responders, and others. Alzheimer's disease is just one form of dementia and comprises about 60 to 80 percent of all dementia cases. In 2017, more than 43,000 Nevadans were estimated to be living with Alzheimer's disease or another form of dementia. Projections estimate that this number will rise to 64,000 by 2025. With the multiplier effect, which includes those who provide constant support and care, this means that hundreds of thousands of Nevadans are directly or indirectly affected by Alzheimer's disease and other forms of dementia. The 2017 Alzheimer's Association "Facts and Figures" estimate that Nevada has 145,000 caregivers for people with Alzheimer's disease or another form of dementia, and they contribute more than $2 billion dollars of care.

I will take a moment to share a brief history of the Task Force in 2011. Then Assemblywoman Debbie Smith was very concerned about the prevalence and impact of Alzheimer's disease in our state. She introduced ACR 10. This resolution, though short, was packed with significance, because it called for the establishment of a task force to create a state plan to address Alzheimer's disease. The ACR 10 Task Force, which was formed by the Interim Committee on Health in the summer of 2012, met five times. By the last meeting in October 2012, the task force had sifted through 117 recommendations from three heavily engaged work groups, which included experts, medical specialists, and the public. These groups had been specifically assigned to address access to services; quantity of care and quality of life, and public awareness.

After careful review, the ACR 10 Task Force adopted 20 recommendations, including potential funding sources and indicators for progress to be included in the first State Plan. This State Plan was submitted to the Governor and the Legislature in January 2013.

During the past three Legislative Sessions, both the original ACR 10 Task Force and the Task Force on Alzheimer's Disease have spearheaded several vital measures that address recommendations in the State Plan. During the 2013 Legislative Session, three ACR 10 bills addressed three recommendations in the State Plan, of which two were successful. The first, A.B. 80, established the Task Force on Alzheimer's Disease (TFAD). This bill required the ten-member TFAD, which is housed in the Department of Health and Human Services, to meet at least quarterly to review, evaluate, and update the State Plan to Address Alzheimer's Disease. In addition, TFAD is required to provide an Annual Report to the Governor and Legislature. Above and beyond what is required in law, TFAD members realized the importance of these issues and decided to meet six times each year. Also, the law requires an updated State Plan, "as needed." Again, TFAD members understood the crucial nature, scope, and impact of this disease and made a commitment to revise the State Plan every two Years. We are proud to have submitted to the Governor and Legislature a State Plan in 2013, 2015, and 2017. You will find the 2017 State Plan, along with the 2018 Annual Report, at your desk.

A second bill in the 2013 Legislative Session, S.B. 62, provided for Advanced Practitioners of Nursing to have independent practices. Though our bill did not move forward, we were thrilled that Assemblywoman Maggie Carlton's A.B. 170, which addressed this pressing need, was passed into law.

Our third measure, S.B. 86, provided for respite services for families of younger-onset Alzheimer's patients. This bill also became law.

During the 2015 Legislative Session, 6 recommendations out of the 20 included in the 2015 State Plan were addressed legislatively.

- A.B. 9 focused on guardianships and the assets of certain persons with Alzheimer's disease and other forms of dementia. Though this particular measure did not pass, it allowed all parties to participate in open and needed conversations about this issue.

- S.B. 77 addressed caregivers of persons being discharged from hospitals or moved to other facilities. This bill was a major effort of AARP and incorporated key concerns addressed in the State Plan. This measure became law.

- SCR 2, introduced by Senator Joseph Hardy, a member of TFAD, addressed 4 of the 20 recommendations in the State Plan. SCR 2 strongly "urged end encouraged" specific training for medical care providers and first responders regarding care for persons with Alzheimer's disease and other forms of dementia.

- S.B. 196, also introduced by Senator Hardy, included a section that authorizes health licensing entities to allow continuing education credits in education related to Alzheimer's disease. This measure also passed.

During the 2017 Legislative Session, the Legislature approved S.B. 92, which removed the sunset on TFAD so that we can continue our work on a permanent basis. Also, during this past session, several recommendations in the 2017 State Plan were addressed legislatively.

Though we submitted the 2017 State Plan in January, TFAD began immediately to review recommendations in this current State Plan, as well as assess several recommendations that have been retired to the Plan's Appendix. Each TFAD member is assigned to "monitor" recommendations (including indicators and funding sources) that align with that member's expertise and/or experience in addition, we are scheduling new presentations and discussions to expand our awareness, engagement, and effectiveness. This commitment is demonstrated in the 2017 State Plan, which added recommendations regarding: driving and dementia; veterans and families; guardianships; caregiver support; and outreach to physicians.

With the support provided by DHHS/ADSD, the Task Force on Alzheimer's Disease is able to address substantial issues and provide a forum for timely and innovative presentations, proposals, and collaborations. These activities help ensure that the State Plan is a premier blueprint for vital policies, practices, and programs, which DHHS/ADSD can support, create, and/or implement to serve the needs of this ever-expanding population.

During our first meeting of 2018, we continue making decisions about which 2017 State Plan recommendations to retain and which to retire to the Appendix. We have already determined which former recommendations to return to the 2019 State Plan. In addition, we will continue our consideration of possible new recommendations for the 2019 State Plan. A sample of possible recommendations related to Dementia-Friendly Nevada, guardianship, out-of-state placements of persons with dementia, the Behaviorally Complex Care Program, ADRC Resources for Nevadans with Dementia, and cultural competency and accommodation.

Chair Woodhouse and members of the Committee, we are here to be the "voice" for the voiceless. We are here to advocate for those who cannot do it for themselves. This includes the families and caregivers who all too often dedicate their entire lives to taking care of persons with Alzheimer's disease and other forms of dementia. We also speak for our dementia-friendly communities who are joining the Dementia-Friendly America and Dementia-Friendly Nevada movements to honor, include, and respect people affected by these health challenges. Members of TFAD are proud and humbled to continue its work of service to these courageous Nevadans, because they are our neighbors, our friends, and our families. I thank you.

I have two suggestions for consideration. These are things the TFAD has considered, but not voted on. I propose them as talking points.

1. Guardianships – this designated with the task force, that in the past we have offered educations for first responders, we believe that the legal community should not only be provided, but those who deal directly with people with guardianship or elder issues, there be a way to mandate certain education in Alzheimer’s and other forms of dementia. We believe that continuing legal education (CLE) units could be provided and/or required of lawyers and judges who deal with guardianship. They would have a greater appreciation of the mental capacities of the people over whose welfare they are making decisions or directing, and if indeed that is possible to expand to any other professionals who might be involved directly in the decision

making around those who might be considered for guardianship. The CLE's, education opportunities are available through the Cleveland Clinic Lou Ruvo Center for Brain Health and the Alzheimer's Association. We are not shy of programs, we just need to make those connections to provide those opportunities.

2. One of our original recommendations regarding advanced practice registered nurses (APRNs) and independent licensure, the intention for us was to provide medical access for people in rural and frontier Nevada with the hope they can serve underserved communities in Nevada, and though the numbers have gone up, we put this into the Appendix and sent the report out. We had a meeting, and we voted to return it to the next state plan, because the newest report indicated APRNs were not showing up in rural or frontier Nevada. We discussed the possibility of training health care providers at higher education institutions, with possibly an arrangement such as tuition waivers or loan forgiveness for those studying to be an APRN. In return, and upon graduation, that APRN would provide direct and regular and ongoing service in rural or frontier Nevada in exchange for the amount of money or time that is waived in terms of education costs, similar to the programs used for doctors who serve in underserved communities.

Chair Woodhouse announced that the 2017 Nevada State Plan to Address Alzheimer's Disease, including Appendices A and B, and the 2018 Task Force on Alzheimer's Disease Annual Report, were included in the meeting packet (Exhibit A).

## VII. PUBLIC COMMENT.

Chair Woodhouse asked for public comment in Las Vegas and Carson City.

Dr. John Yacenda, Ph.D., President, Nevada Silver Haired Legislative Forum (Forum), testified in Carson City and echoed comments made earlier by his colleague, Jeffrey Klein, stating he was encouraged by the charge of the Committee, and that its work will bring great benefit to the state, especially to the seniors. Dr. Yacenda pledged to support the goals of the Committee, and to gate some of the Forum's hearings to support the work of the Committee.

Donna DePauw introduced herself as the caregiver to her nearly 72-year-old husband who has lived with dementia Alzheimer's for approximately 10 years. She thanked the Alzheimer's Association for the support group mechanism they offer to the dementia community and other communities. She testified that when a loved one is diagnosed with Alzheimer's, family and friends disappear because they do not know what to do or say, and it becomes lonely. She referred to Alzheimer's as the "Caregivers Disease," because it requires caring for two people. She said they are very disrespected, especially by public facilities.

Mrs. DePauw stated she is the legal guardian to her husband, that she had no choice. She indicated approximately 10 percent of people who are diagnosed with Alzheimer's disease are mistakenly diagnosed, that other forms of disease exist. She indicated that she had to educate her doctor about Alzheimer's, because the doctor did not know what to do. She directed a comment toward the Alzheimer’s Association and other doctors, stating she was not sure if they would know what to do. She communicated a personal example relative to her husband and a five-year stretch with thyroid disease that happened after bouts of chemotherapy treatment. She relayed that doctors normally do one test for the disease, Thyroid-Stimulating Hormone (TSH), which showed nothing. However, through research, she became aware of a thyroid panel test that resulted in a proper diagnosis. She stressed that many people do not understand that treatments like chemotherapy can trigger the onset of other diseases, and that medical specialists, such as an Oncologist, are not trained in referring their patients to other professionals, such as an Endocrinologist, who specialize in potentially related diseases.

Mrs. DePauw said she has gone through heart disease with her husband, Lymphoma, and Alzheimer’s, and dubbed Alzheimer’s the worst disease in the world. She emphasized, as a middle-class wage earner, her husband receives no benefits or help from Medicare or Medicaid, and they must rely on her pension, her husband’s social security, and inheritance to pay the monthly facility costs. She accentuated the need for a grant program for middle-class people. She noted that most long-term care insurance only covers a person for 2.5 years, and emphasized the 10 years that her husband has been living with Alzheimer’s disease.

Mrs. DePauw focused her attention on care facilities, and stated the lack of training received by staff, specific to dementia, was ridiculous. Her understanding was that caregivers for children received more training than caregivers for Alzheimer’s. She said her and her husband would have to lose everything possible in order to be Medicaid eligible. She conveyed frustration with facilities, nationwide, that promote “memory care” experience, yet their staff is no more trained than the average caregiver. She communicated the need for inspectors to be available around the clock, so when somebody calls on the Elder Abuse hotline, that person can get help immediately. She implied that the facilities know when the state inspector is coming, which gives staff time to clean up and attend to the patients so they do not appear neglected. She said facilities get away with so many things that should never be happening, because inspections are not done around the clock.

Mrs. DePauw said she was devastated when the doctor ordered her husband to transition to a nursing home, and reiterated that she has a very small home, 18-year-old cars, and not a big savings account. She stated she was appalled that people are allowed to work under someone else’s Executive Director’s license, for a fee, and not be educated in dementia. She stated staff at the facility communicated she could visit around the clock, but really they do not want her there around the clock, nor do they want her there two to four hours per day. Mrs. DePauw touched on guardianship and neglect, stating neglect is when people drop their people off in those facilities and never visit them.

Chair Woodhouse thanked Mrs. DePauw for testifying.

In closing, Chair Woodhouse reminded the committee members that staff would be in touch regarding future meeting dates, and repeated the proposed meeting dates.

She instructed the members to contact staff or herself with requests for additional information regarding any discussions that occurred.

## XVIII. ADJOURNMENT.

The meeting adjourned at 1:20 p.m.

Respectfully submitted,

Judy Lyons, Committee Secretary

APPROVED:

Senator Woodhouse, Chair

Date:

**Copies of exhibits mentioned in these minutes are on file in the Fiscal Analysis Division at the Legislative Counsel Bureau, Carson City, Nevada. The division may be contacted at (775)684-6821.**